# Introducing the Sociology of Disability and Theoretical Perspectives

## Learning Outcomes

- 1.1 Explain the sociological imagination as it relates to disability.
- 1.2 Trace the development of sociological thinking concerning disability.
- 1.3 Identify common definitions of disability.
- 1.4 Articulate the significance of disability as a social construct.
- 1.5 Apply the medical and social models of disability
- 1.6 Describe and apply the key theoretical paradigms.

## **Chapter Synopsis**

Chapter 1 introduces the field of the Sociology of Disability, explains the Medical and Social Models of Disability, and familiarizes the reader with a range of theoretical traditions that inform the field. Although diverse, the theories share the idea that disability is a social construct which can be explained through social forces and processes such as culture, economy, and power. As such, a sociological lens is essential to understanding disability.

# Disability and the Sociological Imagination

People with disabilities constitute one of America's largest minority groups. The 2010 US Census estimated that 19% of the American population has a disability (United States Census Bureau, 2012). Looking only at adults (who are more likely to have disabilities than children), in 2016 the Centers for Disease Control and Prevention (CDC) estimated that one in four American adults—61 million Americans—have a disability that impacts major life activities (CDC, 2018). That's a lot of Americans!

Not only do people with disabilities make up a sizable portion of the

population, but they face numerous social disadvantages. Among working-age adults in 2016, only 35.9% of people with disabilities were employed, compared to 76.6% of people without disabilities, a difference of 40.7 percentage points. Of those employed, people with disabilities earned only two-thirds of what people without disabilities earned (\$22,047 vs. \$32,479). Not surprisingly then, people with disabilities were almost eight percentage points more likely to live in poverty (20.9% vs. 13.1%) (Kraus et al., 2018). Across measures of quality of life and satisfaction (e.g., marriage, social activity, education), people with disabilities fare less well than people without disabilities. They are less likely to socialize or eat out, and, when asked to rate their life satisfaction, only 34% reported being very satisfied compared to 61% of people without disabilities (Krane & Hanson, 2004).

To resist these social disadvantages, people with disabilities at times join together, forming powerful social organizations to fight for rights, services, and access. Many artists and scholars with disabilities embrace disability culture, leading to a range of cultural products (e.g., art, dance, books, film) that illuminate and prioritize the lived experiences of people with disabilities and celebrate their value in society (Brown, 2002).

Thus, people with disabilities are a large group who disproportionately experience social disadvantage, many of whom work collaboratively toward social change. These qualities make disability an area ripe for sociological study. Sociology, though, has been slow to incorporate disability into its theories and research (Gerschick & Stevens, 2016; Green & Barnartt, 2016). For too long, sociologists have essentialized disability—or, in other words, viewed disability as a biological, individual-level trait and the social disadvantages that accrue to disabled people as the natural outcomes of biological traits.

The Sociology of Disability aims to change that oversight. In doing so, sociologists take up the call issued by C. Wright Mills (1959) to develop the Sociological Imagination—the process by which we recognize the broader social context shaping individual experiences. According to Mills, many concerns experienced as personal troubles are better understood as public issues shaped by social institutions and historical trends. Disability may feel like a personal trouble that one copes with individually, but the experience of disability is deeply shaped by the social and historical context. These social factors include, for instance, cultural beliefs about disability, policies that may support or demean people with disabilities, and economic systems that provide avenues for participation or sideline people with disabilities. Disability is not simply a biological or medical fact. Instead, society—via social institutions like education and government, relationships, expectations and opportunity structures, and belief systems—shapes what disability means and the effects of it. Understanding disability is fundamentally a sociological task, requiring the use of the sociological imagination.

## Sociology of Disability: An Emerging Field

For most of the history of sociology, disability was primarily discussed in specific subfields, especially medical sociology and the study of deviance (Green & Barnartt, 2016). Medical sociology studies the social constructions and institutional practices related to health, illness, and well-being. Within this framework, sociologists position disability primarily in the context of health and health care, examining issues like the perceptions and expectations of sick and disabled

people, the interaction of patients with the medical system, and inequality in accessing health care. The subfield of **deviance** examines the establishment and violation of social norms. Classical sociologists, including Talcott Parsons (1951) and Erving Goffman (1963), considered sickness and disability to be a kind of deviance insofar as they preclude one from exercising expected roles in society and give rise to a stigmatized identity. Within a deviance framework, sociologists explore issues like the stigmatization of people with disabilities and how stigmatized people manage their interactions with others.

While both fields are relevant to understanding disability, disability as a social phenomenon and the social experience of people with disabilities cannot be reduced to these realms. Such a reductionist view would be like discussing women only when we study family or childbirth; these are relevant topics, but women's lives are not solely defined by family and childbirth. By considering disability only within the confines of medical sociology and deviance, sociology further stigmatizes people with disabilities, reaffirming the idea that people with disabilities are only relevant as objects of medical practice and/or as deviants. However, this is not an accurate representation of the experience of people with disabilities.

Sociologist Irving Zola was among the pioneers who thought more expansively about disability (Bell, 2016; Welsh, 2016). In his 1982 "socioautobiography" Missing Pieces: A Chronicle of Living with a Disability, Zola examined life with a disability and the broader social context shaping the experience of disability. In doing so, he shed light on how the fixation on health, youth, and beauty devalues people seen as frail or broken, leading to segregation and exclusion from the range of human experiences. Other scholars also began approaching disability in new ways. In The Politics of Disablement, Mike Oliver, a British sociologist, theorized the economic and social processes by which society produces disability. And, Richard Scotch, in his book From Good Will to Civil Rights (1984), examined the shift in disability policy from a charity approach to a civil rights approach that guaranteed accessibility and rights for people with disabilities as equal citizens. These new sociological approaches used and created theories related to the state, culture, and stratification, breaking free from the confines of disability as only medical or deviant. These scholars, and many others, forged a new subfield of sociology—the Sociology of Disability.

The Sociology of Disability, like the Sociology of Gender or the Sociology of Race and Ethnicity, seeks to examine a broad range of social experiences, processes, and outcomes in relation to a social concept and identity category—in this case, disability.

As a field within sociology, disability sociologists use scientific methods to develop social explanations (rather than, for example, biological, psychological, or religious explanations) for social phenomena. They study, among other things:

- the ways that disability is socially constructed and given meaning, and as such the variation in the meaning of disability across time and place;
- the social consequences of disability;
- the social position of people with disabilities within the larger stratification structure, the processes through which disability oppression operates, and the intersection of disability oppression with oppression based on race, gender, sexuality, class, and other bases of inequality;

- the ways in which disability is produced and made relevant in and through various social institutions (e.g., education, media, politics);
- the social processes of identity formation and disability as an identity category;
- the ways that disability influences and is shaped by micro processes such as small-group interaction and conversation; and
- the dynamics of social change affecting and led by people with disabilities

### **Common Definitions of Disability**

The first question disability sociologists usually encounter is: What is disability? This is a harder question to answer than you might think! Harlan Hahn (1987, p. 182) famously stated, "Disability is essentially whatever public laws and programs say it is."

There are many ways that people think about and define disability. Below we offer a few definitions that are commonly used in American society. These will be explored at greater length in Chapter 2, which focuses on researching and measuring disability. Disability may be defined as:

- The experience of limitations or difficulties due to biological conditions and environmental constraints. One of the most common definitions of disability is the experience of limitations or difficulties in performing important tasks due to biological conditions as experienced in particular environmental contexts. These tasks are often called Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs include basic self-care activities such as bathing, toileting, feeding oneself, and dressing. IADLs include higher-order tasks like managing money, food shopping, managing medications, and doing housework. According to this definition, if one experiences limitations/difficulties in tasks due to biological conditions, one has a disability.
- A set of significant and chronic health conditions. Another approach to defining disability is to determine a list of chronic conditions associated with physical/mental limitations. For example, a study might consider blind people to be disabled, regardless of whether they experience difficulties in particular tasks or not.
- The inability to work due to a biological condition. The Social Security Administration defines disability quite narrowly, as "the inability to engage in any substantial gainful activity (SGA) by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months." For the Social Security Administration, disability is only meaningful in relation to the ability to work.
- The experience of social disadvantage, prejudice, and discrimination associated with physical or mental impairment or the perception of

impairment. To offer one last example, the Americans with Disabilities Act of 1990 (ADA) is the centerpiece of American legislation prohibiting discrimination against people with disabilities. It provides one of the most important legal definitions of disability. In this law, disability includes persons with a physical or mental impairment that substantially limits one or more major life activities, those who have a history or record of such an impairment, and/or those who are perceived by others as having such an impairment. This definition recognizes that disability is not simply rooted in individual biology or limitations but is also shaped by social views and discrimination.

We could list additional definitions embedded in varied laws, service systems, or cultural frameworks. The key point that we wish to make, though, is that definitions of disability vary widely. These definitions vary in their criteria, who is included, and the percentage of the population that likely falls under any given definition. If we look across time and place, it becomes clear there is no single definition of disability. Disability is what people say it is, especially when those people have power to confer or deny resources based on labels. Disability is a social construct.

## The Social Construction of Disability

Although the definitions and approaches used to study disability vary, sociologists tend to understand disability as produced via social processes. To explore this idea, let's start with the idea of social construction. Social construction is the process by which people create the meaning of the world around them through social interaction. According to phenomenologists Peter Berger and Thomas Luckmann (1966), humans experience the world through our senses. We cannot discern "objective reality"; we can only know our own awareness of it. Through social interaction, we build consensus to some degree about the meaning of the things around us and establish a sense of a shared social reality. We decide things like what range of shades will be called "red," what animals are appropriate to eat and what foods are "breakfast foods," and what traits make someone "beautiful." These shared meanings get institutionalized; for example, certain shades of lipsticks are marketed as red, General Mills sells "breakfast" cereals, and the media promotes particular looks as beautiful. Once institutionalized, these shared meanings seem real and objective, like fixed reality. Meanings seem even more fixed when we are born into a culture and taught meanings as if they represent objective reality. Yet, we know that meanings can and do vary by time and culture, and they change all the time. If you've ever felt culture shock, you probably have realized that the ideas that you hold as "true" are simply cultural beliefs.

So, what does it mean to say that disability is a social construction? Through social interaction, people create meanings related to different bodies/minds. For example, people identify some bodies/minds as preferable to others. These labels then shape interactions and the opportunities available to people with different bodies/minds. **Disability**, therefore, is constructed via the *social processes* by which some bodies/minds are identified, categorized, and treated as "disabled."

Let's develop an example in greater depth using intellectual disability. Intellectual disability is usually understood as an individual-level impairment characterized by subaverage intelligence, rooted in one's biology, that causes difficulties in meeting the demands of one's environment. In contrast, sociologists point out that intellectual disability must be understood as a social construct. Intelligence itself is socially constructed; debates have raged for decades about what it means to be intelligent, what kinds of intelligences are valued, and how to measure intelligence. Furthermore, the beliefs, expectations, and attitudes surrounding intellectual disability vary dramatically across time and place (Carey, 2009; Trent, 1994). The very same intellectual capacities may be considered severe disability in one culture, mild disability in another culture, and not disability at all in another culture. Furthermore, the consequences of intellectual disability vary. Historically in America, a diagnosis of intellectual disability led to institutionalization, compulsory sterilization, and exclusion from public education. Now, these outcomes are less common, but people with intellectual disabilities still experience higher levels of social isolation, poverty, and social control.

Saying that intellectual disability is a social construct does not mean there is no biological basis underlying disability. There may be, or there may not be. Some sociologists distinguish between **impairment** (physical and mental traits determined to be atypical and often perceived as undesirable) and **disability** (the social processes by which some bodies/minds are identified, categorized, and treated as disabled). This distinction is similar to the common sociological practice of distinguishing sex and gender. Sex is determined by the presence of particular sex organs and traits, whereas gender constitutes the broad set of social meanings, expectations, norms, and consequences associated with being male or female. A woman may have a uterus (sex), but having a uterus does not determine the meaning and consequences of being female such as standards of dress or employment opportunities (gender).

Similarly, some people may have physical or mental traits, such as Down syndrome, which affect their intelligence; however, even if the biology of Down syndrome (impairment) affects intelligence, it does not explain the meanings and consequences that flow from it such as the variation in the marginalization of people with Down syndrome over time and across cultures (disability). Furthermore, people may be *regarded* as disabled in the absence of impairment. Women, for example, historically were thought to be physically and mentally unable to engage in high-order reasoning. Scientists declared their bodies/minds were too disabled for learning, and women were excluded from higher education on this basis, although now we know that women can achieve intellectually.

Other sociologists reject a sharp distinction between impairment and disability. They argue that even impairments, one's body, and the experience of one's body are shaped by social experiences and processes. For example, intelligence is a social construct, and Down syndrome cannot be understood without recognizing that people created the construct of intelligence and measures for it. Moreover, social factors, such as exposure to toxins and lack of exposure to positive stimulation, also affect intelligence. Thus, even biology is a product of social processes. Regardless of whether sociologists distinguish between impairment and disability or not, to say intellectual disability is a social construction means that there are vast social meanings and consequences tied to the label of intellectual disability which are not clearly caused by biology.

As a social construct, disability is, most simply, whatever people say it is. **Labeling theory** (Becker, 1966) argues that social phenomena are best understood through the process by which a label is socially created and applied to a group of people, often resulting in various consequences. Drawing on this theory, disability is a label created and applied to a group of people, a label that can

be institutionalized in various ways and that results in various consequences. Across societies and times, various bodies and minds were understood differently. People are "disabled" when they are defined and treated as such.

Because disability is a social construction, we should not be surprised that ideas about disability and what constitutes disability vary by time and place. The same physical or mental condition may or may not be understood as "disability" depending on how common it is, the cultural beliefs in a society, and the extent of the disadvantages that flow from a condition. The very idea of "disability"—an umbrella term uniting an array of physical and mental conditions and experiences—is actually a relatively modern concept (Nielsen, 2012). Definitions of disability depend on who is doing the defining and why they are defining it. For example, educators might want to cast a broad net to deliver supports to all those who need them, while administrators might want a narrow definition of disability that identifies fewer people and thereby saves money by delivering services to fewer people. Moreover, disability is fluid. Both physical abilities and environmental contexts shift, leading to greater or lesser experiences of disablement.

## The Medical and Social Models of Disability

The competing ideas of disability as biological versus disability as a social construct are often referred to as the medical model versus the social model. A model is a way of representing something and putting it in relationship with other things. The **medical model** regards disability as an individual deficit or limitation rooted in individual biology. The **social model** regards disability as a social construct rooted in the physical and social environment.

The most important difference between these models is the understanding of where disability lies—in the person or in the environment. To use blindness as an example, the *medical model* roots disability in physical defects that limit

PHOTO 1.1
A doctor relies on the medical model, examining patients to identify illnesses and problems.

Evren (2020). Reproduced with permission from istock.com.

vision and seeks to remedy these defects through medical and therapeutic interventions to enable the blind person to achieve sight, or to approximate the behaviors and abilities of a sighted person as much as possible. Doctors, for example, typically use the medical model. When they encounter blindness, they assume it is an unfortunate defect of an individual's body that ideally will be fixed through medical intervention. Many nonmedical professionals share this view.

The social model (Oliver, 1990), on the other hand, asserts that the biology of blindness does not need to be cured or fixed. It locates disability, instead, in the social and environmental barriers that deny opportunities and rights to people with different bodies/minds, thereby disabling them. The social model

emerged in Britain in the 1970s as a way for disabled activists to call attention to the social barriers—including physical barriers, prejudice, and social policies that create social disadvantage and to demand that we *fix society* (UIPAS, 1976). In this view, the biological difference is usually far less limiting than the social response to the difference.

Returning to the example of blindness, blind activists argue that the key barriers



PHOTO 1.2
According to the social model, blindness is not disabling when society provides access, such as this student using a Braille textbook.

they face are not due to the physicality of blindness. Rather, the key barriers are low expectations, discrimination, and inaccessibility. Blind scholar and activist Jacobus tenBroek (1966) famously wrote that blind people have "a right to live in this world." To achieve this right, society needs to rectify problematic stereotypes, such as that blind people are incapable of participating in activities like work or travel, should be segregated for their own safety, and should hide their blindness from view.

In the social model, society creates the key social, environmental, and policy barriers that disable people, and, in turn, society can create inclusive and accessible environments that enable people. When blind people are in accessible environments, they successfully learn, attend college, work, marry, have children, and live self-determined lives. In accessible environments, blindness is not disabling.

Table 1.1 summarizes the differences between the medical and social models.

### TABLE 1.1 Medical and Social Models

	Medical Model	Social Model
Disability is	An individual defect or abnormality resulting in functional limitations	A disadvantage produced by the social environment, including attitudes, architecture, and policies
Disability is rooted in	One's individual biology	The social environment; a poor fit between individual biology and one's environment
Disability manifests in	Individual limitations in functionality or activities of daily life (e.g., I can't walk, inability to hear)	Blocked opportunities for valued participation (e.g., this business has no ramp so I cannot work here, this event has no ASL interpreter so I cannot attend)

(Continued)

#### TABLE 1.1

#### Medical and Social Models (Continued)

	Medical Model	Social Model	
Disability is identified by	Identifying individual deficits and their biological reasons: Why can't you see? Why can't you walk?	Identifying social barriers that prevent opportunity: Why is public transportation inaccessible? Why do schools teach Spanish but not ASL?	
Disability is addressed via	Individual-level "fixes" (e.g., medical intervention and therapy to "normalize" the person) and charity	Changes in the environment to increase access and empowerment (build ramps, provide education to reduce stigma);  Rights to access and participation	
Expertise lies in	Medical and the helping professions	People with disabilities	
Advantages of the model	Promotes medical research  May cure or ameliorate painful or even deadly conditions	Identifies social barriers and changes them to make the world more just;  Confers respect and power to people with disabilities	
Disadvantages of the model	May increase stigma for people who cannot be or choose not to be fixed;  May assume people want or need to be "fixed";  May naturalize anti-disability social values	May overlook important physical differences;  May overlook pain, suffering, and negative experiences rooted in biology;  May stigmatize decision to seek medical cure	

While scholarship often treats the medical and social model as mutually exclusive, they are not (Morris, 1991; Shakespeare, 2010; Thomas, 1999). The experience of disability may be rooted in both biology and society. People with disabilities often use both models (i.e., they consider disability from both perspectives). They may draw on medical expertise to attain optimal health and demand rights and the removal of social barriers.

Also, keep in mind that sociologists often recognize that the medical model itself is a social construction. In other words, although the people who adhere to the medical model believe that disability is "natural," sociologists argue that the *belief* in disability as a natural, biological, objective state is itself a cultural belief system, one most commonly held in highly industrialized societies. It is *the* dominant belief system currently in America related to disability. Although particular groups believe that biology and medicine are based on objective facts, medicine is actually a value system, and medical practitioners and those who rely on a medical perspective have a symbolic, constructed culture. This culture celebrates a very particular body that adheres to the statistical norm. It often presents the nonnormative body, such as bodies that shake, drool,

falter, or show other signs of "weakness," as the enemy. Medical culture celebrates the fight for a cure and praises those who overcome their sickness or disability to attain "normality" (Katz, 1998).

Once the social and medical model are framed as belief systems (i.e., social constructions) by which people *construct and understand* disability, it may not be surprising that there are more models/belief systems representing other ways that people and cultures understand and explain disability. For example, scholars have shown the importance of the Moral/Religious Model—the belief that disability is conferred purposefully from god(s/esses) as a punishment, a moral challenge or test, or a gift (Wheatley, 2010). If one understands disability to be caused by supernatural causes, then the responses to disability will likely also be spiritual in nature, such as prayer, strengthening one's faith, and cleansing/healing ceremonies. There is also a Charity Model in which people with disabilities are primarily seen as dependent, helpless, and in need of financial and moral rescue from "good" people. While charity accomplishes

positive goals of redistributing important resources and acknowledging human need and suffering, it can have negative consequences when it is the primary way in which we understand disability. Charity can lead, for example, to the objectification of people with disabilities, the perpetuation of the stereotype that all people with disabilities want or need charity, and the constant evaluation of people with disabilities in terms of their deservedness of charity (Longmore, 2016).



Credit: Green (2020). Reproduced with permission from

# **Explaining the Production and Experience** of Disability

The models already discussed describe the worldviews by which groups of people understand disability. But the social model is very broad, arguing simply that the environment produces and shapes disability. What does this mean? How and why does this happen? Sociologists focus their explanations—or theories—on causal social forces and structures. In each chapter of the book, we will encounter theories to help explain disability, along with the evidence supporting those theories. In this chapter, we offer a foundation of several broad categories of sociological theory that can be used to explain and explore disability. It is not a complete list, and the theories intertwine and overlap. The goal is for you to gain exposure to a broad range of theories that sociologists use, highlighting the varied social forces that may explain disability.

PHOTO 1.3
People with
disabilities may
benefit from
charity, such as this
man receiving a
food delivery during
COVID Quarantine,
but few people
want to be defined
only as charity
recipients.

# The Construction of Meaning and Culture on the Micro and Macro Levels

We begin our discussion of theories with those that focus on the construction of meaning and the role of culture. This set of theories argues that, to understand disability, we must examine how people *create* disability by defining and responding to some phenomena *as* disability.

Max Weber, one of the founders of Sociology, introduced the term **verstehen** (the German word for understanding) to explain the unique task of sociologists. Sociologists must understand the world from the point of view of those being studied. Humans, unlike rocks or plants, create the world by producing and organizing their own understanding of it—the process of social construction that we have already discussed.

George Herbert Mead (1934) and Charles Horton Cooley ([1902] 1983) then developed the theory of **symbolic interactionism** to explain how we create meaning. They argue that, on a micro level, people interact with each other, and through our everyday social interactions, we create and share symbols and meanings. These symbols and meanings are repeated, enacted, preserved, and eventually come to feel "real." We forget, for instance, that we created the idea of "autism" to represent a very broad and complex set of behaviors and over time come to imagine that autism is a real, objective fact. As we accept these meanings, we also shape our behavior in relation to them.

The meaning of disability is created and negotiated in micro settings like family and school. For example, Melvin Juette (Juette & Berger, 2008) was paralyzed in a gang-related dispute. His local context and social relationships—including his peers in the gang, an uninspiring high school counselor, and later access to a competitive wheelchair basketball team and a rousing coach—shaped the way he came to think about his acquired disability and his new identity. In the book *Wheelchair Warrior: Gangs, Disability and Basketball* (p. 3), Juette explained that disability was "both the worst and best thing that happened" to him. Disability cut short his opportunities in his gang, while opening other opportunities to recreate himself as a wheelchair athlete, college student, and later as a professional. While disability opened valuable opportunities for Juette, for others, the shift in status more clearly threatens their established jobs and roles.

While some sociologists look at how meaning is constructed at a micro level, others examine the production and impact of macro cultural discourses in shaping disability. A **discourse** involves the organization of meaning in ways that constitute knowledge and inform our behavior. **Dominant discourses** are organized systems of meaning embedded in and manifest through relations of power and social institutions such as politics, law, medicine, and education. More simply, dominant discourses are the grand stories that are widely told by those in power and are widely believed. Michel Foucault (1980) famously argued that discourse, power, and knowledge intertwine as people with institutional power gain the authority to position their discourse as "truth." Discourse then not only describes what people believe, but it creates, shapes, and constrains people's ideas and behaviors. Discourse reinforces the power of some groups, while legitimating the oppression of others.

The dominant discourse of disability in modern America is the medical model, and this shapes and constrains the opportunities of people with disabilities. This discourse encourages research into cure, the use of therapy, and the pursuit of the perfect, or at least the normative, body/mind. In doing so, it

values the "norm," defines people outside of the norm as disabled, and demands they seek cure and strive to become as "normal" as possible. For those outside of the range of acceptable normality, their exclusion is seen as justified. Thus, the medical model as a discourse encourages some behaviors and confers some opportunities while discouraging other behaviors and blocking access to other opportunities.

Culture on the macro and micro levels intertwine. Sociologist Pierre Bourdieu (1984) famously theorizes how macro cultural systems shape our identities and behaviors and vice versa. Discussed at greater length in Chapter 5 on culture, Bourdieu argues that each social space or "field" produces a complex set of social relations where people engage in everyday practices and create meaning. One's "capital"—a range of resources used to accrue more resources—effects one's access to and position within a field. As one engages in any given field, one develops dispositions, or as Bourdieu explained it, "a sense of the game." Over time, people accrue experiences and develop dispositions across fields. Some of these become deeply ingrained or habitual. Bourdieu referred to these "deeply ingrained habits, skills, and dispositions that we possess due to our life experiences" as habitus. The habitus one develops tends to reflect one's social position across fields and thereby reproduces inequality.

Alan Santinele Martino's work (2020, 2021) offers a compelling example of Bourdieu's theory as related to disability. He shows that people with intellectual disabilities are often excluded from sexual fields (places and interactions where sexuality is discussed, learned about and performed), and as such they lack a "sense of the game." Despite their interest in forming romantic and intimate relationships, they lack the social, cultural, or economic capital (resources) to engage in the practices of sexuality, such as identifying sexual partners or going to places like parties and clubs where romantic/sexual relationships form and advance. Without the opportunity to engage in these social practices, people with disabilities may develop low sexual self-esteem and constricted sexual identities. In a reinforcing cycle, their inferior social access and constricted sexual identities then inform the views others have of them and their own behaviors. As such, macro cultural beliefs about the asexuality of people with disabilities become incorporated into the identities and behaviors of individuals with disabilities and the views of others, which in turn reinforce the macro cultural belief about the asexuality of people with disabilities.

#### **Materialist Theories**

Materialist theories prioritize the role of the economy and the resources people need to survive (the material environment) as the primary systems which determine our social relationships, culture, and disability. Karl Marx ([1845] 1978) proposed that the way a society produces the things its members need and use—its means of production—creates and corresponds to a particular set of relations of production, the patterns of social relationships characterized most simply by who owns/controls the means of production (the "haves") and who does not (the "have nots"). Since the advent of capitalism, the "haves" have been capitalists and the "have nots" primarily have been the working class, also known as the proletariat.

Capitalism is characterized by private ownership of the means of production, mass production, expansive commodification of resources for sale in the marketplace (i.e., almost all things we need must be purchased), profit motive, and exploitation of the working class by the capitalists. Since the working class do not own the means of production, other than their own bodies, they must sell their labor power to survive. In the drive for greater and greater profit, capitalists exploit the workers more and more, forcing them to work longer hours, work faster, live with fewer benefits/securities, and work in poorer conditions.

The imperative for profit is a defining feature of capitalism and operates in a context of competition among capitalists. This means that capitalists have little choice but to exploit their laborers. If they do not, other companies will reap greater profits, their own company will ultimately fail, and they will be pushed into the growing ranks of the proletariat. Thus, benevolence by capitalists cannot be sustained. Marx described the conditions of capitalism as brutal, a system in which naked economic transactions erase all sense of social or human obligation on the part of the capitalist class to care for the working class who actually produce the goods and wealth of the society on which the capitalists live.

For Marx, other social institutions such as politics, media, culture, and education serve as **superstructure**—institutions which are structured to support and legitimate capitalism and the needs of the capitalists. For example, according to Marx, political systems may be superstructure, catering to the needs of capitalists and ensuring that resources and profit flow to this increasingly small class of people. The media also could be superstructure. It celebrates the trappings of capitalism—unabashed consumerism, the pursuit of wealth, the idolization of the rich—while devaluing the working class. In materialist theories, culture plays a role, but its role is largely *shaped by* the economic system and the class interests of capitalists.

The centrality of capitalism and other economic systems in producing and shaping disability is key to many sociological theories of disability. British sociologist Michael Oliver, one of the earliest proponents of the social model, developed a materialist theory in his pioneering work, *The Politics of Disablement* (1990). He argues that the "cultural production of disability is dependent upon a variety of factors including the type of economy, the size of the economic surplus, and the values that influence the redistribution of this surplus" (p. 24). In other words, capitalism produces much of disability, causes many of the social disadvantages (e.g., exclusion and oppression) experienced by people with disabilities, and shapes the social response to disability.

The role of the economy generally and capitalism specifically will be explored in greater depth in Chapter 9. Here, let's briefly consider some of the ways that capitalism shapes disability.

Capitalism produces disability though unsafe and grueling work conditions, the mental onslaught of constant competition with little social safety net, and the devastation of communities with high poverty rates. These negative effects are uneven, as global systems of labor exploitation disproportionately disabled people from impoverished nations and people of color (Erevelles, 2011).

Capitalism disadvantages people with disabilities. The standardization of the work process (e.g., assembly lines, predetermined "efficient" production methods) excludes atypical bodies and minds. The focus on profit demands the fastest, most efficient, or smartest laborers, and the fierce competition for jobs removes the need for capitalists to utilize less profitable laborers or those even imagined to possibly be less profitable. Capitalist culture supports the priorities of capitalism, celebrating individualism and productivity while vilifying dependence and disablement (Charlton, 2000; Oliver, 1990; Russell, 1998).

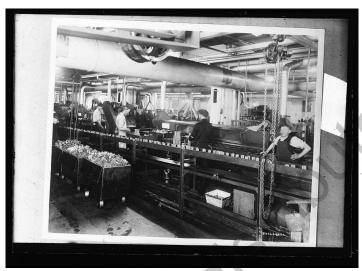
Capitalism shapes our response to disability. According to Bernard Farber

(1968) and Andrew Scull (2015), capitalism creates "surplus labor"—those who are perceived by capitalists to be undesirable or unfit workers—and then must invent solutions for how to deal with these populations. Compulsory education emerges to provide workplace training and supervision for children whose parents are now working away from home; institutions emerge for people increasingly defined as biologically unfit because their bodies do not adequately match the demands of capitalists; nursing homes supervise aging people who have grown less productive and have heightened care demands; and prisons grow larger and larger to contain and control a range of bodies/people, often people of color, deemed deviant and threatening to capitalists (Ben-Moshe et al., 2014).

Capitalism commodifies disability and the needs of people with disabilities, treating care and needs as opportunities for profit. As Gary Albrecht documents in his 1992 work The Disability Business, disability-specific "services" come to operate as profit-generating industries. Care is commodified (placed on the market for a price), and people with disabilities become central to these arenas of commodification (e.g., pharmaceuticals, medical equipment, medical services, nursing homes, therapies, home health and personal aides). Through this process of commodification, people with disabilities potentially gain value in society via their role in producing profit as consumers (DePoy & Gilson, 2018). However, due to economic exclusion and the resultant poverty of many people with disabilities, they rarely control the purchase of commodities, and this potential source of power rarely materializes.

#### Political and State-Centered Theories

Whereas some theories focus on culture and the economy as causal factors shaping disability, **state-centered theories** examine the role of the state in defining and affecting disability. In her classic work *The Disabled State*, sociologist Deborah Stone (1984) analyzes the creation of disability as an administrative category used by the state to distribute resources/benefits, especially to differentiate between citizens worthy or unworthy of assistance. People with disabilities are often judged as a category of people worthy



Credit: Detroit Publishing Company (1924). Library of Congress Call Number: LC-D420-3044 (P&P). Obtained from https://www.loc.gov/pictures/item/2016817039/

PHOTO 1.4 Industrial assembly lines require standardized bodies and speed of work.

of aid, in contrast to the "able-bodied" poor who are denied aid. State laws then must define and distinguish disability to determine eligibility for aid.

Definitions of disability are embedded in other laws and state programs as well. Because the government operates on multiple levels and through many systems, the definitions, policies, and laws regarding disability do not always align, leading to bizarre inconsistencies in who is defined as disabled and the consequences of that label. Brian Grossman's (2019) work, for example, showcases the problems of interstate variation in state policy. Because Medicaid (one of America's public national health insurance systems) is implemented on a state-by-state basis, people with disabilities experience sharply different access to services and supports across states. This affects not only their services in any given state, but also restricts their ability to move across state lines because their benefits and services do not transfer across state lines. Therefore, people with disabilities may not have the same freedom as others to pursue educational, employment, or even romantic opportunities across state (or even county) lines. In contrast, some people with disabilities find that they must move to a different state, away from their families and natural supports, to access necessary state-funded supports.

This theoretical approach is at times rooted in Weber's ([1922] 1968) classic work on bureaucracy and authority which highlights the growth of bureaucratic organizations focused on efficiency. In contrast with Marx's view in which capitalists hold most of the power, for Weber many people exercise authority, often based on their position within bureaucracies. State officials hold such power, as do lots of people who work in agencies that exercise power over people with disabilities. This theory highlights the broad range of people who might exert power over people with disabilities, such as nursing home administrators, teachers, social workers, and employers. It also suggests ways that people with disabilities might approach making social change through occupying positions of authority, influencing people in positions of authority, and reconfiguring the bureaucracies that affect their lives.

Culture, economy, and the state intertwine, often in ways that confer significant power to a few people and usually disadvantage people with disabilities. Political economy approaches explain how economic and political systems interact to shape resource distribution and class stratification. For example, James Charlton's (2000) political economy approach prioritizes the role of capitalism and documents how state policies serve the interests of capitalists, leading to the oppression of people with disabilities internationally.

#### Stratification, Intersectionality, and Relationality

**Social stratification** is the way in which a society groups people and creates a social hierarchy. Stratification is, simply put, the processes by which inequality occurs in a society. Societies have different stratification systems and offer different ideologies to legitimate inequality. Inequality might be justified through claims like meritocracy (those who work hardest and are the most talented rise to the top), religion (some group is god-ordained to have power), or birth-right (some group is born into positions of power). To note, the justification for inequality is not necessarily true, but it is often widely accepted as true by those who live within that society.

The study of stratification is central to Sociology and has historically focused on class, race, and gender; however, people with disabilities are among

the poorest people both in America and globally. Their poverty is often naturalized, seen as a consequence of physical or mental biology rather than as a product of economic, political, and cultural systems. The Sociology of Disability seeks to remedy this oversight.

Some disability scholars have posited a minority model of disability (Asch & Fine, 1988; Barnartt & Seelman, 1988; Barnes, 2016; Hahn, 1985; Scotch, 2000), which argues that people with disabilities are a minority group with systemically inferior access to power and resources. Overwhelmingly, research documents that people with disabilities are disproportionately poor, unemployed, underrepresented in politics, segregated, and incarcerated (Schur et al., 2013). People with disabilities are less likely to graduate from college, and a college degree leads to less economic gain for people with disabilities than for others. Compared to people with disabilities in other industrialized nations, people with disabilities in the United States have higher rates of poverty and are less likely to be employed (Schur et al., 2013). This variation shows that the inferior social position of people with disabilities is produced, not natural.

Increasingly theories of stratification look at intersectionality, the ways in which multiple systems of oppression intersect, often in complex ways (Collins, 1990; Crenshaw, 1989). As a simple example, scholars point out the double disadvantage of women with disabilities or the triple disadvantage of Black women with disabilities. Rather than simply assuming an additive effect, however, intersectional work examines the ways that one system of oppression is constitutive of and influential for another system of oppression. To consider Black women with disabilities as an example, not only are Black women with disabilities more disadvantaged in the workplace than White men without disabilities (an additive effect), but the stereotypes around disability, femininity, and

African Americans intersect and reinforce each other. All three groups (people with disabilities, women, and African Americans) suffer from stereotypes suggesting that they are intellectually incompetent and irrational, and these stereotypes reinforce each other when someone is an African American disabled woman. While there may be similarities, the patterns and stereotypes may also differ across groups. Disabled Black men, for example, are particularly likely to face stereotypes that their



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disability is related to violence, gang-behavior, and criminality. Thus, intersectional scholarship looks at the complicated ways that disability intertwines with other social statuses to shape stratification.

To aid in the study of intersectional oppression, intersectional frameworks such as feminist disability studies, critical race and disability studies, and crip queer studies have emerged. Each looks at how disability interacts with

PHOTO 1.5
Disabled Black
Lives Matter
Actvist- the
intersection of race
and disability
increases
vulnerability to
police violence.

other forms of oppression and vice versa and imagines social justice from this intersectional perspective. For example, feminist disability scholars examine, among other things, how gender shapes the experience of disability, how disability shapes the experience of gender, and how social justice requires addressing sexism and ableism.

Relational models of disability potentially enable both an understanding of inequality and the intersectional dynamics across varied groups. Relational models examine the complicated composition and impact of relationships and relational patterns on disability and the lives of people with disabilities. Alison Kafer (2013, p. 8) argues that a relational model of disability is essential because "disability is experienced in and through relationships; it does not occur in isolation."

#### **Embodiment**

We have two more sets of theory to discuss! Hang in there.

Sociology and the social model of disability turn our gaze toward the social context. While very valuable, more recently sociologists have brought the body back into our work, considering how the body itself is produced by social forces and how diverse bodies lead to different social experiences. Embodiment argues that our bodies matter for how we experience the world. Our engagement with and interpretation of the world is mediated through our



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PHOTO 1.6

The experience of inaccessible environments - such as this female wheelchair user blocked by steps - shapes one's opportunities and outlook.

senses and bodies. People in different bodies will experience the world differently. For example, blind people may have a different relationship to spatial organization, smells, and vibrations than sighted people. People who walk with ease may not even notice a step, whereas those who use wheelchairs may feel excluded. Due to the different ways children process information, some may perform well sitting in rows listening to a teacher, whereas others may not.

Not only do we experi-

ence the world through our bodies, but the world—and inequality in particular—is written and imposed on our bodies. Poverty, war, lack of access to clean water, and exposure to toxins *cause* impairments. The experience of racism leads to disability, as racial minorities experience higher levels of stress, violence, and poverty. The effects of social inequality are not simply social; they are physical.

The bodies of disabled people are also subjected to social control. In addition to violence, people with disabilities often live in institutional settings in which they experience intense surveillance, physical regulation, and systems of rewards/punishments to ensure normative conformity (Ben-Moshe et al., 2014; Foucault, 1965, 1975). While most people are encouraged to follow the

rules more or less, people who reside within the social service system (e.g., group homes) live under constant surveillance. Their lives are often dominated by therapeutic regimes, even when they are trying to relax at home. They face punishments like the denial of leisure time if they "act out." Their bodies are constantly under watch and regulated.

Sociologists also consider the ways in which the body is central to identity formation (e.g., our sense of who we are). Judith Butler's (1990) theory of **performativity** argues that identity is constituted through repeated, enacted performances. Gender, Butler argues, is learned and performed, and our gender identity develops over time through our performances. Because of this, gender identity is fundamentally fluid and dynamic insofar as we have access to learn, enact, and be recognized for different performances. Disability and ableness are also enacted embodied performances. We learn over time how to act "able" and/or what it means to interact as a disabled person. Moreover, disability may affect our ability to perform particular identities and the perception by others of those performances (Siebers, 2008).

In the poem "The Magic Wand," for example, African American blind artist Lynn Manning (2009) explores his control over his identity as well as the constraints he faces in how people perceive him. Manning describes the different stereotypes of Black men and blind men, stereotypes which he encounters based on whether or not he displays his white cane (to note, a white cane is used for mobility purposes among people who are blind). Without the cane, his Black body provokes one set of reactions. People assume he is a gangster or an athlete and he reacts to these stereotypes. With the cane, his blind body now takes priority in how people interact with him. People assume he needs charity or that he has almost supernatural wisdom. As he moves through the world in his body, he must confront the ways in which people react to him as a blind or a Black man. Manning's poetry shows the ways in which the body one inhabits shapes one's interactions with society and how the world is experienced and understood.

#### **Crip Theories**

Crip theories center the experience of disability and explain the world from the perspective of disability. They draw on the tradition of standpoint theory, developed by feminist and race scholars. In classical social theory, W. E. B. Du Bois ([1903] 1994) argued that African Americans occupy a particular social position in society and experience the world and build knowledge from that position—an idea referred to as **standpoint theory**. He drew upon his standpoint as an African American to identify the economic and cultural processes used by Whites to enforce racism. Drawing on standpoint theory as applied to women, Dorothy Smith (2007) advocated a sociology for and by women which would examine women's experiences of the social world and retheorize all social phenomenon (e.g., work, family, violence, war, politics) to consider how gender is constitutive of it and affected by it. Crip theories prioritize the world from the perspective and experience of people with disabilities.

Moreover, crip theory encourages a liberatory commitment to redesign the world in ways that are accessible and inclusive of the broad range of human diversity. "To crip" (e.g., to crip sexuality theory, to crip the arts) becomes a political and academic verb, meaning to recognize the imposition of ableist worldviews and to reimagine a world that values and includes people with disabilities (McRuer, 2006). Crip theories of physical and social geography, for example, identify the ways in which architectural designs exclude people with disabilities and offer new designs that are welcoming to all (Titchkosky, 2011).

One of my favorite examples of crip theory is the discussion of "crip time." Scholars including Alison Kafer (2013) and Ellen Samuels (2017) have pointed out that time is not simply naturally occurring. In the United States, we experience time in a particular way: the relentless demands of production schedules (e.g., you have one week to meet this goal, 45 minutes to take this test); the standardization of daily schedules through education and beyond (everyone must be ready to start at 7:45, must learn in 50-minute blocks, must navigate the halls in 10 minutes, must eat lunch in only 30 minutes and need no more than two quick bathroom breaks); and the developmental and lifespan timeline (children should walk by age 1½, learn their ABCs by age 5, begin algebra in middle school, engage in productive work from their 20s-60s). This imposition of normative time ignores and constrains human variation; it creates disability among those who cannot meet these specific norms. Crip theory not only reveals the social and oppressive forces in the imposition of normative time, but also offers a liberatory framework. By centering the perspectives of people with disabilities, it encourages us to imagine a world that uses crip time, a world in which we have time to be sick and to rest, to perform paid work on our own timeline, to provide care for others and to engage in self-care, and to recognize the varied human experience of development across the lifespan (Samuels, 2017).

## **Theory Overview**

While exposure to all of these theories may feel overwhelming, the key point here is that disability is a social phenomenon and, as such, needs to be explained through examining social processes and structures, such as social interaction, culture, the economy, and the state. In doing so, sociologists take into account systems of inequality, intersectional oppression, and the ways in which our bodies affect and are affected by society. Embodiment and crip theory offer theoretical perspectives that prioritize the lived experiences and perspectives of people with disabilities. Sociologists draw on this rich range of theories, and others, to examine disability in society. Table 1.2 provides a synopsis of the theoretical perspectives.

### **TABLE 1.2** Overview of Theoretical Perspectives

Theories	Main Idea	Embedded Ideas	Example
Symbolic Interactionism and Cultural Theories	Disability is created through social interaction. We create the meaning of disability, which then shapes our experience of disability.	Verstehen Discourse Habitus	Medical model is a discourse that shapes the way we think about and experience disability.
Materialist Theories	Disability is created through and affected by unequal access to resources.	Capitalism Means of production Relations of production Superstructure	In its drive for profit, capitalism exploits workers and excludes those who are not productive enough. Harsh working conditions create disability.

### **TABLE 1.2** Overview of Theoretical Perspectives (Continued)

Theories	Main Idea	Embedded Ideas	Example
Political/ State-Centered Theories	The state creates disability as an administrative category. More broadly, those who exercise authority in a variety of settings define and enforce disability.	Interstate variation Political Economy	State and county governments create different definitions of disability, leading to vastly different experiences of disability.
Stratification/ Intersectionality/ Relationality	Each society is composed of groups, with differential access (or lack of access) to resources. Disability, often in combination with other axes of inequality, shapes relationships and access to resources	Minority Model Intersectionality	People with disabilities have access to far fewer resources. This situation is often made worse when combined with other minority statuses.
Embodiment	One's body shapes one's experiences of the world, and therefore mediates one's disability experience.	Performativity	If one uses a wheelchair and confronts steps, one experiences the world in a different way than others. People also <i>use</i> their bodies to perform certain roles.
Crip Theories	A liberatory perspective that envisions the world from the standpoint of people with disabilities and pursues a world in which people with disabilities are empowered and valued	Standpoint To crip	Society constructs normative ways of doing things, like learning in 50-minute blocks, and these norms disadvantage some people. To crip education is to reconfigure it in ways that are inclusive and center students with disabilities.

### Conclusion

In this chapter, we introduced the Sociology of Disability, presented some common definitions of disability, explained the ideas of the social construction of disability and the social and medical models, and reviewed several of the theories used by sociologists of disability. In doing so, we established some of the key foundations of the Sociology of Disability and provided the tools for students to begin to explore the social construction of disability across time and place and to uncover the social factors that produce and shape disability.

#### **KEY TERMS**

Crip theories 19
Deviance 4
Disability 6
Discourse 12
Dominant discourses 12
Embodiment 18

Essentialized 3 Habitus 13 Impairment 7 Intersectionality 17 Labeling theory 7
Materialist theories 13
Means of production 13
Medical model 8
Medical sociology 3
Minority model 17
Performativity 19
Political economy 16
Relations of production 13

Social construction 6

Sociological imagination 3

Social model 8

Social stratification 16 Sociology of disability 4 Standpoint theory 19

State-centered theories 15

Superstructure 14

Symbolic interactionism

12

Verstehen 12

## RESOURCES

# Classic Readings in the Sociology of Disability

Oliver, Mike. 1993. What's so wonderful about walking? A lecture delivered at the University of Greenwich, available in text (25 pages) at https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/Oliver-PROFLEC.pdf. Oliver offers a sociological analysis of walking, including its cultural meaning and the value accorded to it in rehabilitation.

Zola, Irving Kenneth. 1982. "Chapter 11: Four steps on the road to invalidity: The denial of sexuality, anger, vulnerability and potential." In Missing pieces: A chronicle of living with a disability, 212–237. Philadelphia, PA: Temple University Press. This chapter concludes Zola's thoughts on his experience at a residence designed for people with physical disabilities in the Netherlands called Het Dorp. One of the earliest writings in the Sociology of Disability.

#### **Example of Contemporary Theory**

Samuels, Ellen. 2017. "Six ways of looking at crip time." *Disability Studies Quarterly* 37, no. 3, https://dsq-sds.org/article/view/5824/468424/4684. An accessible essay discussing crip theory and crip time.

# Memoirs Useful for Discussing the Medical and Social Models

Greely, Lucy. 1994. *Autobiography of a face*. Boston, MA: Houghton Mifflin. Documents

Grealy's experience with cancer and disfigurement and offers the potential to discuss the medical and the social model.

Heumann, Judith and Kristen Joiner. 2020. Being Heumann: An unrepentant memoir of a disability rights activist. Beacon Press. Heumann's activism is on the forefront of the shift from a medical to a social model and imaging how to recreate an accessible and empowered world.

#### YouTube

"Social Model of Disability With Mike Oliver." https://www.youtube.com/watch?v=gDO6U0-uao M&t=186s. A discussion of the creation of the social model by one of its original proponents, Michael Oliver (7:41).

"What is the Social Model?" https://www.youtube.com/watch?v=0e24rfTZ2CQ. A very short explanation of the social model expressed by prominent members of the disability community (2 minutes).

#### **Poetry**

Manning, Lynn. Reading of his poem "*The Magic Wand*." http://lynnmanning.com/images/26.The\_Magic\_Wand.mp3 (2 minutes).

### **ACTIVITIES**

1. Using the Medical and Social Models Judy Heumann was born in 1947 and contracted polio when 18 months old. With the help of doctors, she underwent treatment and recovered from the polio, but had life-long effects including becoming a wheelchair user. At the time it was legal for public schools to exclude students with disabilities, and her school did so, calling her a "fire hazard." She eventually graduated from college but was denied her teacher's license because the board believed she could not protect children in an emergency situation. She sued and won her case. She emerged as a leading disability rights activist, fighting against discrimination and for policies that increase access.

If one is using the medical model, what is the problem and the solution?

If one is using the social model, what is the problem and the solution?

What might be useful for each model?

What might be limiting about each model?

- 2. Exploring theories of disability
  - Sociology seeks to explain social patterns by looking at macro social factors. This chapter provides a range of theories about the macro social factors that might affect disability in society, including cultural theories, materialist theories, political/state-centered theories, stratification and intersectionality, embodiment, and crip theories.
    - a. For each theory, summarize in a few bullet points what factors or processes produce and/or

- affect disability in society. (e.g., Cultural theories start by looking at how meanings are created and shift to produce certain social effects.)
- b. Theory allows us to brainstorm possible explanations for social phenomena, and research then provides a way for us to test these explanations. So, let's take a social phenomenon and brainstorm the factors that each theory would call attention to. Let's consider the rapidly increasing rates of autism diagnosis in the United States. Autism was first identified in the 1940s, and the diagnosis was very rare. By 2000, 1 in 150 children was identified as autistic. By 2008 diagnosis increased to 1 in 88 and by 2017 1 in 68. This is an incredibly rapid change, leading some to declare an "autism epidemic." Sociologists look at how social factors might create this rapid increase in autism and/or autism diagnosis.

Read the following short article "The Real Reasons Autism Rates are Up in the United States" at https://www.scientificamerican.com/article/the-real-reasons-autism-rates-are-up-in-the-u-s/. What explanations are offered for the rise in autism rates? Relate these explanations to at least one of the theories discussed in the chapter. For those theories that you haven't connected to the article, brainstorm how each theory might explain or think about this trend.