

# The Invisibilities of Disability: Compiling Conversations

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## Abstract

Disability and chronic illness researchers have long documented the varying ways that disability experience is invisible to us, yet their arguments have often existed in separate and disconnected forums; as a result, it is difficult to perceive the complex and varied nature of the invisibilities of disability. It is also challenging to see how invisibility operates simultaneously at both a macro- and micro-level. The invisibilities of disability are also exacerbated by particular contexts, such as the intersection of other social locations such as race, class, gender, sexuality, age, etc., and the COVID-19 pandemic; we often contemplate these contexts individually rather than collectively. Consequently, we use this article to compile the fragmented conversations about the invisibilities of disability. This review piece pulls explicitly on existing research in the social sciences and humanities to interrogate the numerous ways disability experience has been left unquestioned, marginalized, unnoticed, and ignored. The overarching goal is to show that the invisibilities of disability are many and that they are intertwined, simultaneously experienced, and structured into both our social institutions and individuals' everyday experiences.

**Keywords:** Disability, Chronic illness, Invisibility, Healthcare, Lived experience, Macro- and micro-levels

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## Introduction

More than one out of every four adults (26%) report a disability (CDC 2019).<sup>1</sup> Types of disabilities vary quite considerably, however. There is no definitive list of diagnosed disabilities, but they can be (1) congenital or acquired, (2) physical, cognitive, or sensory, (3) visible or invisible, and (4) severe, moderate, or mild. Higher rates of disability worldwide are primarily attributed to the aging of populations, higher incidence of chronic health conditions such as cardiovascular disease and diabetes, and greater risk of accidental injuries such as in motor vehicle accidents (CDC 2019). Furthermore, according to the World Health Organization (WHO 2002), almost everyone will be temporarily or permanently impaired at some point in life because of eventually acquired disabilities. Considering the

increasing certainty of disability acquisition across the life span and increasing rates of disability in general, it is crucial to explore how individuals experience disabilities.

The International Classification of Functioning Disability and Health (ICF) defines disability as not just an "attribute" or fixed property of a person but, instead, a state that results from the interaction between person and environment (Ustun et al. 2003, p. 40-42, as cited in Tarraf et al. 2016; see also Naples, Mauldin, and Dillaway 2019; WHO 2002). Therefore, while disability may be based loosely on the existence of an underlying impairment of some kind, impairment alone does not determine experience (WHO 2002). How one lives with an impairment is more telling about what an impairment truly is for a person than is any material reality of the body (Thomas 1999; Hughes and Patterson 1997; Shildrick

<sup>1</sup> See Mauldin and Brown (2021) for a slightly higher, yet similar, estimate.

2002). Disability studies scholars in the social sciences and humanities have tried hard to keep the focus on disability as the embodied experience of impairment, as well as the structural barriers that individuals with disabilities confront (Thomas 1999; Hughes and Patterson 1997; Shildrick 2002; Mauldin and Brown 2021; Naples et al. 2019). Within contemporary disability studies, then, disability is situated as a social location (similar to race, class, gender, sexuality, age, etc.) and “an axis of inequality decoupled from any particular impairment” (Mauldin and Brown 2021, p. 4; see also Frederick and Shifrer 2019; Shifrer and Frederick 2019; Shildrick 2002). Individuals with disabilities have particular positions and experiences in society because all individuals with disabilities are “subject to ableist processes that result in their exclusion and marginalization” (Naples et al. 2019, p. 5; see also Frederick and Shifrer 2019; Shifrer and Frederick 2019; Maroto, Pettinicchio, and Lukk 2021). It is worth paying attention to how these positions and experiences affect individuals at both a macro- and micro-level – especially if the lived experience of disability tends to be invisible to others.

In this article, we argue that the lived experience of individuals with disabilities is typically unnoticed or unseen. We propose that this is evident at both a macro- and micro-level. We also gloss over the important patterns in disability acquisition and experience (Mauldin and Brown 2021; Maroto et al. 2021; Shifrer and Frederick 2019; Frederick and Shifrer 2019). Shifrer and Frederick (2019) go so far as to say that while we have begun to interrogate the experiences and positions of those with other types of social locations such as race, gender, class, sexuality, etc., we have often left disability experience unanalyzed and unquestioned (see also Mauldin and Brown 2021, for a similar argument). Additionally, for decades, disability and chronic illness researchers have documented the varying ways that disability experience is invisible to us. Yet, these arguments are often in the form of particular (and marginalized) conversations about just one type of invisibility among many. Suppose conversations about the invisibility of disability experience exist piecemeal in separate forums and spaces. In that case, we propose that it is difficult to see the intertwined and more comprehensive nature of the invisible and often unquestioned nature of disability experience. It is also difficult to understand how invisibility operates simultaneously at both a macro- and micro-level.

So far, we know of no attempt to merge these academic conversations on the invisibility of disability

experience. Therefore, we use this article to compile conversations about the different dimensions or types of invisibility – what we call the invisibilities -- of disability so that readers can begin to connect these dimensions or types. The invisibilities of disability are also exacerbated by particular contexts, such as the intersection of other social locations such as race, class, gender, sexuality, age, etc., and the COVID-19 pandemic; we try to address these contexts well. Finally, we hope that by bringing different conversations together, we encourage a more comprehensive questioning of disability experience, akin to what Shifrer and Frederick (2019) or Mauldin and Brown (2021) are calling for scholars to do.

Therefore, this review piece will pull on existing research in the social sciences and humanities to explore conversations about the various invisibilities of disability. Specifically, we discuss scholarly conversations on major types of invisibility that we feel represent the literature on disability studies and chronic health conditions. In no way do we present this article as a systematic or thorough analysis of discussions of invisibility or disability. We could not discuss all of the vital research we found as we explored this topic due to time and space constraints. Instead, we analyze selected literature mainly for the significant examples of invisibility that they offer and attempt to compile the conversations in one place to present a more comprehensive look at the dimensions or types of invisibility that exist for individuals with a disability. The overarching goal is to show that the invisibilities of disability are many and that they are intertwined, simultaneously experienced, and structured into both our social institutions and individuals’ everyday experiences. This “think piece” is meant to be preliminary, with the primary goal of initiating more theoretical and empirical research on the ongoing and complicated invisibilities of disability. We begin with a discussion of how we conceptualize invisibility.

## Theoretical & Empirical Explanations

### *Conceptualizing Invisibility*

In a world constructed for able bodies -- no matter how temporarily able-bodied individuals may be or how “normal” disability experience may be -- disability is defined as an “abnormal” state, burden, or illness. Yet, as is often the case with so-called “abnormal” experiences, there is a general lack of recognition or acknowledgment of how prevalent disabilities are and how frequently and permanently certain groups confront them. There can also be invisibility simply because a disability is not named or recorded, or large-

scale patterns in disability acquisition are ignored. Furthermore, because of the intersecting effects of other structural inequalities, underrepresented groups with disabilities may be more like to experience being marginalized or sidelined depending on the type and severity of disability (Shifrer and Frederick 2019; Shifrer, Muller, and Callahan 2011; Santinele Martino and Pearreault-Laird 2019; Maroto et al. 2021). Thus, on a basic level, if individuals without impairments or disabilities are the reference point, we may consciously or unconsciously gloss over or disregard the existence and experiences of other individuals in society.

Consequently, social institutions may also be established in ways that do not fully address the needs of individuals with disabilities. As individuals engage with social institutions such as the healthcare system, invisibility can result from an undiagnosed or contested disability or chronic health condition. Invisibility can also be experienced within social institutions because a disability is systematically hidden due to a lack of tracking or record-keeping (Schneiderwind and Johnson 2020). Individuals with disabilities may also have difficulty accessing health insurance to afford care and therefore be absent from healthcare settings (Pettinicchio, Maroto, and Lukk 2021). Individuals with more severe disabilities or individuals over age 65 who often have at least one disability and/or chronic health condition, who live in long-term care facilities, may find themselves further isolated from quality healthcare and unattended to in new policy work or as public health crises occur (Pettinicchio et al. 2021; Mauldin and Brown 2021; Rochon, Stall, and Gurwitz 2021). Healthcare providers may remain unknowledgeable about how to handle care for individuals with disabilities and may develop negative attitudes towards disability as a result. Healthcare offices and diagnostic technologies may not be physically set up to accommodate individuals with disabilities because they were designed with only able bodies in mind (Dillaway and Lysack 2014b).

Moreover, others may be unaware and perhaps even dismissive of what it is like to navigate everyday life with a disability (seen or unseen). As an “abnormal” state – especially one constructed as negative and stigmatized -- disability can easily remain marginalized, erased, ignored, and/or unacknowledged in daily life. Individuals with disabilities may find that others go out of their way to ignore (or pretend that they do not see) a disability or even the person with the disability. In addition, some people possess an impairment and disability that is

“not perceptible, not noticeable, not evident to others. In short – a condition unseen to others” (Vickers 1997, p. 241, as cited in Hoppe 2010, p. 363). In this case, a disability may remain undiscussed, unacknowledged, and unknown unless the individual with a disability makes a concerted effort to disclose it. Finally, we also lack awareness of exactly how many different types of invisibility and how much of the experience of disability we do not see. These invisibilities are aggravated and heightened by other intersecting social locations and the COVID-19 pandemic. We go into more detail about these different types of invisibility in later sections.

In writing this piece, we are guided by tenets of intersectionality (e.g., Weber 2001) and a gendered institutions perspective (Acker 1992). These two conceptual frameworks help highlight the macro-level conditions that cause individuals with specific social locations to remain vulnerable in society. Invisibility is one such experience of macro-level vulnerability, and there are severe implications of the invisibilities of disability -- for entire groups and individuals on a day-to-day basis. Thus, it is important to pay attention to the macro-level, structural conditions that make invisibility possible and the everyday experiences of invisibility once those macro-level conditions are created. We now discuss our lack of attention to the social patterns in disability acquisition and the invisibilities that specific groups of individuals with disabilities experience because of intersecting social locations. We then consider how social institutions can contribute to the invisibility of disability and use healthcare as an example<sup>2</sup>. Subsequently, we discuss the invisibilities in everyday experience for individuals with disabilities and chronic health conditions. Finally, we conclude by discussing additional invisibilities experienced during the COVID-19 pandemic and the implications of these varied and intertwined invisibilities of disability. In each section below, we use examples of specific disabilities or chronic health conditions to make our arguments. Still, we also try to make our points general enough to be applied to other types, onsets, and severities of disability.

#### *Bringing Attention to Social Location and Patterns in Disability Experiences*

Lack of attention to the documented social patterns in disability acquisition makes us unprepared to notice the risks, incidence, and prevalence of disabilities among certain groups and how specific groups by social

<sup>2</sup> We could really discuss any social institution. We have chosen healthcare as an example, and we hope that other disability studies scholars apply the same analysis to other social institutions.

location might experience disability once it is acquired, named, or diagnosed. For example, as discussed in Dillaway et al. (2022, forthcoming), we assume that many injuries (and, therefore, acquired disabilities) are “unexpected” and indeed “accidents”:

When evaluating who is at most risk for “unexpected” injuries, . . . researchers clearly find disparate impacts on certain social groups. For example, the elderly and young males are at the most risk of motor-vehicle-related injuries (Tepperman and Meredith 2016). Workplace injuries (e.g., injured limbs, carpal tunnel syndrome) are more likely in certain groups of employees by gender, age, and type of employment. Children are most at risk of disability and death due to traumatic brain injuries, although we also see increased risk among elderly populations due to falls (WHO 2006). Men are also more likely to be the recipients of gunshot wounds that lead to permanent injury or death, with young Black men most at risk of gunshot wound due to assault and older, non-Hispanic White men most at risk due to attempted suicide (Cook et al. 2017; WHO 2006).

Furthermore, boys and young men have attained more sports-related injuries even though this gendered gap is narrowing (Messner 1992; Dillaway et al. 2022). Because of lead poisoning, poorer children are more likely to develop learning disabilities (Shifrer and Frederick 2019). Women’s greater involvement in housework and childcare (Hochschild 2003) and vulnerability to intimate partner violence (Walton-Moss et al. 2005) means that they are more likely than adult men to sustain permanent injuries in the home (Tepperman and Meredith 2016; Dillaway et al. 2022).

Tepperman and Meredith (2016) propose that our definitions of “accidental” injuries or “unexpected” illnesses are faulty because we ignore the apparent patterns in onset across social groups. In addition, the word “accident” shows how our language can encourage us to dismiss the very significant patterns in impairment acquisition and, more generally, the structural causes of this type of acquired disabilities

(Dillaway et al. 2022). Finally, in concentrating on the “unexpected” or “accidental” ways acquired disability might arise, we hide the very chronic and permanent nature of the physical disabilities created by patterned events. This makes it impossible to measure or track the sociological reasons for acquired disabilities or the outcomes for particular social groups (Tepperman and Meredith 2016; see also Dillaway et al. 2022). Thus, while we have plenty of data indicating sociological patterns in disability risk and acquisition, the lack of consistent conversation about these patterns allows disability experience to remain unquestioned and unnoticed in part.

Disabilities can be part of the manifestation of a chronic disease or illness, and we do not acknowledge this publicly enough. Chronic health conditions are life-long conditions with varying causes, onset timings, symptoms, and severities (Bury 1991; Vickers 1994; Roger, Wetzel, and Penner 2018; Lent Hirsch 2018; Querol et al. 2020). Unfortunately, research on chronic health conditions is often disconnected from research on disabilities<sup>3</sup>. Still, chronic illness and disease experiences often include the management of increasing impairment, both visible and invisible to others (Vickers 1998). Within the United States, six in ten adults have a chronic disease condition, while four in ten adults have more than one chronic disease condition (CDC 2021). Raghupathi and Raghupathi (2018) similarly speculate that nearly half of all adults in the United States live with at least one chronic health condition, with the most common being heart disease, cancer, stroke, and diabetes.

Nonetheless we ignore how many individuals might be living with a disability because they have been diagnosed with a chronic health condition. When we talk about cancer or diabetes, for instance, we do not acknowledge in everyday conversation the temporary and/or permanent impairments that might result from treatment or progression of these diseases and the disabilities that result. Recently, to remedy this, some researchers in disability studies are starting to refer to both disabilities and chronic health conditions as they report their findings (e.g., Pettinicchio et al. 2021; Maroto et al. 2021)<sup>4</sup>.

Existing research also confirms that women have higher diagnosis rates for chronic illnesses than men (Nathanson 1975; Gabe, Bury, and Elston 2004). This gap in diagnosis rates can partly be attributed to the

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<sup>3</sup>This is an important oversight within the social science literature on health and illness until recently.

<sup>4</sup>To align with these very recent trends in disability studies and to prevent further lack of recognition of the connections between chronic health conditions and disability, we also try to use examples of chronic health conditions in later sections, when relevant, to show that disabilities and chronic health conditions often overlap in individual experience.

differences in women's health-seeking behaviors compared to men (Gabe et al. 2004). This means that men's experience of chronic health conditions may be unrecorded more often than that of women's. Nonetheless, chronic illnesses such as fibromyalgia -- currently affecting 4 million adults in the U.S. (CDC 2017) -- appear more prevalent among women (Fitzcharles et al. 2016). However, the more significant usage of healthcare resources may bring stigma to women, especially if their symptoms are invisible or contested. Thus, in coming forward with disabilities associated with a chronic health condition, women may face additional forms of invisibility. We refer to the difficulties in getting diagnoses and managing stigma in provider-patient interactions in later sections. In sum, social patterns in disability acquisition are noteworthy, and we might lessen the invisibilities surrounding disabilities and chronic health conditions if we confront these social patterns more publicly.

In addition, because of intersecting social locations and axes of stratification, certain groups with disabilities may experience "reduced personhood" and, therefore, additional invisibilities (Shifrer and Frederick 2019, p. 8). Shifrer and Frederick (2019) present a comprehensive and historically contextualized review of how certain groups are treated differently because cultural attitudes towards disability remain unquestioned. For instance, because of cultural norms about which bodies represent "ideal workers," individuals with disabilities are often passed over for jobs, which is more pronounced if an individual is disadvantaged by class or race (Shifrer and Frederick 2019). Thus, as employers make hiring decisions, they may disregard certain applicants with disabilities more than others and, in turn, create greater invisibility for these groups in the process. Without job stability and connection to the workforce, these same groups would also be less likely to secure health insurance, access quality health care and safe housing, and maintain healthy lifestyles; therefore, there are severe consequences of this disregard (Shifrer and Frederick 2019; Link and Phelan 1995; Maroto et al. 2021).

Furthermore, Shifrer and Frederick (2019) outline how youth of color are more likely to be diagnosed with a learning disability, not only due to greater lead exposure (caused by an increased likelihood of living in poorer neighborhoods with older housing stock) but also race-based, cultural assumptions about intellectual capacity. Once diagnosed with a disability, youth are often kept out of mainstream classrooms and are met with more restrictive policies in the school setting. Therefore, youth with disabilities -- frequently underrepresented minorities -- may be isolated from other youth within educational spaces and may not be

given as many learning opportunities as their counterparts (Shifrer and Frederick 2019; Shifrer et al. 2011). The result for these groups is poorer educational outcomes and less connection to opportunities later on.

Women with various disabilities are also often assumed to be asexual and incapable of reproduction (Dillaway and Lysack 2014a; Dillaway et al. 2020; Shifrer and Frederick 2019; Frederick 2017; Santinele Martino and Perreault-Laird 2019). Mothers with disabilities may also be labeled "unfit" and "bad" mothers and those around them may be suspicious of their ability to care for and make good decisions for their children (Frederick 2017; Dillaway and Lysack 2014a). While we no longer have compulsory sterilization and marriage restrictions for the "feeble-minded," "the values underlying the eugenics movement persist" (Shifrer and Frederick 2019, p. 8). Then, women with disabilities' desires and expectations for intimate relationships and motherhood are ignored, sometimes dismissed, and often controlled by family members, peers, and care providers (Santinele Martino and Perreault-Laird 2019; Fritz, Dillaway, and Lysack 2015; Frederick 2017).

Santinele Martino and Perreault-Laird (2019) suggest that young men with intellectual disabilities may also face processes of desexualization at times, even though there is a more significant attempt to control the sexuality of women. Men with physical disabilities may also be discounted if they cannot perform sexually and may face considerable stigma due to ideological connections between masculinity and virility (Fritz et al. 2015; Shifrer and Frederick 2019). Accessing sexual education and getting support for good sexual health while also having a disability may feel next to impossible because individuals need to be recognized as sexual and reproductive beings before these things can happen. Ultimately, reproductive and sexual expectations and choices can be curtailed or altered if others cannot see that individuals with disabilities are still sexual and reproductive beings. Underrepresented groups with disabilities may feel this cultural stigma and differential treatment in even more pronounced ways; poor women and women of color, for instance, have also been defined as overly sexual and potentially risky mothers (Frederick 2017; Shifrer and Frederick 2019; Dillaway and Pare` 2008).

In all of these examples, certain individuals with disabilities may find themselves invisible to others, discounted, disregarded, ignored, and isolated from others because of the intersections of disability and other social locations. Thus, individuals with disabilities do not all face the same set of invisibilities because of the intersection of other social locations

with disability. While there may be some common experiences of invisibility, the intersections of disability and other social locations can create unique types of invisibility for some. There are many more examples of these intersections and consequent invisibilities that we cannot discuss here. Instead, we urge readers to think in intersectional terms about the experience of both invisibility and disability going forward. We now move to a discussion of how social institutions reinforce the invisibilities of disability.

### *Social Institutions Reinforce Invisibilities: The Example of Healthcare*

In her discussion of a gendered institutions perspective, Acker (1992) suggests that we examine institutions for how they might reinforce social constructions of and (by default) structural inequalities for specific groups in society. This is important for our purposes because specific social constructions and inequalities can enforce the invisibility of individuals with disabilities. In other words, if institutions have been historically developed with able-bodied individuals as the reference point, and if institutional processes and practices are still carried out by individuals who might not have disability experience, then institutions are established and “defined by the absence of” disability; in this scenario, disability becomes an afterthought within the inter-workings of the institution (Acker 1992, p. 567). Taking our lead from Acker (1992, p. 567), then we can look for how types of invisibility are created and then reaffirmed in the “processes, practices, images and ideologies, and distributions of power” in any social institution, and how this institutional invisibility has severe consequences for individuals’ access to services and opportunities provided by institutions. We use the example of healthcare institutions in this section to show how invisibilities lead to a lack of access to quality healthcare.

Overall, we know that people with disabilities have poorer health outcomes when compared to people without disabilities (WHO 2011; Signore 2016; Dillaway et al. 2020). It is well documented that barriers cause these outcomes that individuals with disabilities face in accessing services and opportunities as they engage with various institutions (WHO 2011; Kiani 2009; Pettinicchio et al. 2021; Dillaway et al. 2020). As detailed in Dillaway et al. (2020, p. 570), “individuals with disabilities are less likely than their peers to receive even the simplest kinds of preventative health care, such as teeth cleanings, vision checks, immunizations, or weight and height checks” (see also Pharr and Chino 2013; Kiani 2009). Individuals with disabilities also report that they need greater access to prescription

medications (McColl 2002; Pharr and Chino 2013). World Health Survey data collected from 51 countries also documents how people with disabilities are “more than twice as likely to report finding health care provider skills inadequate to meet their needs, four times more likely to be treated badly and nearly three times more likely to be denied needed health care” (WHO 2011, p. 9).

Much of what we know about barriers to quality health care for individuals with disabilities comes from research that documents barriers in the physical environment (Dillaway and Lysack 2014b; Dillaway et al. 2020). Structural barriers (e.g., lack of accessible transportation, inadequate disability parking, lack of suitable ramps and elevators, and crowded waiting rooms) block access to health care for individuals with disabilities (Pharr and Chino 2013; Kiani 2009; Dillaway and Lysack 2014b; Dillaway et al. 2020). In the U.S., implementation of the Americans with Disabilities Act (ADA) lessened some, but not all, of these physical barriers. Public access to buildings and transportation has been improved, but less has been done within actual health care offices (Kaplan 2006; McColl 2002; Pharr and Chino 2013). The organization of furniture in providers’ offices and offices that are too small to accommodate a wheelchair or extra aides or support persons makes it clear that individuals with disabilities are not recognized in physical space planning (Dillaway and Lysack 2014b; Dillaway and Lysack 2015). Providers in the U.S. may not even know the extent to which they are non-compliant with ADA policy if they are not intimately familiar with the policy and/or do not treat individuals with disabilities regularly; that is, they may not even realize what they do not know (Dillaway and Lysack 2014b; Dillaway and Lysack 2015; Dillaway et al. 2020).

Various health care technologies and diagnostic tools (e.g., scales, mammography machines) may also not be made for individuals with disabilities (Dillaway et al. 2020). Even if medical providers are amenable to adjusting the use of this equipment to accommodate individuals with disabilities, they may encounter difficulty managing its use with individuals with disabilities because of the inflexibility of the equipment and office space they have to work with (Dillaway and Lysack 2014b; Dillaway and Lysack 2015; Dillaway et al. 2020). The lack of fit between individuals and their healthcare environments is caused by the lack of attention to impairment and disability when considering space and technology design. Suppose we are using Acker’s (1992) logic when analyzing the experiences of individuals with disabilities as they encounter healthcare institutions. In that case, the institutional decisions, designs, and practices established without disability in mind

inevitably exclude individuals from specific physical spaces or, at the very least, limit their access to quality healthcare.

Many other barriers contribute to inadequate access to health care for individuals with disabilities, including lack of provider knowledge and negative attitudes towards disability (Pharr and Chino 2013; WHO 2011; Kiani 2009; Symons et al. 2014; Dillaway et al. 2020). Worldwide, medical providers lack training in the unique needs of people with disabilities or how to manage care for those with diagnosed disabilities (WHO 2011). To receive the best possible care, the unique needs of people with disabilities must be met by a provider well-educated on the needs and experiences of this population. Despite the “calls locally, nationally, and internationally” to create curricula that instruct medical students on how to interact and care for people with disabilities (Symons et al. 2014, p. 89), very little has been done in this regard. Medical students, residents, and even practicing physicians have demonstrated deficiencies in working knowledge of disability (Symons et al. 2014; Dillaway and Lysack 2015). Patients with disabilities often report the need to educate their physician about the fundamental aspects of their disability (Symons et al. 2014; Dillaway and Lysack 2014a; Dillaway and Lysack 2014b; Dillaway and Lysack 2015). In the face of this lack of education and training, providers may develop negative attitudes when treating a disabled patient, ultimately resulting in low-quality care and vulnerability within the healthcare system (Symons et al. 2014). As they engage with healthcare systems, persons with disabilities face regular instances within which both a lack of recognition and macro-level environmental constraints are established, which means their healthcare needs may not be fully addressed.

Individuals with chronic health conditions broadly face structural constraints when trying to seek healthcare as well. The simple process of getting a diagnosis highlights our inability to acknowledge impairments and chronic symptoms of various kinds. Symptoms and impairments -- especially those acquired progressively over time due to developmental, aging, or chronic conditions -- do not always match up with strict symptom checklists and can change in intensity. That is, not all individuals with a particular chronic illness experience the same set of symptoms or impairments, but doctors may follow a rigid checklist when trying to diagnose. A symptom or impairment might also be minor or intermittent at first. Doctors might not diagnose (or even test for confirmation of certain conditions) until the symptom is more acute or consistent.

Moreover, there are many chronic conditions (e.g., autoimmune diseases, arthritic conditions,

neurological conditions, etc.) that have not been acknowledged fully by healthcare institutions which creates greater invisibility for individuals who seek diagnosis and treatment. Individuals with chronic health conditions are at the mercy of existing medical knowledge, healthcare policy, and patient care practices as they pursue diagnoses and treatments. In fact, for some patients with the experience of chronic impairments, the “exact cause of [the] condition [may be] unknown, the prognosis [may be] unpredictable, and there [may be] no effective treatment” (Robinson 1988, p. 1, as cited in Hoppe 2010, p. 365). Knowledge (and, therefore, recognition) of particular chronic illnesses may remain stagnant due to lack of emerging research for a specific illness, unclear etiologies, or overlapping symptomology that can complicate diagnosis experiences and health outcomes post-diagnosis.

This burden of undiagnosed disability gains an additional layer of complexity if the signs or symptoms of impairment are invisible to the naked eye. Furthermore, scheduling visits with healthcare professionals during the time of a symptom flare-up or acute impairment experience provides additional challenges if the duration of a flare-up or impairment is unpredictable (Brennan and Creaven 2016). For example, suppose an individual cannot get an appointment during the time of a flare-up. In that case, they must then document a past flare-up and show how a particular symptom or impairment affects their ability to complete their daily activities. Finally, individuals with chronic illnesses such as chronic headaches, fibromyalgia, inflammatory bowel disease, cancer, rheumatoid arthritis, multiple sclerosis, Parkinson’s disease, etc., may not “look” like they are sick, which further complicates how their illness is perceived and understood by healthcare professionals (Lonardi 2007; Querol et al. 2020; Bury 1982; Hoppe 2010; Roger et al. 2018). Mauldin and Brown (2021) note that much of our understanding and treatment of disability and chronic illness comes from our knowledge of the “sick role.” Unfortunately, healthcare institutions remain staunchly committed to ideologies and practices that reinforce that one must look “sick” to receive care. Individuals with permanent impairments or disabilities – especially individuals who have impairments that are not visible to others – call images of both health and illness into question, for we have yet to acknowledge that 1) impairment is relatively typical in contemporary times, 2) health and illness conditions can be either visible or invisible, and, finally, 3) individuals with impairments are not always sick.

Full acceptance of chronic health conditions and any symptoms, impairments, and corresponding disabilities – by both the individual and their provider

-- is very important if individuals are to obtain quality health care (Roger et al. 2018). Roger et al. (2018, p. 1058) explain:

Patients and providers need to see and acknowledge symptoms that exist in the shadows . . . , so that diagnoses are not delayed, and effective and timely treatment and care can be provided. . . . The medical model of care, which places emphasis on diagnosis and treatment, dominates the health-care system and can at times ignore or devalue . . . [patients'] stories. As this system becomes increasingly impacted by financial and time pressures, and as the reliance on technology and medical tests increases, those who suffer with invisible symptoms may be more vulnerable to being ignored or discredited.

The unpredictable and unseen nature of some chronic illnesses (and their associated symptoms and impairments) complicates how an individual navigates through a healthcare system; Roger et al. (2018) characterize this as a “dance” between invisibility and visibility. Querol et al. (2020) and Bury (1982) also discuss individuals’ negotiations with the process by which a “non-visible” disease becomes “now visible” to healthcare providers. Power struggles ensue between patients and healthcare providers, and the burden falls on the patient to prove they have symptoms or impairments that interfere with their daily lives; the psychological and/or emotional effects of this pursuit of acknowledgment can be weighty (Querol et al. 2020, p. 8; see also Lonardi 2007). Existing research also reports greater stigmatization and discrimination by healthcare providers in these cases. With greater stigmatization and discrimination -- and, by default, invisibility -- come poorer health outcomes (Quinn et al. 2017; Hatzenbuehler, Phelan, and Link 2013; Roger et al. 2018).

An intricate web of invisibility experiences can be created within social institutions such as the healthcare system. As we have tried to show in this section, individuals with disabilities confront physical infrastructure, technological equipment, provider knowledge and attitudes, and types of contested or unseen disabilities that contribute to their experiences of being ignored, marginalized, unacknowledged, dismissed, underserved, or unable to access services and opportunities within healthcare systems. We now move to discuss other, potential everyday experiences of invisibility for individuals with disabilities.

*Everyday Experiences of Disability and Chronic Conditions*

There are additional, everyday invisibilities attached to the micro-level, lived experience of disability that must be unearthed as well. For example, medication and treatment routines, how individuals get through symptom episodes or bodily routines, the extra effort that it takes to get ready to appear in public, the adjustments made to daily activities over time, self-management around other people (so that other people do not feel uncomfortable but also, so others recognize a disability), the things individuals decide not to do or say in the face of their own or others’ disabilities, how others purposely look past visible disabilities, etc., are all part of a private, unacknowledged, lived experience. Emotional labor, as well as substantive changes to physical and interactional routines in some cases (especially in the case of acquired disabilities), comprise part of the invisible experience of living with a disability (Roger et al. 2018; Hoppe 2010; Charmaz 2002; Bury 1982; Bury 1991; Querol et al. 2020). Understanding how individuals with disabilities adapt and adjust to manage and succeed on any given day is essential to recognize and comprehend if our goal is to peel back the layers of invisibility surrounding the disability experience. On the other hand, we also need to understand that impairments do not permanently alter lived experience in the ways others around us might assume, and there may be additional, invisible, daily work attached to the process of convincing others that impairments are typical and do not change daily experience that much. There are some common, everyday experiences of disability that represent dimensions of invisibility, and we try to discuss some of the major ones in this section.

First, for those who live with impairment or disability, adjusting to a diagnosis and/or a change in one’s health may sometimes warrant micro-level adjustments to everyday life. Bury (1991), Charmaz (2002), and Lent Hirsch (2018) discuss how those who have impairments and disabilities often experience a point in their life courses where they are faced with having to reconstruct their image of self, their thought processes, and the daily habits that support their view of self. Our view of self tends to shift during the process of modifying daily habits to accommodate disability and impairment (Bury 1991; Charmaz 2002; Lent Hirsch 2018). Part of this reconstruction process of self, thoughts, and habits may also entail navigating others’ reactions and managing the effects of stigma in the context of our daily lives; this process is often invisible to others.

Managing stigma can be a significant part of the invisibility of lived experiences of disability and chronic illness. Per Goffman (1963, p. 3), stigma derives from “an attribute that is deeply discrediting.” Further, “[a] discredited attribute could be readily



discernable, such as one's skin color or body size, or could be hidden but nonetheless discreditable if revealed, such as one's criminal record or struggles with mental illness" (Clair 2018, p.1). Stigma can manifest in many different types of lived experiences, however. For example, Earnshaw et al. (2013, p. 271) describe how a diagnosis can be a source of stigma in and of itself: "The mark or attribute is the diagnosis of chronic illness itself. With this diagnosis, a person transitions from 'normal' to 'discreditable' (Goffman 1963), from the 'kingdom of the well' to the 'kingdom of the sick' (Sontag 1991)."

In addition, adapting to symptoms or impairments in public (or even around family members and peers in private spaces) can solicit unwelcome reactions from others, contributing to stigma. Monaghan and Gabe (2019, p. 1882) suggest that in the context of disability and chronic health conditions, unwanted reactions from others "spoil identities through enacted or felt stigma." Lemert and Branaman (1997) and Goffman (1963) also suggest that our social interactions and public presence play a role in how others form their impressions of us and whether stigma occurs. We are taught to think negatively of those who go against, or break, the prescribed norms of society; therefore, individuals with either temporary or permanent impairments may compensate in varied ways to manage the potential or actual stigma that they confront in public spaces. Hoppe (2010, p. 369) explains that this means individuals with impairment and disability make moment-to-moment choices about how visible or invisible to make their disability: "People do not merely make [their disabilities or chronic conditions] visible or invisible, but they do so in different context[s]. They decide in each case to whom, how, when and where they hide or disclose (Goffman 1963, p. 57; Charmaz 1991)."

However, the emotional labor involved in reconciling perceived and real versions of self and negotiating societal expectations of what someone "should" be like in public may take its invisible toll on individuals. For example, Lent Hirsch (2018, p. 87) reflects on an experience that she had out in public after having hip surgery:

[While walking down a street] I felt my hip ache. Three blocks later, I was experiencing searing pain. . . . I knew that I might have done damage to the still-healing incision that went all the way from the top layer of my skin to the inside of my hip bone. There was nothing to do but pretend I was fine, or so I thought. My goal while healing from surgery was this: act like I was a sprightly young thing, and make sure nobody thought I had health issues.

The micro-level experience of adapting to the needs of a disabled body in public (as well as private spaces) can remain unseen by others but, to those with disabilities or impairments, it is significant and a genuine part of the daily living experience with disability. Part of this experience involves managing whether others should "see" one's disability at all.

Hoppe (2010, p. 369) suggests that individuals may fear that others might discover a disability and/or chronic illness that they have not disclosed: "People whose illness is not visible can pass as normal if they want to, but the empirical examples show that this is not always felt to be desirable." On the other hand, when a disability is easily seen or disclosed, individuals may worry that their disability will "overshadow" the rest of their identity, at least in others' minds (Hoppe 2010, p. 365). Individuals may also have an impairment (visible or invisible) that does not affect their lived experience as much as others around them think it does. The intersection of disability with other social locations makes the navigation of disclosure decisions even more important; for instance, individuals belonging to racial-ethnic minority groups may make choices not to disclose a disability when they do not have to if racial-ethnic locations already marginalize them; in fact, "other oppressed groups [may try hard to] establish their lack of disability to raise their status" (Shifrer and Frederick 2019, p. 10).

In Hoppe's study of individuals with multiple sclerosis, most participants had told their family, friends, and colleagues about their disease. Still, some had not because they were worried about whether others would understand and be considerate of their disabilities. Hoppe (2010) also found that even those who know about a disability and/or chronic health condition might misunderstand the experiences. Especially when an impairment or disability is "not directly visible," "knowledge [of the impairment or disability] often fades into the background and people are not aware of it all the time" (Hoppe 2010, p. 368). Consequently, "few will be understood by relatives, friends or colleagues, simply because the symptoms cannot be seen" (Vickers 1997, p. 241; as cited in Hoppe 2010, p. 368). Roger et al. (2018, p. 1055) go further in explaining that "family members may be invested in minimising symptoms [or impairments and] managing them to the extent of normalising them – protecting their own lack of acceptance or denial in the face of 'looking normal.'"

Managing diagnoses and changes in health on a day to day basis, confronting social norms about how bodies should look and behave around others, managing information about one's disability, managing others' reactions to one's disabilities and/or chronic conditions, and managing stigma are just some

of the invisible, everyday, lived experiences of disability and chronic health conditions. These invisible, micro-level experiences are reinforced and negotiated alongside the macro-level invisibilities discussed in previous sections.

#### *Heightened Invisibilities for Individuals with Disabilities During COVID-19*

Finally, contemporary contexts reinforce and heighten the invisibilities that individuals with disabilities face over time. Notably, the invisibilities described in earlier sections have not dissipated during the COVID-19 pandemic; the invisibilities already discussed have shaped and reaffirmed how individuals with disabilities have been affected by COVID-19. In addition, some invisibilities have intensified during this public health crisis. Because we focused on healthcare institutions in earlier sections, we maintain that focus while investigating the effects of COVID-19. To organize our discussion, we focus on how the move to telehealth, the distribution of the COVID-19 vaccine, the halting of supplemental healthcare services, and care allocation policies in hospital settings have affected individuals with disabilities in adverse ways. In these discussions, we attempt to show how macro-level invisibilities reinforce micro-level invisibilities. We describe the onset and initial contexts of this global pandemic to set the stage.

In late 2019, a novel coronavirus (SARS-CoV-2) emerged in China. Due to the global nature of our economy, ease of travel between countries, and the infectious nature of the virus, “COVID-19” spread quickly. By March 11, 2020, the World Health Organization (WHO) recognized the new virus as a pandemic (O’Reilly 2021, p. 15). Countries worldwide began to develop public health protocols to contain the virus. In the U.S., state-mandated shutdowns and other targeted public health protocols started during March 2020; many of these shutdowns and other public health orders have only just been lifted in full (AJMC 2021). State-level and other local government orders were intended to slow or limit the spread of COVID-19 while ensuring adequate hospital capacity and care allocation. For example, orders to shut down paid workplaces were accompanied by “stay home” orders indicating that individuals could only leave their homes to satisfy essential needs (e.g., acquiring healthcare, food, or necessary household goods). As COVID-19 rates peaked in Spring, Summer, and Fall 2020, approximately 95% of U.S. residents were required to adhere to “stay home” mandates of varying lengths (Mervosh, Lu, and Swales 2020). Orders to stay at home were issued at the macro-level with little consideration for the differential impact on social groups, especially those who might have already faced

vulnerabilities within social institutions and the larger society. There is little analysis of how individuals have coped with these directives or the forced social isolation that has resulted on the micro-level (O’Reilly 2021; Pettinicchio et al. 2021; Shafiq et al. 2020). Shafiq et al. (2020) suggest that as many as 40 percent of adults with disabilities or chronic conditions reported feelings of loneliness and social isolation before the pandemic, but little is known about this social problem during the pandemic. Additional research is needed on this pandemic’s varied micro-level, everyday experiences. While we have all been affected differently, some groups have been impacted more adversely than others.

Turning specifically to healthcare, the declaration of an international pandemic led to many macro-level changes in protocols and practices within healthcare systems that directly and seriously impacted individuals with disabilities. First, the wholesale move to telehealth appointments increased the solitary nature of the disability and chronic illness experience. As a result, it exacerbated routine and emergency healthcare inaccessibility for some individuals with disabilities (Annaswamy et al. 2020). While the shift to telehealth services might have prevented COVID exposure among potentially vulnerable groups, and this form of care can be more accessible for some groups with physical disabilities or transportation constraints, telehealth was not as accessible for individuals without personal computers and stable internet access. This inaccessibility of telemedicine has been more significant in rural and low-income communities where rates of disability and chronic conditions are higher (Annaswamy et al. 2020; Shafiq et al. 2020).

Additionally, with the rapid implementation of many telehealth services, the system technologies adopted to handle such a transition did not always include adaptive technology services for patients who need them (Annaswamy et al. 2020). Therefore, individuals with visual, auditory, or cognitive impairments have been excluded entirely from the use of telehealth at times, which further contributes to their experience of invisibility within healthcare institutions. More than half of individuals living with a disability in the U.S. report that their disability makes navigating websites “challenging” (Shafiq et al. 2020). Because telehealth relies on a patient who is fully connected to and capable of utilizing technology to access healthcare, the very nature of telehealth creates greater inaccessibility of care for individuals with disabilities.

This oversight in the conceptualization and implementation of telehealth solutions derives from existing invisibilities within the healthcare system and the fact that individuals with disabilities (as well as

those disadvantaged by other social locations) are often forgotten or unrecognized by those with decision-making authority; therefore, conditions of invisibility before the pandemic were exacerbated during this crisis via the switch in appointment modality (Annaswamy et al. 2020). Furthermore, the inability to consult providers in person also meant that symptoms and impairments have been harder to recognize, explain, and address (Annaswamy et al. 2020); thus, the micro-level experience of being unable to secure a diagnosis or treatment intensified for many individuals with troubling symptoms (especially symptoms not visible on-screen)<sup>5</sup>. Consequently, telehealth's inaccessibility and the increased inability to procure diagnoses further cemented the lack of acknowledgment of disability and chronic illness.

In addition, the macro-level processes by which COVID-19 vaccines have been distributed and administered have affected individuals with disabilities in negative ways. While individuals with disabilities are twice as likely to report that they desire the COVID-19 vaccine, individuals with disabilities have lower COVID-19 vaccination rates than groups without disabilities (Diament 2021; Heasley 2021; Ryerson et al. 2021). Lower vaccination rates for individuals with disabilities have resulted from three major accessibility problems: (1) inaccessibility of online scheduling platforms, (2) inconsistent accommodations at vaccine sites, and (3) lack of reliable transportation to vaccine sites (Ryerson et al. 2021; Alismail and Chipidza 2021; Diament 2021; Heasley 2021).

Especially early in the pandemic period, vaccine appointments were secured primarily via online portals, and, as with telehealth, this automatically created accessibility barriers for individuals with disabilities. In addition, online vaccine registration portals have been inconsistent in how they provide

accommodations for those with a range of impairments (Ryerson et al. 2021; Alismail and Chipidza 2021). These inconsistencies offer further evidence of just how habitual it is for healthcare decision-makers to ignore accessibility, impairment, and disability issues as they come up with broad protocols about how to deliver a healthcare service. The example of COVID-19 vaccine distribution efforts also demonstrates how we often learn about problems with the implementation of protocols only after certain social groups have been adversely affected on the micro-level. Still, today, individuals with disabilities are more likely to report trouble getting an appointment online (Diament 2021; Heasley 2021). Mainly because of the efforts of disability advocacy organizations and individuals with disabilities to file complaints, a new national call line is known as the Disability Information and Access Line (DIAL) is just now beginning to help individuals with disabilities with appointment scheduling and logistics (Heasley 2021; Diament 2021). Thus, micro-level efforts to interrupt macro-level invisibility have recently succeeded in a small way.

However, the problems with vaccine distribution and administration are more complicated than this. While several federal laws and policies<sup>6</sup> mandate vaccination site locations to be accessible for individuals with disabilities, these laws do not specifically dictate that additional support services (such as ASL interpreters or staff trained to work with individuals with cognitive disabilities) be on-site (Ryerson et al. 2021; Diament 2021). Mask mandates also lead to accessibility concerns for individuals with auditory disabilities who may rely on lip reading to communicate<sup>7</sup>. Therefore, the vaccination sites themselves pose structural barriers for specific individuals with disabilities, and accessibility at vaccination sites is uneven at best. Fragmented efforts to provide accommodations at vaccination sites – often

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<sup>5</sup>Securing a diagnosis in person during the pandemic was not any easier. During the rare, in-person, medical visits that remained early on in the pandemic, patients were not allowed to bring support persons to medical appointments unless medically necessary, which further curtailed patient-doctor discussions of the everyday experiences of disability and chronic health conditions. Attending appointments alone has, in some cases, also made it more difficult for patients to confirm symptoms or impairments and receive adequate diagnoses (since partners and caregivers can sometimes be helpful in explaining the manifestation of symptoms or impairments). When family members and/or caregivers are not in attendance at medical visits, they may also be less cognizant of the significance of a disability or chronic illness in an individual's life and, therefore, less able to offer support on a day-to-day basis. This is an under-researched, micro-level effect of a macro-level change in policy (however temporary) that exacerbates experiences of invisibility.

<sup>6</sup>Sections of the Patient Protection and Affordable Care Act (ACA), American with Disabilities Act of 1990 (ADA) and the Rehabilitation Act of 1973 require that healthcare services are fully accessible to individuals with disabilities (Pendo, 2020).

<sup>7</sup>While a potential solution, clear face masks that provide protection for patients and healthcare workers and allow for lip reading are sparse (Grote and Izagaren 2020).

only after individuals have had negative experiences at these sites and complaints have been filed -- demonstrate once again how individuals with disabilities are generally an after-thought in the rollout of new healthcare services. While systematic research on stigma at vaccination sites does not yet exist, we can imagine the weighty stigma felt by individuals with disabilities as they confront the lack of accommodations and untrained staff at these sites.

Individuals with disabilities also report not knowing where to go or having issues getting to a vaccination site (Diament 2021). Thus, transportation to vaccine sites also poses a structural barrier for individuals with disabilities (Ryerson et al. 2021; Cochran et al. 2021). During the pandemic, there have been reduced public transit options and limitations on special transportation services for individuals with disabilities (e.g., reduced vehicle capacity because of social distancing guidelines and decreased numbers of routes) (Cochran 2020). This lack of ability to get to vaccination sites maintains, if not exacerbates, the invisibility of disability and chronic illness on both a micro- and macro-level as specific individuals are unable to connect to an available healthcare opportunity. Especially in geographic locations where vaccination sites are centralized (i.e., not dispersed in communities), transportation is a significant barrier (Cochran 2021). This pandemic experience demonstrates just how important and precarious transportation services for individuals with disabilities are (Cochran 2020; Cochran 2021; Wolfe, McDonald, and Holmes 2020; Pettinicchio et al. 2021).

Broadly, we have yet to understand fully the effects of “stay home” orders and other public health protocols on supplemental healthcare services, particularly on the continuity of service delivery in local areas (Pettinicchio et al. 2021). Because support for individuals with disabilities is often secured through “extra” service delivery (sometimes titled a “social care sector”), the shutdown of more “marginal” healthcare services during the pandemic negatively influenced the daily experiences of individuals with disabilities. For instance, Pettinicchio et al. (2021) detail how many people with severe disabilities who depended on home healthcare services or who lived in long-term care did not receive the physical or mental health supports they needed during the pandemic. Furthermore, there were many disruptions in food delivery, medication delivery, physical and occupational therapy, speech therapy, and personal care. These disruptions disproportionately affected individuals with disabilities and chronic health conditions (Jumreornvong et al. 2020). Because many of these services are seen as ancillary and because these groups were already marginalized (perhaps hidden from view

even before the pandemic), healthcare decision-makers did not attend to the effects of halting these services on the everyday experiences of regular users of these services. Once more, those involved in high-level COVID-19 policy decision-making disregarded, or forgot to pay attention to, the differential effects of macro-level pandemic protocols on particular groups in society. While some healthcare services seem less essential, they often represent a lifeline for individuals with severe disabilities or those who live in long-term care (including elderly populations) (Rochon et al. 2021; Pettinicchio et al. 2021). In addition, these services often make healthcare accessible to a wide range of individuals who would otherwise not be able to connect to care. Home healthcare services, prescription delivery services, and transportation services alone are critical in connecting a range of individuals with disabilities to both routine and emergency care. Other services (e.g., physical and occupational therapy, speech therapy) make the day-to-day experience of impairments much easier and more manageable; thus, supplemental health services increase the quality of life and ease individuals’ ability to navigate everyday life. Without these regular services, individuals with disabilities remain disconnected from healthcare systems and face increased vulnerabilities in everyday experience.

Finally, individuals with disabilities have encountered more significant stigma and discrimination in their pursuit of healthcare during the pandemic; the American Psychological Association proposes that during times of crisis, “policies around rationing of medical care can intensify discriminatory attitudes towards disabled individuals” (APA 2020). These attitudes often lead to differential treatment. For example, individuals with disabilities who contract the virus may confront abridged care once admitted to hospital settings:

[B]ecause the COVID-19 pandemic places tremendous strain on our health care system, states, health care facilities, and professional organizations are developing triage protocols to determine how to allocate critical health care resources, especially ventilators, when there is not enough capacity to treat all patients. Disability advocates and organizations have raised serious concerns about the impact of triage policies that exclude, disadvantage, or otherwise discriminate on the basis of disability (Pendo 2020, <https://www.americanbar.org/groups/diversity/disabilityrights/resources/covid19-disability-discrimination/>).

Pendo (2020) catalogs ways in which, in the face of discriminatory triage or “care allocation” policies, individuals with disabilities have been treated differently by medical providers during COVID-related care compared to individuals without disabilities. For example, Pendo (2020) discusses how providers’ adherence to stereotypes and implicit bias affects treatment decisions. For example, medical providers have assessed quality of life and long-term survival differently when determining choice of treatment for individuals with diagnosed disabilities compared to counterparts without disabilities. Further, providers have assumed that individuals with cognitive or developmental disabilities cannot follow post-treatment protocols. In addition, numerous instances of failures to modify COVID-related treatments in reasonable ways in the face of impairments, reallocation of ventilators from patients with disabilities to patients without disabilities, and failures to consult with families before issuing treatments for COVID-positive patients with disabilities have all been documented in hospital settings (Pendo 2020).

While federal laws and policies are supposed to protect individuals with disabilities against discrimination within healthcare settings and disability advocacy organizations have been consistently challenging current care allocation policies (as well as biases in the implementation of these policies) (Pendo 2020), individuals with disabilities continue to report instances of differential treatment within COVID-related care. Ultimately the provision of care in this contemporary moment is still colored by value judgments and prejudices towards individuals with disabilities. This, in turn, affects individual experiences of medical treatment. Furthermore, because family members and caregivers were not allowed in hospital settings except in extreme situations during the height of the pandemic, they were not as able to step in to advocate for individuals with disabilities during the time of care provision as they were before the pandemic.

The above examples represent exacerbations of invisibilities that existed long before March 2020. Many of these COVID-related inequities also represent unintended consequences resulting from larger, longstanding invisibilities of disability within healthcare institutions. Our contemporary contexts have reaffirmed that the “processes, practices, images and ideologies, and distributions of power” within healthcare continue to render individuals with disabilities invisible (Acker 1992, p. 567). Even though the need for accommodation and adaptation is not new and even though impairment and disability are increasingly typical in contemporary times, decision-makers within healthcare institutions continue to fall

back on an ableist lens when creating, planning for, and implementing new practices and processes in healthcare systems. Therefore, newly established, macro-level procedures and techniques continue to sideline individuals with disabilities as a group and thwart many micro-level attempts to access healthcare services and acquire high-quality care.

Some care allocation policies promote individual stigma, bias, and discrimination in hospital settings, to make matters worse. Individuals and their families, alongside disability advocacy organizations, have challenged the discriminatory treatment of individuals and tirelessly pushed for accessibility and equity to be at the forefront of decision-making during this pandemic period. Some individual successes have resulted, but we are a very long way from eradicating the complexities of invisibilities that exist at the macro and micro levels of society. We are also a long way from understanding precisely the micro-level experience of disability and chronic health conditions during this public health crisis. We have plenty of anecdotal reports and have findings from some initial survey research projects. Still, we need substantially more research on what it is like to live with a disability or chronic condition and pursue healthcare during this contemporary moment.

### **Thinking Broadly about Invisibilities & Their Implications**

This article brings together conversations about the different types of invisibility experienced by individuals with disabilities. The goal is to present what we know about varied invisibilities in one place and orchestrate one comprehensive discussion of the invisibilities in the disability experience. In this way, we can begin to recognize the simultaneous and multi-level nature of invisibilities surrounding impairment and disability and how these invisibilities are exacerbated by particular contexts, such as the intersection of other social locations such as race, class, gender, sexuality, age, etc., and the COVID-19 pandemic. We have presented a discussion of just some of these contexts; there are many more. Disability scholars are recently encouraging a more comprehensive questioning of disability experience and thorough, intersectional analyses of disability alongside other social locations and sources of structural inequality (e.g., Mauldin and Brown 2021; Naples et al. 2019; Shifrer and Frederick 2019; Frederick and Shifrer 2019; Maroto et al. 2021; Pettinicchio et al. 2021). We join these scholars in trying to present a more comprehensive and complicated exploration of the lived experiences of disability.

Invisibilities are maintained because we have left disability “unquestioned” (Shifrer and Frederick 2019); we have done so in part because we have not problematized thoroughly the “lesser” status of individuals with disabilities or the “abnormality” associated with impairment and disability. Invisibilities also exist because we have structured a lack of recognition of disability into social institutions themselves. We continue to discredit and erase impairment even though it is an increasingly common reality. The individual, micro-level experience of impairment and disability goes unacknowledged or disregarded by others while, simultaneously, macro-level, institutionalized absence, marginalization, and dismissal is secured. Because we have not normalized impairment or disability and encouraged public conversations about impairment and disability in most mainstream forums, and because certain time and space contexts reinforce the marginalization of disability, we have exacerbated rather than lessened some experiences of invisibility over time.

Ultimately, if there are experiences of invisibility that weigh on individuals’ abilities to access services and opportunities or be acknowledged and regarded as worthy of consideration, entire groups risk the reduced personhood that Shifrer and Frederick (2019) discuss. This means that part of the movement for disability justice must be (1) normalizing discussions of impairment and disability, (2) talking about intertwined visibilities and invisibilities of disability (Nowakowski 2016) and the multiple ways in which personhood might be reduced, and (3) understanding how invisibilities exist in the first place because of the reduced personhood of individuals with disabilities. As Roger et al. (2018, p. 1057) argue about chronic illness, part of accepting impairment and disability is “witnessing it, as compared with denying its existence or significance.” This means we must prioritize seeing, knowing, and then reducing the invisibilities of disability, no matter how hard that might be. Race scholars such as Michael Omi and Howard Winant (2014) remind us that it takes generations to undo systems of institutionalized discrimination and that we often have to take steps backward as we try to move forward. The first step forward is to pay attention to the connections between macro- and micro-level invisibilities and accept disability as something we should see.

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## Author Biographies

**Heather E. Dillaway** is a Professor in the Department of Sociology at Wayne State University in Detroit, Michigan. Before coming to Wayne State in 2002, she completed a Bachelors of Arts in Sociology and History at Cornell University, a Masters of Arts in Sociology at the University of Delaware, and a PhD in Sociology at Michigan State University. Her research primarily focuses on two topics: (1) women's experiences of menopause and midlife and (2) the reproductive health experiences of women with physical disabilities. She has published research on women's experiences of physical disability in a range of journals and book volumes, including *Sex Roles, Disability Studies Quarterly, Disability and Health Journal, American Journal of Occupational Therapy, The Journal of Spinal Cord Medicine, Research in Social Science and Disability, The Oxford Handbook on the Sociology of Disability, The Routledge International Handbook of Women's Sexual and Reproductive Health*, and *Reframing Reproduction: Conceiving Gendered Experiences*. She has also been Chair of the American Sociological Association's Section on Disability and Society, and has co-edited a special issue of *Gender & Society* on intersectionality, gender, and disability. Additionally, she is co-editing volume 14 of the book series, *Research in Social Science and Disability* (under contract with Emerald Publishing); the theme of this volume is “disabilities across the life course,” to be published in 2023. Dr. Dillaway typically teaches courses on race, class, and gender inequalities, women and health, health disparities, families, qualitative methods, and research methods. She has also taught public health courses such as social and behavioral aspects of health, principles and practices of public health, and a public health capstone course for undergraduate seniors. In addition to faculty responsibilities, Dr. Dillaway is Associate Dean of Undergraduate Studies in the College of

Liberal Arts and Sciences at Wayne State. She lives in Ann Arbor, Michigan, with her husband and two children. In her free time, she tries to spend time with her two teenagers and be outside as much as possible. If she is not at work, you might find her gardening or walking along the beaches of the Great Lakes.

**Allison Jendry James** is a PhD candidate in the Department of Sociology at Wayne State University in Detroit, Michigan. She is also a full-time Visiting Assistant Professor in the Department of Anthropology and Sociology at Albion College in Albion, Michigan. Allison's dissertation work focuses on the identities and experiences of LGBTQ parents after the legalization of same-sex marriage. Some of her related work on same-sex families has been featured in the *Michigan Family Review*. Allison enjoys teaching courses such as Introduction to Sociology, Sociology of Families, Sociology of Sex and Gender, Social Inequality, and a first-year seminar course called "Families in American Sitcoms". While currently following her passion for teaching, Allison was previously employed full-time as a Senior Research Technician at the University of Michigan Institute for Social Research's Inter-university Consortium for Political and Social Research (ICPSR) where she worked on data projects involving the study of mortality in correctional institutions, Native American and Indigenous experiences of Head Start programming, and social work collaboration in palliative care. She holds a Bachelor of Arts in Sociology and Women and Gender Studies from the University of Michigan-Flint, and a Masters of Arts in Sociology at Eastern Michigan University. She expects to complete her PhD in Sociology at Wayne State University in 2022. Allison lives in Brighton, Michigan, with her spouse and two dogs, Balto and Mac.

**Amanda J. Horn** is a PhD student in the Department of Sociology at Wayne State University in Detroit, Michigan. She received her Bachelors of Arts and Masters of Arts in Sociology from Indiana University Purdue University Indianapolis (IUPUI) in Indianapolis, Indiana. Amanda's dissertation work explores women's experiences of both invisible and visible chronic illnesses, with special focus on the ways that social stigma, gender norms, and medicalization influence their everyday lives. Previously she completed a Master's thesis on women's and men's experiences of Celiac Disease. Broad research interests include patient health outcomes, healthcare organizations, and the social determinants of health. Amanda also teaches introductory courses in both Sociology and Public Health at Wayne State. Outside of academia, her hobbies include drawing, playing video games with her significant other, and trying out new, gluten-free recipes.