

Researching Disability

Learning Outcomes

- 2.1 Articulate why sociologists conduct research.
- 2.2 Evaluate the varied approaches to measuring disability.
- 2.3 Explain the ethical concerns raised by including and excluding people with disabilities as research participants.
- 2.4 Identify methodologies that empower people with disabilities in the research process.

Chapter Synopsis

Chapter 2 examines the conduct of sociological research on the topic of disability and doing research with people with disabilities. The chapter discusses the difficulties of measuring disability, the history of harm to people with disabilities by researchers, the underrepresentation of people with disabilities as research subjects, and methodologies developed that seek to upend traditional power relations and challenge disability oppression. Students in the field need to be mindful of these issues to increase their data literacy and to inform their own research practices.

Why Study Disability?

Sociology is a science committed to producing knowledge about our social world. Let's take a quick look at some of what we know about people with disabilities in America by looking at findings from the 2018–2019 American Community Survey (Houtenville & Rafal, 2020):

- **Prevalence:** The overall disability prevalence rate is 13.2%.
- **Employment:** Of adults 18–64 living in the community, 38.9% of people with disabilities are employed compared to 78.6% of people without disabilities, a gap of 39.7 percentage points.

- **Earnings:** Of those 16+ years of age who work full-time and year-round, the median annual earnings of people with disabilities is \$40,360, compared to \$48,406 for people without disabilities, a difference of \$8,046.
- **Poverty:** 25.9% of people with disabilities live in poverty, compared to 11.4% of people without disabilities, a gap of 14.5 percentage points.
- **Education:** Of Americans 25–34 years old, 16.1% of people with disabilities have a bachelor's degree or more, compared to 39.2% of people without disabilities, a gap of 23.1 percentage points.
- **Health Insurance:** 89.9% of people with disabilities have some form of health insurance, compared to 86.9% of people without disabilities, a positive gap of +3 percentage points. If we look at private insurance though, only 46% of people with disabilities have private insurance compared to 75.8% of people without disabilities, a gap of 29.8 percentage points.

What stands out to you about these findings? Was any of the information surprising to you?

Sociologists collect data for many reasons. They may want to *describe* a social phenomenon, in this case the experiences of people with disabilities. Data reveal, among other things, the way people experience the world, what challenges they confront, and what successes they enjoy. Descriptive information also allows sociologists to distinguish fact from myth. There are many myths about disability. One myth is that employment has increased steadily among people with disabilities, especially since the 1990 passage of the Americans with Disabilities Act (ADA); however, statistics over time reveal that employment rates have not increased since 1990, and unemployment continues to be a significant problem among people with disabilities (Maroto & Pettinicchio, 2015).

Sociologists also conduct research to *evaluate or build theories*. As discussed in Chapter 1, theories offer explanations. Continuing with the issue of employment, if a sociologist wants to know *why* employment rates have not increased, they might, for example, use the deductive method of science in which they propose testable hypotheses, gather data, and confirm or refute their hypotheses. Research expands knowledge base by identifying broad patterns and causal relationships.

Research findings are often used to *inform action*, such as establishing and modifying policies and programs. For example, we might propose different employment policies depending on whether obtaining employment is challenging for all groups, for people with disabilities specifically, or for subsets of people with disabilities (e.g., people with less education, racial minorities). Data also provide a way to assess the effectiveness of established policies and practices. For example, the American Community Survey indicates that, whereas three-quarters of people without disabilities have private health insurance, only 46% of people with disabilities do. This is likely because private insurance is largely secured through employment. Given the current disparities in employment, the public health care system (e.g., Medicaid, Medicare) provides an essential safety net for many people with disabilities who would otherwise be left without necessary care. Politicians, policy makers, and/or

activists may use this knowledge to build policy initiatives or enact social change. Across these purposes (description, assessing theory, and informing action), conducting research is a very important job of sociologists.

Although researching disability is very important, it is not easy. In the following sections, we explore several challenges and opportunities related to researching disability, starting with the challenges of measuring disability.

Measuring Disability

If you google the question “what is the rate of disability in the United States?” you will find a tremendous array of numbers. Page one of my quick search yielded rates ranging from 12.6% to 26%. Relying on the 2018–2019 American Community Survey, 13.2% of Americans have a disability. In contrast, according to the 2010 Census, 19% of Americans have a disability. You may wonder, how could the numbers be so different? Which number is right? The better question is: what does each number represent? Different studies use different definitions of disability and research methods, leading to different findings.

In deductive science, concepts are transformed—or **operationalized**—into variables that are measurable and used in the collection of empirical data. In other words, when sociologists study social phenomena like gender, juvenile delinquency, unemployment, or disability (concepts), they must decide how they are going to actually define and measure these ideas (creating variables). If a sociologist wants to measure juvenile delinquency, they must decide if their definition will include all actions performed by minors that are against the rules (a definition which would yield *a lot* of delinquency), only actions that are against the law (yielding fewer instances), or only illegal actions for which minors are officially convicted (yielding far fewer instances). In the process of operationalization, there is always a gap, so to speak, between the concept and how it is defined and measured.

The process of operationalization is fraught for disability. Because definitions of disability vary widely by time, place, and culture, there are a wide variety of measures of disability (Altman, 2001; Mont, 2007). The continued stigma of disability and diverse language conventions further complicate measurement (US Census Bureau, 2017a). Each measure yields different rates of disability and provides different information about disability. The discussion below offers several ways that sociologists measure disability. It is not a complete list. Rather, it is meant to help you see a variety of measures and the implications of how one measures disability.

Quantitative Approaches to Measuring Disability

Quantitative research gathers data in a way that transforms data into numbers. For disability, this often means identifying and counting the number of people with disabilities. Within quantitative research, there are many approaches to disability measurement, of which we will discuss five.

1. **Disability as limitations and difficulties in activities due to health conditions and embedded within environments.**

One of the most common definitions asserts that disability is the experience of limitations or difficulties due to health conditions or impairments within

certain environments. This definition is elaborated upon in the **International Classification of Functioning, Disability and Health Model (ICF)**. According to the ICF, disability is not defined as a medical condition/impairment. Rather, it is the experience of limitations or difficulties in body structure and function, activity, and/or social participation (Mont, 2007). *Body structure and function* refer to specific impairments in the functioning of one's body systems, such as the inability to move one's legs or to see. *Activity limitations* refer to limitations in performing basic actions, such as getting dressed or feeding oneself. *Participation limitations* refer to difficulties performing higher-order social activities, such as working and attending school. In the model, limitations in these three domains are potentially affected by environmental factors (e.g., job market, accessibility of the school) and personal factors (e.g., age, gender). Thus, this model defines disability as the limitations resulting from a condition, not the presence of a condition or its cause.

Figure 2.1 offers an example of these factors, using a case study of a woman with cerebral palsy (CP). CP is an impairment but having CP does not mean that she is disabled. People with CP vary tremendously in their skills, experiences, and resources. Disability—represented in the second row—is the set of limitations which result from CP as she experiences it, such as her inability to grasp with her hands, inability to self-transfer to a toilet, and limitations in attending social events without a personal assistant. The third row indicates that these limitations may also be affected by her environment and her personal characteristics. Greater accessibility, for example, might enable her to attend social events and self-transfer. Thus, environmental changes can reduce/erase disability even if the biological impairment is stable.

To research disability, sociologists move from this definition to specific measures of disability. Given the ICF's definition of disability, the corresponding measurement tends to be a set of questions assessing limitations and difficulties rooted in impairment.

FIGURE 2.1 ICF Model

The 2000 US Census (US Census Bureau, n.d.a) used this approach when it asked:

Because of a physical, mental or emotional condition lasting 6 months or more, does this person have any difficulty in doing any of the following activities: (a) Learning, remembering or concentrating (b) dressing, bathing, or getting around inside the home (c) (if the person is 16 years or over) going outside the home alone to shop or visit a doctor's office and (d) (if the person is 16 years or over) working at a job or business?

The American Community Survey (remember, the data presented at the beginning of this chapter are from the ACS) also defines disability as difficulties and limitations, but it asks six questions covering the following areas (US Census Bureau, n.d.b):

Hearing difficulty—Is this person deaf or does he/she have serious difficulty hearing?

Vision difficulty—Is this person blind or does he/she have serious difficulty seeing even when wearing glasses?

Cognitive difficulty—Because of a physical, mental, or emotional problem, does this person have serious difficulty remembering, concentrating, or making decisions?

Ambulatory difficulty—Does this person have serious difficulty walking or climbing stairs?

Self-care difficulty—Does this person have difficulty bathing or dressing?

Independent living difficulty—Because of a physical, mental, or emotional problem, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?

Respondents who report any of the six difficulties are usually considered to have a disability (US Census Bureau, 2017b). Note that even though both the Census and ACS drew on a definition of disability as limitations and difficulties, the questions

from the 1990 Census and the 2019 ACS were different and yielded significantly different counts.

There are several advantages to measurements of disability based on difficulties. These measures make an important distinction between the impairment and the experience of difficulty. Information on difficulties may be more relevant for decisions regarding policy and service delivery than the presence

PHOTO 2.1

One of the American Community Survey Disability Questions.

Credit: U.S. Census Bureau (2022). Obtained from <https://www.census.gov/acs/www/about/why-we-ask-each-question/disability/>

of impairments. Compared with some other measures, like self-identity, this approach yields higher rates. This approach has also been more widely adopted internationally, allowing for some global comparisons (Pettinicchio & Maroto, 2021).

However, there are important disadvantages. Critics argue that, because this approach reduces disability to a set of difficulties, it represents an individual-level deficit orientation. In other words, disability is measured by what one cannot do, rather than the environmental barriers that produce disability. Moreover, the ACS measures tend to be biased toward physical and sensory disability and offer a less accurate count of intellectual, behavioral, and mental disability.

2. Disability as biophysiological conditions/impairments.

Drawing on the medical model, some research defines disability as the presence of significant impairments. Disability is conflated with (seen as the same as) impairment. Given this definition, researchers may measure disability by asking respondents to report their impairments or offer them a checklist of chronic and significant health conditions.

Using this strategy, the US National Medical Expenditure Survey, which provides national data on access to and cost of health care, asks respondents to list all “health problems, physical conditions, accidents, or injuries that affect any part of the body as well as mental or emotional health conditions, such as feeling sad, blue, or anxious about something.” As another example, the National Institute on Mental Health collects data on the prevalence of all conditions listed in the Diagnostic Statistical Manual (DSM, the reference manual that lists and defines mental illnesses). Excluding developmental and substance use disorders, they state that one in five Americans (46.6 million in 2017) live with mental illness (National Institute on Mental Health, 2019).

As an advantage, this strategy provides details about the prevalence of specific conditions, which can be very useful. We learn, for example, how many people have been diagnosed with depression or autism. However, it also has an important disadvantage. Impairments are not necessarily disabling. In other words, they may not result in a functional limitation or social disadvantage. Thus, there seems to be a significant gap between a list of conditions and the concept of “disability.” There is also tremendous variation in the rates of disability produced based on the list of impairments provided to respondents.

3. Disability as an identity.

Disability may be defined as a personal identity. Some people define themselves as disabled and others do not. The decision to identify as disabled is shaped by numerous factors. Disability as identity may be measured, for example, by asking people whether they identify as a person with a disability or whether they have a disability. Many surveys ask a simple question like: “Do you have a disability?” Zambia’s 2000 Census, for instance, asked, “Are you disabled in any way?” (Washington Group on Disability Statistics, 2009).

The primary advantage of measures based on self-identity is that they reveal the extent to which people actively identify as a person with a disability at that moment in time. It also tends to be a single question, which is attractive

to those designing and taking surveys. There are many disadvantages to this approach though. Although self-identification is a common technique for measuring race and gender, its use for disability is far more problematic (Washington Group, 2009). The likelihood of disability identification is complicated by stigma; many people avoid the term “disabled,” as well as related labels like mentally ill. Diverse belief systems about disability and language conventions across cultures further complicates the use of self-identification. Disability is a broad umbrella category encompassing varied impairments and experiences, but many cultures do not have a word, or a belief system for that matter, that corresponds conceptually to “disability” as it is intended in American surveys. They may have only narrower terms that relate to specific impairments (e.g., words for blindness, deafness, mental illness) or broader, vaguer terms like “unfortunates” (Groce, 2006). Disability is also fluid in its manifestation, its sociocultural relevance, and its salience for one’s identity. In other words, someone may have multiple sclerosis, but the extent to which they feel or identify as disabled may vary by factors like fluctuations in symptoms; the social environment, its expectations, and accessibility; and their own values, conceptions of disability, dispositions, and identity composition.

Due to the reasons listed above, self-identification typically yields low rates of disability. This is especially true in low-income nations where people with disabilities tend to experience significant stigma and social isolation, and where the idea of “disability” is uncommon (Me & Mbogoni, 2006). In Zambia, measures based on self-identification found a disability rate of 2.7% (Washington Group, 2009), whereas measures based on functional limitations yielded a rate of 13% (Üstün et al., 2010).

4. Disability as social disadvantage related to impairment or perception of impairment.

The social model argues that the environment creates disablement. Building on the social model, some researchers try to measure the environmental barriers that disable. Kenjiro Sakakibara (2018), for example, created a disablement score in which respondents rank from 0 to 100 the level of social adversity and exclusion (e.g., the negative effect on finding a job, marriage, joining social clubs) associated with a variety of conditions (0 = no adverse effect, 100 = completely adverse effect). The disablement score, therefore, assesses the *social* constraints faced by people with varied conditions, presenting the context as more or less disabling depending on your body/mind. He found, using a relatively small sample in Japan, sensory disabilities like deaf-blindness and blindness received the highest “disablement” scores, while being a person of short stature received one of the lowest scores. Other researchers may examine the experience of inaccessibility and exclusion, asking questions such as: In the last six months, have you had difficulty in doing activities or interacting with others due to the inaccessibility of communication systems, physical environments, or transportation, or due to negative attitudes, beliefs, or policies related to disability?

There are several advantages of this approach. It is aligned with the social model, which is one of the most common sociological definitions of disability. As such, it moves away from the individual deficit-model and instead documents environmental barriers/problems that disable people. Because it focuses attention on the environment, findings rooted in this approach may better inform social reform.

There are important disadvantages, though. The social model suggests that the barriers *create* disability; therefore, disability is only present to the degree that the barriers are present. This means that one's status as a disabled person shifts as the environment shifts; if the environments are not disabling, the people are not disabled. Hence, the unit of analysis is the person/environment interaction, not the person, which is far more complex to measure. For example, a blind person is not disabled by the lack of sight, or the personal difficulties of mobility, but only when they experienced situations like a lack of Braille menus, websites that do not work with software that reads the website aloud, stigma against the white cane, or prejudice in the workplace. In one setting or interaction, a person may be disabled, and in another the same person is not disabled. This is very fluid, dynamic, and difficult to count.

Furthermore, many researchers argue that there is good reason to keep disability and the experience of barriers conceptually distinct. Keeping these concepts distinct allows for the analysis of the rates of inclusion/exclusion and the factors that promote each. If researchers define disability *as* the experience of social disadvantage, they cannot see *if* people with disabilities are advantaged or disadvantaged because they have defined disability as disadvantage. Thus, it becomes more difficult to examine for whom or how exclusion or inclusion increases.

5. Disability as the receipt of disability benefits or program eligibility.

A final definition and measure that we will discuss (we could discuss more!) ties disability to the definitions and eligibility requirements embedded within disability policies and programs. In this approach, one is disabled if one is eligible for and/or enrolled in some program for people with disabilities. For example, we might measure disability as anyone who receives disability benefits through Social Security or has an Individualized Education Program (IEP) at school.

The key advantage to this approach is its direct policy relevance. It informs us how many people are eligible for and/or participating in particular programs, and we can then examine their profile and needs. It is also a relatively convenient measure since a program has already identified a group of people as disabled. As a disadvantage, though, while it is useful to know how many people are eligible for or receive such benefits, the definition is then tied to the goals of the program. For example, the Social Security Administration (SSA) uses a narrow definition of disability tied to the total inability to work, which is a *much* narrower definition than one

PHOTO 2.2
Form for Disability
Benefits.

Credit: Designer491 (2018). Reproduced with permission from iStock.com.

based on activity limitations. Not only is the SSA definition narrower, but becoming a recipient of benefits involves a complex application process that favors people with greater cultural and economic resources. People are more likely to be approved for social security benefits if they have access to a well-qualified personal physician who will attest to their disability, an educational level sufficient to work through many forms and procedures, transportation to attend meetings at the SSA, and the resources to hire a lawyer if needed. As such, if we measure disability by the receipt of SSA benefits, we exclude a wide array of people who live with disability but who have not applied for or been enrolled in SSA programs.

Qualitative Approaches to Measure Disability

Using a very different approach, **qualitative research** foregoes the goals of counting disability and standardizing the measurement of disability across time and place, and instead it offers techniques to dive deeply into examining the meanings and experiences of disability (Mazumdar & Geis, 2001; Taylor et al., 2016). Qualitative researchers ask broad, open-ended questions to delve into the meaning of disability and the meaning-making processes among groups, institutions, and societies. They may ask something as simple as “What does disability mean to you?” or they may ask many in-depth questions to understand the complexity of disability identity and experience.

This approach has many advantages. It corresponds with the common sociological idea that disability is a social construction that varies by time and place (Taylor et al., 2016). For example, work on intellectual disability has shown that the meaning of intellectual disability has changed over time, and as the meaning changed, so too did stereotypes and policies (Carey, 2009; Trent, 1994). Some groups, like the D/deaf community,¹ actively debate the meaning of disability and how and if it applies to their community. Qualitative inquiry enables researchers to explore the varied meaning systems at play, who believes what, why, and to what consequence.

This strategy also encourages sociologists to explore the complex ways that disability may or may not be understood across diverse cultures. For instance, some cultures may have no concept comparable to modern America’s idea of “disability.” In her work among modern Indian immigrant communities in America, Susan Gabel and her coauthors (2001) found that there was no meaningful translation of the US Census questions on disability for these communities. Hindu ideas of the body, sickness, and disability are rooted in beliefs about karma, mind-body-spirit connection, and spiritual well-being, not biomedical perspectives. Although pre-determined quantitative measures seek to generalize and standardize notions about disability, sociologists find that the meaning of disability shifts through time, place, and social context. Therefore, quantitative measures yield a count, but not one that necessarily reflects the varied understandings and experiences of disability. In-depth, inductive, qualitative research better enables this type of “meaning” research.

¹People who are “deaf” with a lowercase “d” consider deafness to be an impairment. People who are “Deaf” with an uppercase “D” consider Deaf people to be a linguistic and cultural minority.

As a key disadvantage, though, qualitative work does not typically yield widely generalizable statistics. Insofar as statistics aid in policy planning, qualitative work may come up short in this regard. Also, in-depth and open-ended questions can also be very time-consuming to analyze, and different researchers may find different patterns.

Table 2.1 summarizes the varied approaches to measuring disability.

TABLE 2.1 Approaches to Measuring Disability

Definition Disability Is	Sample Measurement	Advantages	Disadvantages
The experience of limitations and difficulties	Do you experience difficulty in self-care?	Distinguishes impairment and disability Gathers data on a variety of difficulties Policy relevant Yields high rates	Uses a deficit-approach Might be too broad Requires many questions
The presence of biophysiological conditions	Do you have any of the following conditions?	Gathers prevalence rates for a variety of impairments	Conflates impairment and disability
Self-Identification	Do you have a disability?	Measures self-identification Easy, one question	Many people with impairments and difficulties do not self-identify Yields low rates
The experience of social disadvantage	Have you encountered buildings which were inaccessible?	Connects well to social model Gathers information on the environment Useful for social reform	People only “count” if and when they experience disadvantage Fluid and dynamic Harder to measure person/environment interaction Requires many questions
Eligibility or receipt of disability benefits, services	Are you eligible for disability services at your university?	Policy relevant Relatively easy to measure	Policies are created for specific purposes so the counts are limited based on program
Not predefined (Qualitative)	What does disability mean to you?	Treats disability as a social construction Allows diverse definitions	Harder to “count” disability or determine prevalence rates Challenging to compare “disability” across groups or cultures

Considering Data Literacy

Once you understand these different approaches, you can evaluate the implications of the statistics in research. For example, this chapter opens by using statistics from the American Community Survey (ACS), which measures disability by asking six questions that assess difficulties with key tasks.

What do the data tell us? Because the ACS asks six questions covering different types of difficulties, we learn the prevalence rate of these difficulties. We can then examine if these difficulties correlate with social disadvantages such as unemployment and poverty, which may be very useful for considering policy.

What do the data not tell us? First, the ACS does not ask specific questions about mental, emotional, or learning disabilities, although these are relatively common forms of disability. They may be captured in the question measuring difficulties in remembering, concentrating, and making decisions, but they may not be. Thus, the ACS may lead to a considerable undercount of particular kinds of disability. Furthermore, from these questions, we do not learn about the environmental contexts and barriers. We do not know, for instance, if people have difficulty working because of their biological impairment (the question assumes this reason), because employers will not hire and accommodate people with their impairment, or because of a lack of accessible transportation given their impairment. Without this information, we may struggle to formulate the best policy solutions.

Once we understand the range of measurement approaches and their advantages and disadvantages, we can best assess the quality of the information gathered and the biases and perspectives built into the data.

Ethical Issues in Researching Disability

In many ways, researchers who study disability rely on the same research methodologies and face the same challenges as sociologists who study any other topic. However, disability does present several particular issues for researchers. This section explores several important ethical and methodological challenges of researching disability.

Harm to Research Participants

Any discussion of disability and research must acknowledge the long history of harm imposed on people with disabilities by researchers (Oliver, 1992, 2002; Stone & Priestly, 1996). People with intellectual and mental disabilities, forced into institutions and wielding little power by which to protect themselves, were among the populations especially vulnerable to the abuses of experimentation (Stobee, 2011).

To offer some examples, in 1942 as part of a federally funded research project, doctors injected male patients of a Michigan mental hospital with an experimental flu vaccine and later exposed them to the flu without patient consent. In 1963, researchers injected elderly, ill men at New York's Jewish Chronic Disease Hospital with cancer. From 1963 to 1966, researchers exposed children diagnosed with intellectual disabilities at Staten Island's Willowbrook State hospital to hepatitis (Goode et al., 2013). Most infamously perhaps, in the **Tuskegee experiments** from 1932 to 1966, the US Public Health Service

denied treatment to 600 Black men with syphilis in order to track the progression of the disease. The US is not alone in its history of abuse. Nazis in Germany targeted people with disabilities and people in concentration camps for experimentation (Caplan, 1989). Unethical research on people with disabilities continues to be a global problem.

The above examples focus on medical experimentation, but the history of harm is broader. People with disabilities have withstood countless psychological and sociological research studies to study topics like their maturation, deviance and obedience, reactions to various rewards and punishments, and techniques to improve their performance at school and in jobs. This research, however, may not have yielded a significant improvement in the lives of those who endured being a research subject or even for people with disabilities broadly.

In response to various scandals involving research with human subjects, in 1974 the National Research Act established **Institutional Review Boards** (IRBs) to proactively monitor research on human subjects and ensure its adherence to ethical guidelines. Federal guidelines identified **vulnerable populations**—groups who, based on the history of abuse and continued vulnerability, would be protected by IRB protocols. These populations include (not an exhaustive list) children, people with physical and mental disabilities, people with chronic health conditions, prisoners, and people who are economically disadvantaged. Research on vulnerable populations now faces heightened scrutiny, and researchers must justify their reasons for researching these populations, document the process for obtaining informed consent, and justify any potential for harm.

Exclusion from Research and the Silencing of Disabled Voices

While the harm of research with disabled participants is a concern, so too is their exclusion from research. Systematic exclusion from social research silences the voices of people with disabilities and erases their experiences (Mietola et al., 2017; Santinele Martino & Schormans, 2018). This is particularly troubling because people with disabilities have a unique set of experiences and perspectives, and without an understanding of them, our knowledge is shallower.

Research often builds knowledge based on the perspective of White, able-bodied men, but this is inadequate. Indeed, the inclusion of a diversity of people fundamentally shifts one's understanding of the world. Feminist sociologist Dorothy Smith (2005), for example, argued that sociology must try to see the world from the perspective of marginalized populations and to use sociology for the benefit of those populations, serving as a “sociology for people.” Taking up this call, feminist sociologists (e.g., Heidi Hartmann, Patricia Hill Collins, Nancy Naples) have examined how women's perspectives lead to the reconceptualization of sociological theories. For example, Marjorie DeVault's (1991) scholarship reconceptualized the study of work. Whereas male scholars typically defined work as paid work, she included the varied forms of unpaid and invisible labor in which women engage. By doing so, she showed how women's invisible labor often undergirds male privilege and patriarchy.

Similarly, the inclusion of people with disabilities in research transforms the way sociologists conceive of the world. To offer an example, including people with disabilities in research has transformed the way researchers understand domestic violence. Measures of domestic violence usually begin with a list of violent activities (e.g., hitting, pushing, kicking) and inquire if people have experienced those forms of violence perpetrated by intimate partners. Through interviewing people with disabilities about the violence they endure, though, researchers identified additional forms of domestic violence more unique to this population, such as the removal of assistive technologies, the denial of basic care, and threats of institutionalization. Without this broader conceptualization of domestic violence, sociologists would overlook these occurrences, even though people with disabilities and older Americans are among the groups most likely to experience domestic violence. Thus, research that does not include the experiences and perspectives of people with disabilities yields an incomplete and skewed picture of the world. In effect, disability serves as an analytic lens, providing new questions to ask, new ways to gather data, and new interpretations in understanding the world.

Although we need to include people with disabilities in social research, they are underrepresented in it. Why? We'll discuss a few important reasons.

Let's start with a consideration of biased sampling. Sampling is the process by which researchers select who will be included in the research study. **Biased sampling** is a type of error that occurs when decisions about sampling lead to an incongruence between the sample and the population, in this case a systematic underrepresentation of people with disabilities. Social research often purposefully excludes people in "institutional settings," including nursing homes, psychiatric hospitals, and even group homes for people with intellectual disabilities. Yet, many people with disabilities reside in these kinds of settings. For example, one-third of people receiving services for intellectual disabilities live in group homes (Parsons et al., 2001). People in institutional settings have very important experiences and opinions, but they rarely have the opportunity to share them.

The process of ethical review through the Institutional Review Board (IRB) may compound this problem. As discussed, the IRB reviews research proposals to ensure compliance with ethical guidelines, and they focus extra attention on populations identified as vulnerable to harm. Although people with disabilities are identified as vulnerable for good reasons, the IRB may be reluctant to approve almost any research involving disabled research subjects in an effort to protect people with disabilities from harm and to protect researchers and universities from controversy and liability (Santinele Martino & Schormans, 2018). Researchers are steered away from people with disabilities and encouraged instead to speak with family members and professionals about disability, as if nondisabled people can fully represent the disability experience. People with disabilities are effectively silenced.

Furthermore, people with disabilities are more likely to live in settings with **research gatekeepers**—people whose approval is necessary for people with disabilities to participate in research. For example, to access people who live in nursing homes, group homes or other agency-run facilities, researchers must get agency approval. Agencies, though, may deny access to their participants for a wide variety of reasons. They may see research as inconvenient, an invasion of privacy, or a liability issue. For example, Steve Taylor and Robert Bogdan (1998) argued that state institutions denied

researchers access to residents in an effort to hide poor conditions and silence resident complaints. Parents and legal guardians also act as gatekeepers, adding an additional layer of complexity to access (Matysiak, 2001). If people have been legally adjudicated incompetent, guardians must consent to research participation; however, there is no easy way for a researcher to know who is under guardianship or who is not. Not all people in institutional settings or group homes are under guardianship, and not all people who live in the community are legally competent. To be “safe” (to protect respondents from harm and researchers from liability), the IRB and researchers may decide to treat all people with disabilities as if they are incompetent. This assumption of incompetence, though, unfairly stereotypes and excludes people with disabilities, especially people with intellectual and mental disabilities (Santinele Martino, 2018).

Even if people with disabilities are included in the overall sample, they are still less likely to participate in research due to *inaccessible data collection techniques*—techniques to gather data that fail to offer a range of ways for a diversity of people to participate. For example, national surveys often utilize telephone surveys, but this method undercounts people who are economically disadvantaged, homeless, deaf, or have communication disabilities (as a note, people with disabilities are also disproportionately among those who are economically disadvantaged and homeless). Internet surveys face many similar disadvantages. Interviewers usually have no training in ASL or communication technologies and often do not make materials available in accessible formats like large print, Braille, or electronic formats.

Few researchers have even tried to best capture the lived experiences and perspectives of nonverbal people with significant disabilities (Mietola et al., 2017). Instead of interviewing people with disabilities, researchers will sometimes rely on **proxy respondents**—people who participate in research on behalf of another person. Proxy respondents are asked to answer the questions as closely as possible to the imagined answers that would have been given by the person with a disability. Research, though, has shown that proxies do not reliably answer in the same way as the person with a disability and that the use of proxy respondents is likely more common than necessary. Too often, proxies are used for the researcher’s ease and to lower research costs rather than because people with disabilities are unable to communicate for themselves (Parsons et al., 2001).

PHOTO 2.3

Internet surveys are increasingly common and not always accessible.

Credit: Andrey Popov (2020) from istock.com.

Power and the Research Process

Including people as research respondents is an important step in knowledge production, but it is only a step. Researchers set the research agenda, including the goals and outcomes of any given study. However, very few researchers are people with disabilities. The underrepresentation of researchers with disabilities is related to many factors, such as the accumulated disadvantages in education which hinder the attainment of advanced degrees, employment discrimination, and ableism in higher education. The expectations and the lack of accommodations in the research process—such as the expectation to conduct research in inaccessible homes and communities, to communicate in standardized ways, and work long hours on tight deadlines—also may present barriers (Burke & Byrne, 2020). Therefore, people with disabilities have little opportunity to shape the research agenda, and instead the priorities of disability research are established primarily by people without disabilities.

Some activists and scholars argue that disability research can only truly be useful to the disability community to the extent that people with disabilities participate in and *exercise control over the research process*. Research methodologies such as Feminist Methodology, Participatory Action Research and Emancipatory Research take up this call. Before we explain these methods, let's take a step back and look at the broader debate in Sociology regarding power and the research process.

Since Sociology's formation as a science, sociologists have debated the reasons and the methods for doing research (Guba & Lincoln, 2005; Taylor et al., 2016). Durkheim ([1938] 2013), for instance, promoted **positivism**—the view that there is an objective world to be discovered through scientific methods conducted by unbiased researchers. In this view, it does not matter who conducts the research as long as they are well-trained, objective, and unbiased. In order to remain unbiased, the researcher must not be committed to any particular finding or political action; science and politics must be kept separate. Many contemporary sociologists, including some who do disability research, adhere to this belief.

Other scholars, like Karl Marx ([1888] 1978), however, argued that the claim to objectivity was false. Humans can only understand the world through our subjective, and intersubjective, experience of it. Because meaning is created through social interaction, science cannot be emptied or removed from this process. Indeed, science in any given society often relies on and represents the values, relationships, and social structures of that society. For Marx, elites typically control science, and therefore science too often supports and legitimizes inequality. Michel Foucault (1980) expanded on this idea, arguing that power and knowledge are inseparable; those in power create dominant discourses that then reinforce the power inequities. Rather than a single objective reality, knowledge is produced within a power structure and wielded by those in power. Resisting the power imbalance often embedded in research, some scholars promote critical theory and praxis. **Critical theory** seeks to develop knowledge that reveals and challenges unjust power structures, while **praxis** is the use of theory and research to achieve social justice. Who wields science and for what purposes, then, is a central issue in the ethics of research.

Taking up the call for a science committed to social justice, feminist scholars created a range of methodological strategies to guide feminist methodology (Harding, 1987; Reinharz, 1992; Smith, 2005). Some key principles of **feminist methodology** (Davis & Craven, 2016; Leavy & Harris, 2019) include:

- The production of knowledge that prioritizes the voices and experiences of women;
- A commitment to reveal and challenge power differentials, focusing on gender analysis and an intersectional view of women's realities (i.e., taking into account race, class, sexuality, ability, etc);
- A rejection of the positivist orientation to instead embrace subjectivity and reflexivity, acknowledging the researchers' values, social position, and impact on a given community;
- A rejection of the traditional researcher-subject hierarchy and the creation instead of processes that empower everyday women to act as experts of their own lives and contribute to knowledge production;
- A commitment to serving as an active ally in the feminist movement and producing knowledge useful for the improvement of women's lives.

Patricia Leavy and Anne Harris (2019, p. vi) state that feminist methodology is “about doing research that is embedded in and accountable to ‘real life’ and making real life better—not just for women, but for all—and to realize that these are not separate projects but interconnected ones.”

As disability activism grew and the social model took hold in the academy, disability scholars also demanded a change in methodology. Some disability scholars, such as Jenny Morris (1993), Linda Blum (2015), and Laura Mauldin (2017), draw on feminist methodologies to inform their work, highlighting the intersection of disability and gender oppression and/or utilizing methods that prioritize the voices and expertise of women in relation to their disability experience.

Other scholars articulate a model of “emancipatory research” specific to disability research (Barnes & Mercer, 1997, 2008; Oliver, 1992, 2002). Explicitly tied to the social model of disability which sees disability as an experience of social oppression, **emancipatory research** is a research methodology with “an avowed commitment to the empowerment of disabled people through a process of political and social change while also informing the process of doing disability research” (Barnes, 2008, p. 2). In this approach, researchers actively engage in the political struggle of people with disabilities for justice. Formulations of emancipatory research vary, but they tend to stress the following principles:

- Conducting research that reveals and challenges social inequity and oppression of people with disabilities;
- Empowering people with disabilities and their representative organizations to control the research agenda, process, and product, thereby to transform the researcher-researchee relationship as larger social-political relations of power are also transformed;

- Practicing researcher accountability to the disability community, including the conduct and dissemination of research that is useful and accessible to the community;
- Serving as an ally for the political empowerment of people with disabilities.

Another methodology commonly used by scholars with an orientation toward praxis is participatory action research. **Participatory Action Research (PAR)** addresses issues identified by specific communities, in ways that are useful to the community, with the full and active participation of all relevant stakeholders. Like feminist and emancipatory approaches, PAR challenges traditional power inequalities in research, engages with communities, and includes community members as coresearchers. However, this method is broader in some ways than feminist or emancipatory methods, because it encourages active engagement with any community to meet any pressing research needs. Thus, the goal is not necessarily social justice. A community might want, for example, to evaluate a particular type of assistive technology or address a problem in Medicaid policy—issues that are relevant and useful but may not lead to political emancipation. Another distinction is the level of commitment to the community. PAR researchers do not necessarily sustain a long-term political commitment to the same community. They may conduct a single research project with a community, and then move on to assist another community.

These methodologies—feminist, emancipatory, and PAR—encourage researchers to take on the role of **scholar-activist**, using research to advance social justice. Scholar-activism is not without critics of course. Criticisms include, for instance, that a commitment to only transformative methodologies may diminish the quality and variety of knowledge produced (Danieli & Woodhams, 2005). Furthermore, the demand to disclose disability and unite with the disability community potentially may burden scholars with disabilities (Rinaldi, 2013). Yet, despite criticisms, many scholars remain deeply committed to transformative research.

Research methods in the study of disability continue to evolve. For example, contemporary researchers continue to explore best practices in the inclusion of people with disabilities as research partners (Hollinrake et al., 2019; Tregaskis & Goodley, 2005). Mietola and colleagues (2017), for instance, developed strategies to explore the experiences of people who are nonverbal and have significant intellectual disabilities, a population often excluded from research. Current scholars conducting intersectional scholarship also continue to challenge the control of scholarship by White scholars with and without disabilities. For example, Leroy Moore Jr. and his collaborators (2016) wrote a provocative piece criticizing the privilege of White disability scholars who exercise greater control over the research agenda and disproportionately reap the rewards that flow from research, such as recognition as experts and the receipt of grant funding, while doing little to support the expertise, activism, and scholarship rooted in communities of color. Thus, disability research continues to struggle to be broadly inclusive and to empower the range of people with disabilities in the processes and benefits of research.

Conclusion

Disability offers a window into many of the challenges and debates within sociological research, such as how to best define “disability,” if and how

researchers should strive to create research opportunities accessible to all, and the role of the researcher in challenging oppression. If you conduct research on disability, you might consider issues like:

- How should I define disability and how does this choice shape my findings?
- Are my method and research materials—the consent form, the survey, the method of administration—accessible to people with a variety of disabilities?
- Will the research process and the research products benefit the community I am studying or do they primarily advance my own interests?
- What are my ethical obligations to the people and community being studied?
- How might I best create and disseminate knowledge that is useful to a community?
- How might people with disabilities be included in the research process and/or in the processes of dissemination and policy-making based on the research?

And even if you do not conduct your own research, hopefully now you will be better able to assess the meaning behind the statistics related to disability and the quality of the research.

KEY TERMS

Biased sampling 36	Institutional Review Boards (IRBs) 35	Proxy respondents 37
Critical theory 38	Operationalized 26	Qualitative research 32
Emancipatory research 39	Participatory Action Research (PAR) 40	Quantitative research 26
Feminist methodology 39	Positivism 38	Research gatekeepers 36
International Classification of Functioning, Disability and Health (ICF) 27	Praxis 38	Scholar-activist 41
		Tuskegee experiments 34
		Vulnerable populations 35

RESOURCES

Suggested Reading

Barnes, Colin. 2008. "An ethical agenda in disability research: Rhetoric or reality?" In *The handbook of social research ethics*, ed. Donna M. Martens and Pauline E. Ginsberg, 458–473. London: SAGE. Explains emancipatory research and assesses its potential.

Burke, Ciaran, and Bronagh Byrne, eds. 2020. *Social research and disability: Developing inclusive research spaces for disabled researchers*. Routledge. A collection focusing on barriers to inclusion in research and strategies for inclusion.

Houtenville, Andrew, and Marisa Rafal. 2020. *Annual report on people with disabilities in*

America: 2020. Durham, NH: University of New Hampshire, Institute on Disability. <https://disabilitycompendium.org/annualreport>. A nicely formatted research report compiling disability statistics that can be used both for the statistics alone as well as to assess the information garnered from particular measures of disability.

Mietola, Reeta, Sonja Miettinen, and Simo Vehmas. 2017. "Voiceless subjects?: Research ethics and persons with profound intellectual disabilities." *International Journal of Social Research Methodology* 20(3): 263–274. An example of recent methodological innovations to develop inclusive research methods.

Videos and Film

"The Grounded Academic: Disability, Poverty, and Health Care – Action Research in Rural Guatemala." <https://www.youtube.com/watch?v=5CYhKFmlvSk>. A short discussion by Dr. Shaun Grech about action research in poor, rural areas in Guatemala (7 minutes).

"Participatory Data Collection for Disability-Inclusive City: Solo City." https://www.youtube.com/watch?v=FUkvQ_NwNSk. A short video documenting participatory data collection in Solo City, Indonesia (5 minutes).

ACTIVITIES

1. Measuring Disability

Imagine that your university wants to conduct a survey to assess the degree to which students feel a sense of belonging and community at your university. The university wants to measure this sense of belonging among several different groups of students, including students with disabilities. Considering the various measures of disability discussed in this chapter, lay out (a) three approaches you could use to measure disability, (b) develop specific question(s) to measure disability at your university using each of the three approaches, and (c) discuss advantages and disadvantages for each approach. Finally, select an approach and question(s) and explain why it is the most advantageous for the university to use.

2. Examining and Evaluating Data

Click on the link to Houtenville, Andrew, and Marisa Rafal. 2020. *Annual report on people with disabilities in America: 2020*. Durham, NH: University of New Hampshire, Institute on Disability. <https://disabilitycompendium.org/annualreport>.

What kind of measure is used for disability in this report? What are the advantages and disadvantages of this measure? What are some of the report's most interesting findings? What does this report tell us about disability in modern America? What doesn't it tell us that you wish you knew?

3. Including Underrepresented Populations

Read *Voiceless Subject?* by Mietola, Miettinen, and Vehmas (listed above). Consider why people with significant disabilities are often excluded from social research and why/if it matters. What strategies did the authors develop to include this population? How effective were the strategies? What information could they gather? What information could they not gather? How broadly applicable is this technique for, say, the Census? Would you say this is emancipatory research?

4. Considering the role of the IRB and accessibility

Review your university's IRB submission forms and suggested consent letter.

Consider how/if the IRB protects people with disabilities. Also consider how/if the IRB allows inaccessibility and/or if it demands accessibility. In particular, review the IRB sample consent letter and consider its accessibility for diverse populations.

5. **Debate the researcher's role in fostering social justice**

Should scholars be a neutral party or should they be scholar-activists in the fight for social justice? What are the advantages and disadvantages of either role?

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