

# Social Work Practice and Disability Communities: An Intersectional Anti-Oppressive Approach



# **SOCIAL WORK PRACTICE AND DISABILITY COMMUNITIES: AN INTERSECTIONAL ANTI-OPPRESSIVE APPROACH**

An Intersectional Anti-Oppressive Approach

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ROTEL (Remixing Open Textbooks with an Equity Lens) Project



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# INTRODUCTION

Elsbeth Slayter and Lisa Johnson

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Given the high prevalence of disability worldwide (World Health Organization, 2023), it is important for practitioners to be prepared to effectively and respectfully engage with disabled people and disability communities (Slayter, Kattari, Yakas, et al. 2023). We set out to develop a peer-reviewed, edited, open-access textbook that would provide social work students and practitioners, and those in other helping professions, with free, accessible information and resources to support their preparation for work with disabled people and communities using a framework informed by critical theoretical approaches and the [disability justice movement's ten principles](#) (Sins Invalid, 2019).

## Social Identities

We feel it is important to acknowledge our backgrounds and the impetus for our work as co-editors of this textbook. Elsbeth identifies as a White, disabled cisgender woman who specializes in health services research related to the experiences of the disability community in the addictions and child and family services sectors. Lisa studies racial and ethnic disparities in child welfare systems and identifies as a queer, Black, non-disabled, cisgender woman. We are research and writing partners using an intersectional lens to consider the experiences of disabled people with different social identities in the child welfare system. This work led us to thinking more critically about all social work practice with disability communities, causing us to see the need for a different kind of textbook than is currently available on this topic.

## Language

We recognize the importance and power of language and have worked to be intentional about how we use language, especially that which speaks to individual or group identity. Below we explain our approach with regard to disability and racial identities.

There are varying perspectives on how to refer to members of disability communities. For many years, 'person-first' language has been deemed a respectful approach as it highlights one's personhood while recognizing disability as part of their lived experience. More recently, disability rights and disability justice advocates and members of some disability communities have rejected person-first language in favor of 'identity-first' language to embrace disability as an integral part of their identities. In this introduction, we use identity-

first language as it is the preference of the co-editors. Throughout the book, both person-first and identity-first language are used depending on the preference of the chapter authors and people whose stories are highlighted. However, there is no one-size-fits-all approach, so it is always best to check with and take the lead of the person or people you are interacting or working with.

Similarly, there is no universally shared preference for language related to racial or ethnic identity. In fact, debates about how to write about identity abound. One article that captures the spirit and scope of these debates as related to race is presented by the Columbia Journalism Review (Perlman, 2015), which recommends capitalizing Black, but not White. Arguments in favor of capitalizing White are made by Appiah (2020), the National Association of Black Journalists (2020), and the Diversity Style Guide (2023) who argue that it is important to call attention White as a race and to the way this racialized identity functions in our society. Our approach as co-editors is to capitalize both Black and White when referring to racial identity, which is also the guidance of the American Psychological Association (2020) publication manual, which our discipline of social work utilizes for formatting written work. When discussing concepts such as whiteness and white supremacy, we do not use capitalization. As with disability identity language, chapter authors have taken various approaches to capitalizing racial identity. We encourage the readers of this book to make their own decisions about language use based on a thoughtful review of the literature and based on their contexts.

## Theoretical Frameworks

A key goal of this book is to introduce an intersectionality-informed and critically culturally competent approach to anti-oppressive social work practice with disabled people, primarily in the United States. To do this, we present an innovative practice model for social workers to use in their work with disabled people and communities, which is incorporated throughout the book in a variety of practice considerations. The main themes woven throughout our practice model are intersectionality theory, critical cultural competence, and anti-oppressive practice. These concepts are introduced and explained in chapter 2 of this textbook.

An intersectional perspective focuses on the mutually determined influence of multiple, intersecting social identities on our lived experiences within systems of privilege and oppression (Cho et al., 2013). Moving beyond basic cultural competence, “critical cultural competence notes that “awareness, knowledge, and skills alone are inadequate” (Danso, 2015, p. 574). We believe that critical cultural competence is about “social workers’ ability to engage in high-level action-oriented, change-inducing analyses of culture and diversity-related phenomena” (Danso, 2015, p. 574). This concept also recognizes issues such as intersectionality, power differentials in the worker-client relationship, and examination of one’s social location or social position held in society based on social characteristics (Lusk et al., 2017). Anti-oppressive practice involves interrogating institutions and structures to recognize how even when social workers are trying to do good, we can replicate bad (Baines, 2011). Our full practice model is explained, with a helpful case example, in [chapter two](#).



## Voices and Narratives

In honoring the theoretical frameworks noted above, we also set out to present the experiences of a range of disabled people with different social identities in various service areas as a way to inform better social work practice and to do so using the social model of disability as our primary lens for understanding the environment as disabling given the medicalization of disability in many social work textbooks. In addition to bringing disabled people's stories about their experiences with social work to light, we accomplish this task by pulling together a team of authors who are practitioners, educators, researchers, and advocates with a range of social identities, including disability identities. When we speak of "disability identities," we are referring to not only physical, medical, and sensory disabilities but also neurodivergence, chronic illness, chronic pain, mental illness, madness, and so on.

Designed as a main textbook for social work courses at the bachelor's and master's level or for social work practitioners in the field, this work moves beyond a traditional medicalized and segregated approach (i.e., chapters organized around impairments) to the exploration of disability-specific populations, instead taking a more intersectional approach in discussing specific service areas and practice issues while weaving in stories about the lived experiences of disabled people with a range of social identities. These issues include parenting, mass incarceration, ableism, aging, and employment, among many others.

Our book acknowledges difference and multisystemic privilege and oppression while also drawing readers' attention to the importance of solidarity and allyship when it comes to meaningful social work practice with and social change for disabled people. In our work, we prioritize the voices of disabled people and their experiences with different parts of the health, education, justice, and social service arenas. We hope this textbook's structure and the theoretical frameworks it presents will make it a useful tool for educators, students, and practitioners in social work and other helping professions.

## Book Cover

Finally, the cover of our book represents some of the important decisions we made in editing this volume. The cover consists of the accessible icon in black at the bottom corner of the 2021 version of the disability pride flag. The disability pride flag, which was [designed by Ann Magill](#) in collaboration with others, is set on a black background and has a diagonal band of five stripes of different colors oriented from top left to bottom right. The flag has all the standard flag colors signifying that the disability community spans borders between states and nations. The black background symbolizes mourning and rage for victims of ableist violence and abuse. The diagonal orientation of the band represents "cutting across" the walls and barriers that separate the disabled from normative society, as well as light and creativity cutting through the darkness. The stripe colors represent the following disability identities: invisible and undiagnosed disabilities (white), physical disabilities (red), neurodivergence (gold), psychiatric disabilities (blue), and sensory disabilities (green). The different color

stripes also represent the variety of disabled people's experiences and needs, but the stripes are parallel to each other to illustrate unity among disabled people. We embrace the disability pride stance that comes along with the flag and take a strengths-based and empowerment-oriented approach to thinking about disability. Similarly, we use the [accessible icon](#) image over the flag in order to honor the disability community that made this icon in response to the more static and unempowered traditional wheelchair user symbol.

## Conclusion

May this book be helpful to you as you work to develop and/or hone your disability lens for practice with the disability communities you connect with over the course of your career. We would love to hear from you (please email us at [eslayter@saalemstate.edu](mailto:eslayter@saalemstate.edu) or [ljohnson2@saalemstate.edu](mailto:ljohnson2@saalemstate.edu)) regarding your reactions to the book, areas you would like us to add or improve upon, and the ways in which you have used this book in practice.

Elsbeth Slayter and Lisa Johnson, Co-editors

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# EDITORS' LAND ACKNOWLEDGEMENT STATEMENT AND COMMENTARY

Elsbeth Slayter and Lisa Johnson

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## Editors' Land Acknowledgement Statement and Commentary

At Salem State University, we work to illuminate the ways in which our university came to occupy the land upon which we engage in teaching and learning. We also recognize the limitations of land acknowledgements and support the fact that the use of land acknowledgements does not take away from the need for reparations in the form of giving land back (see the [#LandBack movement](#)).

The land occupied by Salem State University is part of Naumkeag, a traditional and ancestral homeland of the Pawtucket band of the Massachusett. We acknowledge the genocide and forced removal of the people of Naumkeag and their kin and we recognize the ongoing colonization and dispossession of Indigenous homelands. We respect and honor the Massachusett tribe and the many Indigenous Peoples who continue to care for the land upon which we gather. We recognize our own responsibility to this land we occupy. We commit to continuously learning and sharing its history and that of the Massachusett and other Indigenous People who have been and remain here. We commit to develop and implement initiatives that work toward repairing the injustices continuously being committed on the Indigenous People of this land. We commit to making our own environmental impact on this land as sustainable as possible. We commit to a renewed and ongoing engagement with the Massachusett and all Indigenous People in and around Salem State.

May this acknowledgement also mark a commitment to continuously learn and share the history and stories of the Massachusett and other Indigenous People who have been and remain here, develop and implement initiatives that work toward repairing the injustices continuously being committed on the Indigenous People of this land, make our own environmental impact on this land as sustainable as possible, and to engage with the Massachusett and all Indigenous People in and around the Salem State community (for more information see: [Salem State University Land Acknowledgement](#) and [The People Here: Interrogating Indigenous Dispossession of the Land Occupied by Salem State University](#)).

Resources: Native Organizations and Activist Movements:

[Massachusetts Center for Native American Awareness](#)

[North American Indian Center of Boston](#)

[First Light – Repairing, returning at the speed of trust.](#)

[LANDBACK – Building lasting Indigenous sovereignty.](#)

[NDN Collective: Defend. Develop. Decolonize.](#)  
[Land Reparations & Indigenous Solidarity Toolkit](#)  
[Seeding Sovereignty](#) and [@seedingsovereignty](#)  
[Native-Land.ca](#) and [@nativelandnet](#)

# LAND ACKNOWLEDGEMENT STATEMENT FROM THE ROTEL GRANT

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## Land Acknowledgement Statement from the ROTEL Grant

As part of the ROTEL Grant's mission to support the creation, management, and dissemination of culturally-relevant textbooks, we must acknowledge Indigenous Peoples as the traditional stewards of the land, and the enduring relationship that exists between them and their traditional territories. We acknowledge that the boundaries that created Massachusetts were arbitrary and a product of the settlers. We honor the land on which the Higher Education Institutions of the Commonwealth of Massachusetts are sited as the traditional territory of tribal nations. We acknowledge the painful history of genocide and forced removal from their territory, and other atrocities connected with colonization. We honor and respect the many diverse indigenous people connected to this land on which we gather, and our acknowledgement is one action we can take to correct the stories and practices that erase Indigenous People's history and culture.

Identified tribes and/or nations of Massachusetts

Historical nations:

- Mahican
- Mashpee
- Massachuset
- Nauset
- Nipmuc
- Pennacook
- Pocomtuc
- Stockbridge
- Wampanoag

Present-day nations and tribes:

- [Mashpee Wampanoag Tribe](#)
- [Wampanoag Tribe of Gay Head Aquinnah](#)
- [Herring Pond Wampanoag Tribe](#)

- [Assawompsett-Nemasket Band of Wampanoags](#)
- [Pocasset Wampanoag of the Pokanoket Nation](#)
- [Pacasset Wampanoag Tribe](#)
- [Seaconke Wampanoag Tribe](#)
- [Chappaquiddick Tribe of the Wampanoag Indian Nation](#)
- [Nipmuc Nation](#) (Bands include the Hassanamisco, and Natick)
- [Nipmuck Tribal Council of Chaubunagungamaug](#)
- [Massachusetts Tribe at Ponkapoag](#)

In the event that we have an incorrect link or are missing an existing band/nation, please let us know so that we may correct our error.

Suggested readings:

[Massachusetts Center for Native American Awareness](#)

[A guide to Indigenous land acknowledgment](#)

[‘We are all on Native Land: A Conversation about Land Acknowledgements’](#) YouTube video

[Native-Land.ca | Our home on native land](#) (mapping of native lands)

[Beyond territorial acknowledgments – âpihtawikosisân](#)

[Your Territorial Acknowledgment Is Not Enough](#)

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Elsbeth Slayter and Lisa Johnson

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- All of the authors who dedicated so much time towards preparing thoughtful and poignant chapters on a range of topics relevant to disability social work
- The chapter peer reviewers who provided additional expertise and helpful feedback to the chapter authors and book editors (see list below)
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# ACKNOWLEDGEMENT OF CHAPTER PEER REVIEWERS

Elsbeth Slayter and Lisa Johnson

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## Acknowledgement of Chapter Peer Reviewers

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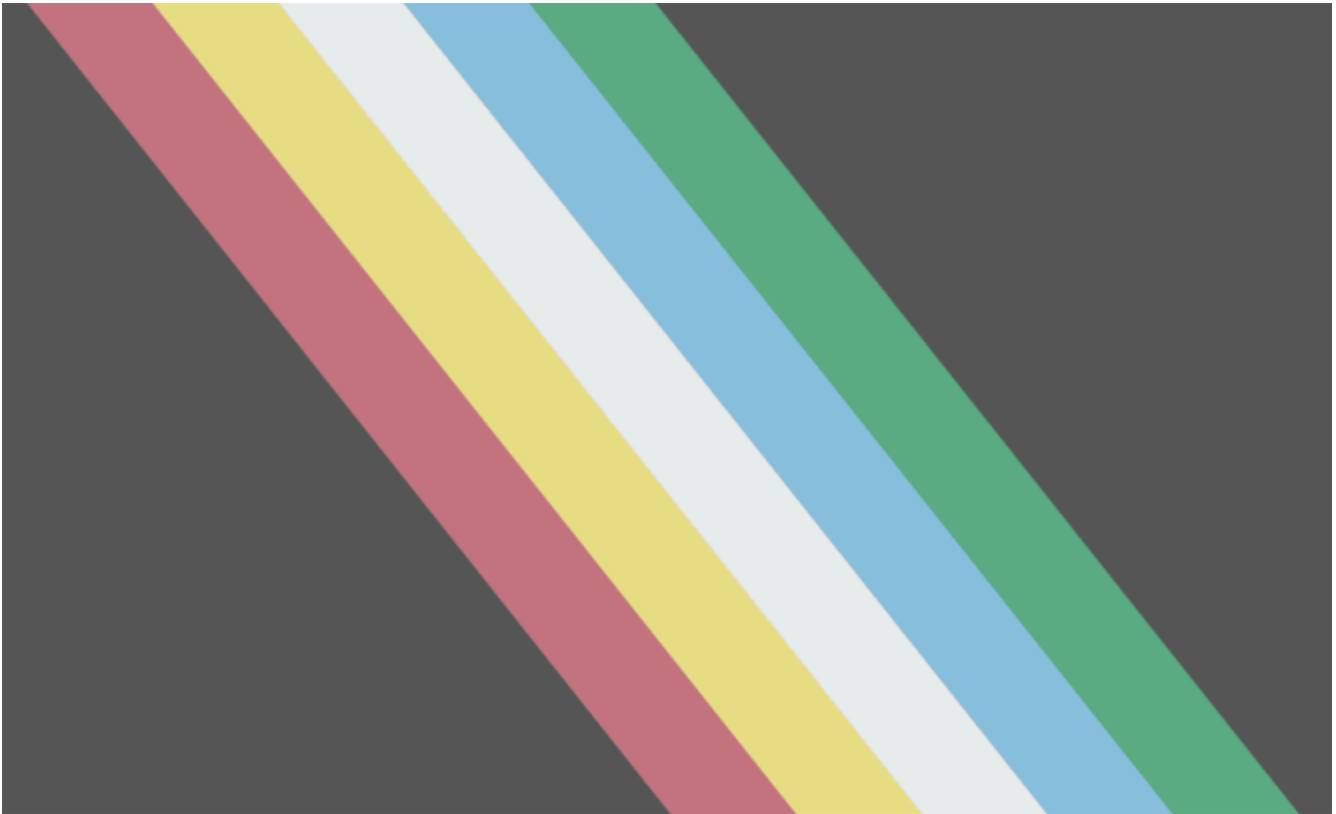
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1.

# DISABILITY SOCIAL WORK CONCEPTS AND PRINCIPLES

Elsbeth Slayter and Lisa Johnson

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Disability Pride Flag

Learning Objectives:

- To conceptualize different social constructions of disability
- To understand disability as a social identity
- To summarize empowerment-oriented disability practice principles

This chapter presents an introduction to disability social work concepts and principles. We define disability in the United States context, while illustrating the social and medical models of disability. We move on to explicating disability identity and disability culture. A section on explaining various perspectives on **ableism** in the United States context is presented. We conclude with an introduction to basic principles for empowerment-oriented disability social work along with the disability justice movement's ten principles.

## The Social and Cultural Construction of Disability

We will focus on learning about broad categories of disability and understanding prevailing models of disability, though it is beyond the scope of this chapter to cover every type of disability one might encounter in practice with the disability community. Defining **disability** is not a simple process, given that disability, like many identities, is socially constructed. A **social construction** is an idea that has been created and embraced by people in society. Wendell (2013) offers a perspective on the social construction of disability:

I see disability as socially constructed in ways ranging from social conditions that straightforwardly create illnesses, injuries, and poor physical functioning, to subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies. (p. 481)

When thinking about how to define disability, it is helpful to make a distinction between a person's impairment and a person's disability. **Impairment** is a physiological condition that can lead to disability while disability is a result of people living with impairments when there are physical, attitudinal, communication, social, or other barriers in the environment (People with Disabilities Australia, 2016; Cameron, 2014). Wendell (2013) points out that:

Many of the struggles of people with disabilities, and much of what is disabling, are the consequences of having those physical conditions under social arrangements that could, but do not, either compensate for their physical [or mental] conditions, or accommodate them so that they can participate fully, or support their struggles and integrate those struggles into the cultural concept of life as it is ordinarily lived (p. 483)

Wendell (2013) also offers thoughts about the cultural construction of disability, noting that:

Culture makes major contributions to disability. These contributions include not only the omission of experiences of disability from cultural representations of life in a society, but also the cultural stereotyping of people with disabilities, the selective stigmatization of physical and mental limitations and other differences (selective because not all limitations and differences are stigmatized, and different limitations and differences are stigmatized in different societies), the numerous cultural meanings attached to various kinds of disability, and illness, and the exclusion of people with disabilities from the cultural meanings of activities they cannot perform or are expected not to perform. (p. 484)

An example that speaks to impairment and the social and cultural constructions of disability is found in the fact that many people, an estimated 75% of U.S. adults, have vision impairments for which they wear eyeglasses or contact lenses (The Vision Council, 2017). The availability and social acceptability of these corrective lenses means that this impairment is not necessarily disabling if an individual's access and functioning is not impeded. However, if someone with a vision impairment does not have access to corrective lenses (perhaps due to lack of financial means, or limited insurance coverage), or if their vision is not sufficiently corrected by the lenses, their impairment coupled with the ways our physical, social, and policy environments are structured (e.g., requiring yearly eye exams to update lens prescriptions while only covering the cost of the exam every other year), would be disabling.

## Understandings of Disability in the United States

Disabilities can vary widely and be related to vision, hearing, motor skills, cognition, health, mental health – or a combination of any of these. One common understanding of disability in the United States is mapped out by the Americans with Disabilities Act, 42 U.S.C. § 12101 et seq. (1990). To be covered by this law, a person must be disabled, which is defined as being “a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment” Americans with Disabilities Act, 42 U.S.C. § 12101 et seq. (1990). The law does not outright name all of the impairments that are covered, so we categorize the major categories here.

People with visual disabilities include people with total blindness, low vision, partial sight, or color blindness – different people embrace different language/identifiers for themselves. Disability aids such as glasses and screen readers may be used by people in this population. Hearing disabilities are experienced by people who have deafness or are hard of hearing, though it should be noted that many people who are d/Deaf do not identify as disabled or consider deafness a disability. Disability aids such as captions or cochlear implants may be used by this population. Those with motor disabilities may have motor challenges or issues with gross or fine motor controls. Cognitive disabilities are experienced across a spectrum from intellectual and developmental disabilities to learning disabilities (who tend to use person-first language, that is, “person with a disability” vs. “disabled person”, which is identity-first language) and memory challenges. Mental health conditions exist along a spectrum from neurotic to psychotic symptoms, including depression and mania, for example

(people in this community also tend to use person-first language). Physical disabilities may include movement challenges, requiring disability aids such as canes, walkers, wheelchairs, and scooters. Health challenges may be acute, long-term/chronic, or episodic.

Disability can also be temporal. Some disabilities may be temporary, while others may be permanent (Zola, 1993). Some disabilities are experienced from birth while others can be acquired later in life. Castañeda and colleagues (2013), use the term “**temporarily able-bodied**” to raise consciousness that people who do not have disabilities may become disabled by illness, the process of growing older, accidents, and war, for example” (p. 461).

Disabilities are commonly thought of as either visible or invisible disabilities. Visible disabilities include, for example, conditions experienced by a person with Cerebral Palsy who uses a walker, or by a person with Down Syndrome. An invisible disability might be a condition such as traumatic brain injury, the B/blind community (when they have partial sight), Systemic Lupus Erythematosus (an autoimmune disorder), or bipolar disorders, all of which are not visible and must be disclosed in order to be identifiable. For an extended and intersectional discussion of the hard-to-see line between visible and **invisible disabilities**, [please see this essay by Zipporah Arielle \(2019\)](#). The take-home message here is that we cannot rely on assumptions and tropes as we work to identify and engage with disability in our social work practice.

Debates about the right language to use in talking about disability are ongoing. For many years, ‘**person-first language**’ has been deemed a respectful approach to describing people with impairments, and for some practitioners and communities, it still is. More recently, many disability rights advocates have rejected person-first language and have embraced **identity-first language** (sometimes called ‘disability-first language’) with an unapologetic embrace of disability as a social (and cultural) identity. In this chapter, we use both identity-first language due to the preference of the authors and person-first language when citing other sources. However, in practice, always take the lead of the person or people you are working with when considering whether to use identity-first or person-first language.

## Prevalence of Disability

Over one-fourth of Americans live with an impairment that causes a disability (Center for Disease Control and Prevention (CDC), 2021). As noted in the above discussion of disability and impairment, differentiating between impairment and disability is a challenge, so establishing the prevalence of disability in a given locale is not a straightforward matter and generally uses a medicalized approach. In the United States, public health officials define disability across a spectrum, including challenges to mobility (i.e., walking or climbing stairs), cognition (i.e. concentrating, remembering, or making decisions), sensory (i.e. seeing, hearing), self-care (i.e. dressing or bathing, known as some of the activities of daily living) and independent living (i.e. cooking or doing errands alone, known as instrumental activities of daily living). Drawing on this approach to the definition of disability, 27% of U.S. adults had a disability – over 61 million people (Varadaraj et al., 2019).

The most common types of disabilities were related to mobility (13.7%), cognition (10.8%), independent living (6.8%), vision (4.6%), and self-care (3.7%) (CDC, 2021).

In addition to obtaining an overall prevalence rate, it is important to look at age variations, geographic differences, and social identity categories in order to consider the potential for disability intersectionalities. Looking within the U.S. population with disabilities, 51.0% were people aged 18-64 (Kraus, Lauer, Coleman, et al., 2018). Those aged 65 and older comprised 41.4% of the population (Kraus, Lauer, Coleman, et al., 2018). Disabled children and youth comprised only 7.3% (ages 5-17) and 0.4% (under 5 years) (Kraus, Lauer, Coleman, et al., 2018). We know that significant differences in the overall rate of disability exist state to state, ranging from 16.4% in Minnesota to 31.5% in Alabama, suggesting that social conditions may impact disability prevalence. While southern states had the highest prevalence rate, lower rates were reported in the Midwest and West. Disability may also be gendered in nature because women report higher rates of disability (24.4%) than do men (19.8%), while data on other genders remains uncounted and unknown (Courtney-Long, Carroll & Zhang, et al., 2013). This gendered pattern continued when specific types of disability were considered.

It is also important to consider both race and ethnicity when analyzing disability prevalence rates. One example relates to adults who identify as Black or African American who reported the highest rates of any disability and of each disability type at one in four population members (Courtney-Long, Romano, Carroll, et al., 2017). While people of color have traditionally been under-reported in disability prevalence statistics, Black and African American children are simultaneously overly diagnosed with intellectual and developmental disabilities (Innovate Public Schools, 2019) – and often tracked into lower-level courses and special education programs at disproportionate rates. For example, non-Hispanic/Latinx Black children (16.9%) were more likely than non-Hispanic/Latinx White (14.7%) or Hispanic/Latinx (11.9%) children to be diagnosed with either attention deficit hyperactivity disorder or learning disability. Yet at the same time, we see Black children are less likely to be identified as having an autism diagnosis than White children (Mandell, Wiggins, Carpenter, et al., 2009).

Patterns also emerge when considering the intersection of disability with sexual orientation. Rates of disability among people who identify as lesbian, gay, or bisexual were higher than in the heterosexual population, even when age was taken into consideration. Data suggest that lesbians and bisexual women were more likely to be disabled than were gay or bisexual men. Overall, among lesbian, gay, and bisexual adults, 30% of men and 36% of women reported being disabled (Fredriksen-Goldsen, Kim & Barkan, 2012).

Finally, socioeconomic status is a primary factor related to disability prevalence. Poverty rates among people with disabilities are more than twice the rate of people without disabilities and people with disabilities account for more than half of those living in long-term poverty (National Council on Disability, 2017). People with higher incomes and more years of education had lower rates of any disability – a pattern that continued within each disability type. Almost half of adults with an income of less than \$15,000 and 40.0% of adults without a high school diploma had a disability compared with only 10.8% of adults with an income of over \$50,000 and 11.8% of college graduates. Unemployed adults were more than twice as likely to have a disability (33.5%) as compared to people who were employed (12.6%) (Courtney-Long, Carroll & Zhang, et al., 2013).

Most recently, we have seen an increase in the number of people in the U.S. with a diagnosed disability due to the ongoing effects of COVID-19 (known colloquially as ‘long covid’), which is considered a mass disabling event, especially for people of color ([Kendi, 2021](#)). Many people will develop ‘long COVID’ after testing positive for COVID-19 and experiencing substantial limitations in at least one daily life activity ([U.S. Department of Health and Human Services, 2022](#)). This is now designated as a disability. U.S. studies suggest that between 10-30 percent who have been diagnosed with COVID-19 develop ‘long COVID’ (Government Accounting Office (GAO), 2022). This indicates that between 7.7 million and 23 million people may have developed this condition as of February 2022 (GAO, 2022).

Taken together, all of these data points tell us that disability is experienced by many communities of people in many different ways – and that disabled people are likely to have multiple social identities which can lead to the experience of intersecting oppressions, all of which are at the expense of losing privilege and facing further marginalization.

## Historical Perspectives on Disability

Disability is woven into the history of the United States – and from the other Western civilizations influencing the development of it – whether hidden or well-known (Stiker, 2019). The United States has a long, reprehensible history of placing constraints on disabled people instead of allowing them to live life the way they want to. At times, this has involved the development and implementation of policies and even social work practices that inhibit the lives of disabled people (Powell & Stein, 2016). In order to understand how this came to be, we need to look at history for sociocultural and political context. We acknowledge that this discussion centers on European and U.S.-based contexts as these have been the primary drivers of perspectives about disability in the U.S.

If we venture back to Greek and Roman times, we know that society valued physical perfection along with intelligence leading to a very low quality of life for disabled people as objects of scorn (Stiker, 2019). Over time into the medieval period, we saw religion as having a major role in how society thought about disabled people and acted in response to or in support of this population (Stiker, 2019). This was related to people’s fear of god and the belief that disabled people were cursed in some way, or being punished for a sin (Stiker, 2019). These views conceptualized disabled people as subhuman, leading to the development of shelters and, for example, leper colonies (Stiker, 2019). Some people saw disabled people as ‘closer to god.’

Between 1563-1601, Queen Elizabeth in England developed and implemented the “poor laws” that obligated the state to take care of disabled people, among others (Nielson, 2013). Almshouses were created for the “aged poor” and workhouses were created for people who “refused” to work. Conditions in these places were grim (Nielson, 2013). The state’s role overlapped some with Christian beliefs about civic duty, leading to individual parishes offering some support to people who were both destitute and disabled (Stiker, 2019).

In the 1800s, we began to see the development of asylums, or institutional settings for disabled people,



which represented a shift towards the medicalized understanding of disability that began in the 1700s. This shift led to the involvement of medical professionals in the care and support of disabled people. By understanding disability as a biological or physiological deficiency, society moved beyond the idea that disability was rooted in sin, for example. With disabled people now more dependent on professional care, attitudes towards this population embraced the idea of this group of people being pitiful or childlike. Unemployment was a major problem for disabled people, as it is today (Nielson, 2013).

In the late 1800s and early 1900s, the eugenics movement had a major impact on disabled people – with the idea that they were a threat to society and the well-being of nations. This movement focused on ridding the human race from all physical and mental deficiencies in order to have a more perfect society. Later, we saw this eugenic philosophy applied in Nazi Germany in the Aktion T4 program, in which Hitler ordered ‘mercy killings’ of sick and disabled people deemed ‘life unworthy of life’ (Stiker, 2019).

But in 1927, involuntary sterilization was supported by the Supreme Court in the *Buck v. Bell* decision. Carrie Buck, who was considered ‘feeble-minded’ or what we now might call intellectually or developmentally disabled, was raped by a relative of her foster parents (Cohen, 2016). As a result, Carrie was involuntarily institutionalized at the Virginia State Colony for Epileptics and Feeble-minded, along with her mother. Sterilization was sought for Carrie by the Colony per the state’s compulsory sterilization law. This law was upheld based on the idea that it served “the best interests of the patient and of society” with Justice Oliver Wendell Holmes, Jr. declaring, “Three generations of imbeciles are enough.” (*Buck v. Bell*, 1927). Due to state laws such as this, many disabled people, people of color, poor people, or people with all of these intersections were sterilized against their will by the 1970s (Lombardo, 2008).

Starting in the 1960s and 1970s, questions emerged in society about the care of disabled people in asylums and institutions. A series of scandals in the United States, such as the Willowbrook incident, revealed the abuse and neglect that disabled people often experienced in these settings. This led to the movements for community inclusion, self-determination, and community-based mental health and disability services. Many disabled people transitioned to life in the community although this was not always as ideal as it might sound (Nielson, 2013).

## The Medical and Social Models of Disability

There are two primary models influencing how our culture has conceptualized disability. Historically and most commonly, a **medical model** has been used to understand and respond to disability (Shakespeare, 2013). In this model, disabling conditions are considered inherent to the individual and often in need of a cure or a ‘fix.’ In this way of thinking, conditions that are different from a standardized norm are individual problems that impact individual people. Therefore, the medical model centers on the identification and treatment of disabilities and considers clinicians as the experts on that condition instead of the people with the condition. This model is also based on what disability advocates refer to as the ‘personal tragedy theory of disability’

or the idea that having a disability is a terrible thing, a tragedy, from which no good can come, something disability advocates seek to subvert (Oliver, 1990). Unfortunately, many of the financial structures that support the practice of disability social work are based on the medical model of disability in their billing practices. This makes the use of the medical model a requirement for social workers to provide services and supports and for disabled clients to receive services and supports. While some disabilities are easy to identify through the use of functional assessments (i.e. visual impairment, physical limitations requiring the use of a wheelchair), some disabilities require identification through clinical assessment tools such as diagnostic tools for mental health disorders or intelligence testing for intellectual disability, formerly referred to as mental retardation. In the United States, the medical model is also used to define disabilities via a person's eligibility for federal and state social service programs, such as Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI).

Emerging from the United Kingdom in the 1970s (UPIAS, 1976), the social model of disability was built upon by disability scholar Michael Oliver (2013). The **social model of disability** has a diametrically opposed vision to that of the medical model. In the social model, disability is considered an indicator of an ableist and inaccessible society, in which disability is a socially-constructed concept (Shakespeare, 2013). This model considers the ways in which society develops barriers for disabled people – and fosters a cycle of ableist oppression and able-bodied privilege. In other words, the social model suggests that the social and physical world itself is disabling, versus focusing on the body part or process that is constructed as a disability in the medical model. This model does not deny specific disabilities or the ways they impact a person, but it does challenge barriers (i.e. attitudes, physical barriers, communication challenges) that restrict access to people with all forms of human diversity, including disabilities.

Widely viewed as a political tool by the disability civil rights movement, the social model of disability counters the personal tragedy theory of disability and demands both dignity and independence for people with disabilities. Disabled people have also called for community inclusion and access to the living of everyday life – be that access to adaptive medical equipment, access to employment, or physical access in the form of a ramp (McCarthy, 2003).

The social model of disability is not, however, without limitations (Owen, 2015). As noted by Shakespeare and Watson (2002) and commented upon further by disability rights activist Lydia X.Z. Brown (2018), the social model approach to disability may not adequately capture the individual's lived experience of impairment; recognize the diversity of perspective in adopting a disability identity; or sufficiently acknowledge the experience of impairment and/or disability among multiple, intersecting identities. Despite these limitations, the social model continues to be a powerful one for the disability civil rights community – a community that is fighting for the rights of and justice for over one-fourth of the U.S. population (CDC, 2021).

The models of disability are related to two areas of theory that inform the present book, '**Crip Theory**' and '**Disability Critical Race Theory**' or '**DisCrit.**' Crip theory is helpful to draw on in practice with queer, disabled people. This theory challenges the separation of what is defined as 'normal' and that which

is ‘abnormal’ (McRuer, 2006). Goulden & Katz Kattari (2022) note that “this phenomenon is named compulsory able-bodiedness in crip theory – the expectation that normalcy is something everyone wants to achieve” (p. 7). In many disability communities, ‘crip’ is considered to be an inclusive term that can represent all disabilities, which are broad in their diversity. ‘Crip’ is not only used to describe a disabled person (a within-community word use only) but it can also be a verb, i.e. ‘cripping’ focused on revealing able-bodied assumptions as well as exclusion. Crip theory considers impairment as more than an unwelcome presence.

Disability critical race theory, known colloquially as ‘DisCrit,’ responds to the erasure of disability and the manner in which it is connected to race (Annamma et al., 2013; Erevelles & Minear, 2010). For instance, in the context of elementary-level special education, despite the fact that researchers within critical race theory share “many overlapping interests and concerns with DisCrit scholars, we see a dearth of theories and studies examining the relationship between race, ethnicity and disability” (Annamma et al., 2013, p. 1). Also, the whiteness of the field of disability studies has also been challenged by various scholars (Bell, 2017). DisCrit scholars demonstrate how Black and brown bodies are “viewed as less developed than White bodies” and considered to be more “primitive;” sometimes even considered “subspecies of human” (Annamma et al., 2013, p. 2). Further, the authors state:

We believe that students of color who have been labeled with dis/abilities live in this same complex world where they do not fit neatly into any one category. ... We believe that issues of perceived dis/ability constitute issues of equity that involve all people. ... We believe, for instance, that racism and ableism are normalizing processes that are interconnected and collusive. (p. 6)

## Intersecting Identities, Oppression, and the Disability Experience

Building on the Crip Theory and DisCrit perspectives, we know that disabled people are an oppressed and underserved population in the United States due to their disabilities in addition to their social identities (Fredriksen Goldsen, Kim & Barkan, 2012). Living with a disability is often characterized by the experience of intersecting oppressions such as racism, homophobia, transphobia, and sexism – among other forms of oppression. Unfortunately, ableism is often a common experience among people in the disability community. **Ableism**, when looked at through the lens of a singular oppression, is:

the belief that because persons with disabilities are not typical of the nondisabled majority, they are inferior. Ableism precipitates devaluation, while the results of devaluation, including exclusion, ostracism” and a lack of privilege, can reinforce the attitudes, behaviors, and government actions of those who oppress. Four manifestations of oppression characterize ableism, “containment, expendability, compartmentalization and blaming the victim” (Mackelprang & Salsgiver, 2015: 105). Containment refers to the practice of limiting choices, exposure, and life experiences. Expendability refers to the idea that disabled people are unimportant or disposable. Compartmentalization refers to the stereotyping of disabled people in a way that places people in predetermined categories (Mackelprang & Salsgiver, 2015).

In a society characterized by ableism, disability intersects with all social identities as it affects people of all races, ethnicities, religions, genders, gender identities, sexualities, and socioeconomic classes (Hirschmann, 2013). Understanding the ways in which disability-related discrimination intersects with various forms of oppression is vital for social work practitioners working with disabled people, especially given the history of disability discrimination in social work – a history that has not been ‘solved’ by recent legislation (e.g. Americans with Disabilities Act of 1990). In an analysis of ableism, developed in conversation with Dustin Gibson and other colleagues, Talila Lewis (2021) has explicated the ways in which ableism and racism are connected with lasting bonds that inform one another, saying “the root of racism is ableism; and the root of ableism is anti-Blackness” (Lewis, 2021, n.p.). Addressing and solving ableism is impossible without addressing and solving racism, they argue. Lewis also points out that “ableism is also at the root of every other oppression” (Lewis, 2021, n.p.). Pulling this argument together, Lewis offers a working definition of ableism that is intersectional in nature, moving beyond the more traditional, uni-dimensional definition of ableism that is traditionally presented, such as the one we share above.

Ableism is “a system that places value on people’s bodies and minds based on societally constructed ideas of normality, intelligence, excellence, desirability, and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, misogyny, colonialism, imperialism, and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person’s language, appearance, religion and/or their ability to satisfactorily [re]produce, excel and “behave.” You do not have to be disabled to experience ableism. (Lewis, 2021, n.p.)

In addition to ableism, **sanism** is an important concept to understand for social workers. Perlin (1992) describes sanism as “as insidious as other “isms” and is, in some ways, more troubling, since it is largely invisible and largely socially acceptable... Sanism is a form of bigotry that “respectable people can express in public” (p. 374–5). Sanism, as developed in the work of Poole et al. (2012) and Reid and Poole (2013), specifically refers to the marginalization experiences of those who are living with mental health conditions. Sanism also refers to how people living with mental health issues have been thought of as ‘incompetent, not able to do things for themselves, constantly in need of supervision and assistance, unpredictable, violent and irrational’ (Chamberlin, cited in Poole et al., 2012: 3). In summary, Reid and Poole (2013) state that sanism subjugates people who have had mental health diagnoses or treatments. For more information on understanding sanism, Dr. Poole elaborates on this concept in a Ted talk that frames this concept. The video can be found at this link: <https://www.youtube.com/watch?v=hZvEUbtTBeS>.

## Disability Culture and Identity

Understanding **disability identity** begins with an understanding of **disability culture**, because to develop a strong disability identity, one must connect with other disabled people and the disability culture. Let’s begin with a definition of disability culture (Dupré, 2012). Marilyn Dupré (2012) writes that social workers need

to move beyond an assumption of the possibility of cultural competence to an embrace of learning about disability culture.

Disability culture is the sum total of behaviors, beliefs, ways of living, and material artifacts that are unique to persons affected by disability. Particular definitions of culture take many different forms and are context-bound (dependent on the cultural and geographic context in which they are formed), but three common ways of thinking about disability culture are (1) historical, (2) social and political, and (3) personal and aesthetic. Historical definitions of disability culture focus on art, poetry, language, and social community developed by disabled people. Definitions of disability culture that blend the social and the political focus on a minority-group distinction with common values of social and economic justice, radical democracy, and self-empowerment. Notions of disability culture grounded in the personal and the aesthetic emphasize a way of living and positive identification with being disabled (Peters, 2015, n.p.).

Disability identity is a unique aspect of identity that includes identifying one's sense of self as disabled, as well as their unique connection to the disability culture and community overall (Mackelprang & Salsgiver, 2015). Developing a strong identity as a disabled person is considered by many in the disability community to be a fundamentally important step toward long-term psychological and emotional well-being. Developing a disability identity does not happen solo; it only can occur when in relationship with others through mirroring and modeling processes with other disabled people (Mueller, Minotti & Forber-Pratt, 2020). Recognizing and supporting the development of disability identity, then, can be an absolutely essential part of working with disabled people. When designing service plans, planning for supports, and looking at disability culture and community options to assist in developing disability identity in positive ways, social workers should be engaged in dialogue with their clients every step of the way. Connecting with disability culture may offer individuals the opportunity to be part of that strong community that provides support and camaraderie to its members. This is an especially important resource for social workers to know about when working with people who are isolated and without resources.

Some people also do not wish to see disability as a positive thing, nor do they wish to identify with disability as a cultural group. Even those who view disability through the social model lens tend to highlight the disabling nature of social forces and structures. While there are many disabled people who do have a strong identity as a member of the disability community, for those who do not, social workers may play a role in promoting the potential for disability to be integrated as part of one's personal, social, cultural, and political identity/ies when using the social model lens. Disability is an identity like other social identities although it is important to know that not all want to identify as a cultural group or understand that as a possibility. There is so much variety and difference within each disability identity that does not allow us to go into detail here and this connects to intersectionality. We approach groups with a homogeneity expectation – that people will have shared experiences and expectations but there are often so many different experiences within, so this is important to watch out for and to be open to. Mueller, Minotti, and Forber-Pratt (2020) comment that:

Disability identity, because it is about an individual's own experience of their disability, is experienced in some way by everyone who has a disability. How this identity is expressed might look different based on

each individual's ideas, communication styles, and relationship to their own impairments. For example, they might participate in community by visibly seeming excited or comfortable when they go to certain disability community events. Most importantly, we think it is important that all people with disabilities are seen as part of a broader, powerful and rich disability community (n.p.).

One question to ask is: does society make the claim for us or do we have a choice of social identity? Another question is how can helping clients embrace their disability identity assist them in achieving their case goals?

## Central Tenets of Empowerment-Oriented Disability Social Work Practice

In this section, we discuss two sets of principles that should guide social workers' practice with the disability community so that we are doing empowerment-oriented work. Empowerment-oriented practice, while drawing on a strengths-based approach, differs from strengths-based practice in its focus on promoting the self-efficacy of the individual or group. First, we draw on the six principles developed as part of the disability civil rights movement. We then move on to review a newer set of principles that have emanated from the **disability justice movement** which was founded in 2005 by members of the disability organization Sins Invalid. The disability justice movement centers the priorities and approaches of people who are most historically excluded, such as women, people of color, immigrants, imprisoned individuals, and LGBTQIA+ people (Berne, no date). This movement's principles work together but are not part of one established theoretical framework.

Six central tenets can be used to guide empowerment-oriented social work practice with disabled people. The first concept, community inclusion, posits that all people have the right to be respected and appreciated as valuable members of their communities (Vaughn-Switzer, 2003). This includes, for example, a focus on helping people to participate in recreational activities in neighborhood settings as opposed to institutional settings, and to generally being part of the larger community. Second, there is the concept of circles of support. This concept honors the fact that people may have a range of friends, family, or other supports in their life who can provide friendship and support. Circles of support are either formal (such as social workers, personal caregivers, occupational therapists, physical therapists, paid group home staff, etc.), informal (i.e. friends, family, and neighbors) or a mix of both. Members of a person's circle of support are often crucial to the success of any social work intervention. However, it is important for social workers to honor that the client at the center of the circles of support has the right to direct their care – including how they want their circles of support to be included in that process – or not! Circles of support are not “responsible for” disabled individuals, nor are they caring for them, but rather they are looking out for the person and protecting their interest. This concept recognizes that humans don't exist in isolation, rather, they function in an interconnected manner.

The third tenet is linked to the phrase “nothing about us without us.” This phrase became the rallying cry of the disability civil rights movement adopted in the 1990s (Owen, 2014). This phrase is said to derive



from Latin, *nihil de nobis sine nobis*, later used in “Polish foreign policy in the 1930s to communicate the idea that no policy should be decided by any representative without the full and direct participation of those whom the policy affected” (Owen, 2014, p. 7). More recently, disability civil rights advocates have reframed this saying to read “about us, by us” (Disability Policy Consortium, 2020). Fourth, there is the concept of self-determination. This is conceptualized as the process of making something happen in one’s own life. It is the opportunity to make choices, set goals, solve problems, and make a range of decisions for oneself. Fifth is the idea of interdependence, or the notion that we are not and do not need to be as independent as we think we are in this society, we are actually much more interdependent than we realize (Lightfoot & LaLiberte, 2011), and this should be recognized and honored. Interdependence honors the goal of working to meet each other’s needs without always reaching for state solutions (Sins Invalids, 2021).

The sixth tenet, the dignity of risk, is perhaps the most controversial and challenging of all of the tenets. This is the idea that everyone can learn from everyday risks. Central to honoring the dignity of risk is respecting an individual’s autonomy and self-determination to make choices. Also important is the right to make choices even if social workers or other professionals in the person’s life feel that they could endanger the decision-maker in question. In order to respect a person’s dignity of risk, one should provide intermittent support even if others do not approve of the unsafe choice. As there is inherent dignity in the experience of everyday risk, this concept suggests that limiting a disabled person’s ability to make a risky choice or limiting their access to the community does not foster overall wellness in the long run. Robert Perske (1972) famously writes:

Overprotection may appear on the surface to be kind, but it can be really evil. An oversupply can smother people emotionally, squeeze the life out of their hopes and expectations, and strip them of their dignity. Overprotection can keep people from becoming all they could become. Many of our best achievements came the hard way: We took risks, fell flat, suffered, picked ourselves up, and tried again. Sometimes we made it and sometimes we did not. Even so, we were given the chance to try. Persons with special needs need these chances, too. Of course, we are talking about prudent risks. People should not be expected to blindly face challenges that, without a doubt, will explode in their faces. Knowing which chances are prudent and which are not — this is a new skill that needs to be acquired. On the other hand, a risk is really only [a risk] when it is not known beforehand whether a person can succeed. The real world is not always safe, secure, and predictable, it does not always say “please,” “excuse me,” or “I’m sorry.” Every day we face the possibility of being thrown into situations where we will have to risk everything...In the past, we found clever ways to build avoidance of risk into the lives of persons living with disabilities. Now we must work equally hard to help find the proper amount of risk these people have the right to take. We have learned that there can be healthy development in risk taking and there can be crippling indignity in safety. (p. 196)

Arguably, the dignity of risk may be the most challenging of the tenets for social workers to embrace in their practice with clients, but it is a vital one to work toward given its intersection with self-determination. Taken together these central tenets of disability social work will inform your practice and improve your ability to do empowerment-oriented work with the disability community.

These six central tenets of empowerment-oriented social work practice with the disability community work well with the ten principles set out by a group of disability activists working with disability—the culture

organization Sins Invalids. These principles are outlined below. Further detail can be found on the organization's [website](#) (Berne, no date).

Intersectionality refers to the idea that each person has different social identities that intersect in different ways, and they all impact us in a unique manner.

Leadership of the most impacted calls on us to move beyond academics and other experts to listening to the people most impacted by ableism, etc. This allows us to be grounded in the real world.

Anti-capitalist politics references the fact that a focus on accumulating wealth encourages competition as a way to survive. This harms disabled people who may not be seen as productive in the dominant-society sense. This lifts up the idea that worthiness is not dependent on productivity.

Cross-movement solidarity argues that the disability justice movement can only grow in connection to, alignment with, and support for other movements, such as queer and trans liberation, racial justice, and gender justice.

Recognizing wholeness honors that each disabled person is a whole person with their own history and life experience.

Sustainability focuses on maintaining well-being in the long term through listening to our bodies and experiences as a critical guide toward liberation and justice.

Commitment to cross-disability solidarity relates to the need for all disabled people and communities to work together, especially those often left out of political conversations or who may be isolated.

Interdependence moves us beyond western society's lifting up of the concept of independence alone. This relates to the liberation of all living systems, including the environment. Also, this means focusing on self/community support as opposed to state solutions where we can.

Collective access embraces the idea that access needs are not to be ashamed of, can be shared in community, can be met without one's integrity being compromised and with autonomy balanced.

Collective liberation means that no body-mind is left behind, and honors people of all social identities within the disability communities.

Questions to ask yourself after reading about these central tenets and principles include—how am I already using these principles in my practice? In what areas can I improve the use of these principles? In what areas am I not using some of these principles at all? Let these central tenets and principles guide you as you read the rest of this textbook on social work practice with the disability community.

## Conclusion

In summary, this chapter explores disability definitions, identity, history, and culture. It is important to understand how disability has been and is framed by society through medical, social, political, and cultural lenses. Using this first chapter as a foundation, we now move to the next chapter which focuses on theoretical and practice guidance for empowerment-oriented social work with disability communities.



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2.

# A MODEL FOR SOCIAL WORK PRACTICE WITH DISABILITY COMMUNITIES: CONNECTING CRITICAL CULTURAL COMPETENCE, INTERSECTIONALITY AND ANTI-OPPRESSIVE PRACTICE

Elsbeth Slayter; Rose Singh; and Lisa Johnson

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## Learning Objectives:

- To understand how critical theoretical perspectives can inform social work practice with the disability community
- To apply the model, inclusive of the planned change process, to social work practice with the disability community

- To identify elements of the model for social work practice with the disability community that may be used within one's own professional context

## Introduction

This chapter presents a model for social work practice with disability communities, which follows the social work planned change process and is informed by the theoretical perspectives of critical cultural competence, intersectionality, and anti-oppressive practice. We first review the planned-change process as a facet of social work practice. We then offer an overview of key theoretical perspectives that inform the practice model, including their application to disability social work practice. Next, we introduce a model for social work practice with the disability community and include a detailed case example following the work of a social worker and client using the planned-change process. Finally, we offer a comparison of the model to existing disability practice models.

## Introduction to the Planned-Change Process

The “planned change process” is the foundation for much of social work practice in the United States that is focused on the development and implementation of an approach to change behaviors, a condition or circumstance that will improve the life of a client in some way (Kirst-Ashman, 2012). This process can be applied at multiple levels – micro, mezzo, and macro – and with a spectrum of populations. This process is one that social workers can use to plan and implement change with clients and client systems.

Consisting of a series of steps that can be summarized as client engagement, assessment, intervention, termination, and evaluation, the planned change process provides a basic framework from which social workers can frame their practice with clients and client systems. Although the planned change process is typically visualized as linear, it is not linear when put into practice. For example, work with a client might vacillate between assessment and intervention as the client-social worker relationship evolves and/or as new challenges arise or become clearer.



Planned Change Process

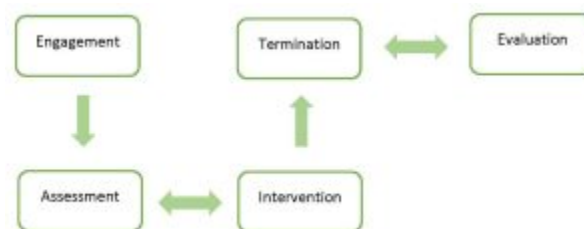


Although the planned change process is at times conceptualized differently with respect to the number of steps included, the following is a summary of the commonly used steps in the planned change process. The first step, engagement with the client, refers to the beginning interaction between client and social worker. As the relationship develops differently for every client and every circumstance, there is not a set timeframe in which engagement happens. Skills used by social workers during the engagement step include active listening, use of eye contact (depending on cultural preferences, traditions, and expectations), demonstration of empathy, and reflection on what the client is engaging in. This step is all about fostering rapport and trust between the client and the social worker.

The second step, assessment, is led by the social worker who gathers, analyzes, and synthesizes information from the client in order to develop a picture of the client's functioning, needs, and strengths. Assessment is the foundation of the action steps that follow it. According to Johnson and Yanca (2010), there are five important activities in the assessment step: identifying the need; honing in on the nature of the problem; identifying strengths and resources; collecting client data; and analyzing all of the above information for development into an implementable plan.

The third step focuses on the implementation of an action plan that is guided by goals and objectives co-created by the client and the social worker. The fourth step, termination, takes place once goals and objectives have been met and there is no more need for social work services. This involves a situation in which the client and social worker reflect on the work that they have done together before closing out the professional relationship.

The fifth step, evaluation, may be considered important to engage in throughout the planned change process and may also be an aspect of termination. During the previous steps, the social worker is ethically mandated to always evaluate how the client is doing throughout the course of the social work process through either implicit or explicit evaluation (i.e. supervision vs. formal data analysis). However, when the goals have been met, the client and social worker should review the goals and objectives and evaluate what change did take place and what could be improved upon vis-a-vis process or content. If a change did not occur, the client and social worker should reconsider the goals and objectives to make alterations focused on achieving the goal.



Nonlinear Planned change process

## History of the Planned Change Process

As critical consumers of knowledge for social work practice, it is important to note that the planned change

process was developed in the context of the United States and may be somewhat culture-bound based on the era in which it was developed and who was involved in academic social work at that time. Based first in the United States social diagnosis-informed social casework model developed by [Mary Richmond](#), this process is also informed by the problem-solving model put forth by [Helen Harris Perlman](#) (1957).

Mary Richmond is well-known as the person who developed the concept of social diagnosis, in which a person and their problem are considered within the larger socio-political context (Richmond, 1917). Richmond is also known for the development of the social casework framework in which she highlighted the importance of including clients in the solving of their problems (Richmond, 1922).

The problem-solving process builds on Richmond's work and can be thought of as a synthesis brought together from several sources including Perlman's background in the humanities and her philosophical reflections together with her knowledge of psychodynamics and the social sciences. In this process, the social worker supports the client in learning how to analyze problems while providing consultative education in the art of effective problem solving. Perlman had significant clinical expertise, and her process demonstrates strong emphasis on the importance of the helping relationship in direct practice (Perlman, 1957). Perlman formulated a unique cognitively focused and client-centered problem-solving process for social work practice.

Over time, these ideas were shared and further developed by social workers and came to be known as the planned change process, supplanting the problem-focused language. Though there is a dearth of information about the origins of the term "planned change process," authors Kirst-Ashman and Hull (2010) are often credited with bringing this idea to the fore of social work education through their textbook writings on generalist practice.

## Critiques of the Planned Change Process

Despite the widespread use of the planned change process, there are important critiques of the process that we must consider. First and foremost, there are always limitations to a generalist framework, which is not considered a treatment modality in and of itself. As in any consideration of practice approaches, it is important to consider who developed the framework and who has been left out of its development. Considering that this framework was created in the context of **White** middle-class culture, some have raised questions about whether the approach may be unsuitable for clients from other cultures or social strata. Some argue that the planned change process might be especially ill-suited to people who are thought to rely on less organized and less focused approaches to difficulties (Sue, 1981; Galan, 2001). Furthermore, it does not take into account 'other' ways of doing social work, such as the use of religious helping, the ways informal kin networks function, or the non-professional helping approaches found in Indigenous communities. The discipline of social work has both pulled from (e.g., family group conferencing) and ignored (e.g., suicide prevention interventions) these communities in practice over the last century (Baskin, 2016, Cox et al., 2019, Drywater-Whitekiller, 2014; Pon et al., 2011; Wexler & Gone, 2012). Along the lines of this critique is that professional problem-

solving is only one approach and one that may restrict the ways in which a client tells their story, thus failing to consider alternative thinking and reflecting approaches.

Another major critique of the planned change process is that it is not data-driven or evidence-based in its origin. As Perlman developed the problem-solving model when research was not a major factor in social work practice, her supporting documentation was taken from clinical and anecdotal sources, as well as her clinical experience. In other words, when creating her model, Perlman used the now-discredited authority-based argument in her research (Gambrill, 1999). Authority-based practice is based on what is known as ‘practice wisdom’ as opposed to evidence-based practice (DeRoos, 1990).

Finally, the most recent critique of the planned change process is presented in the South African context (van Breda, 2018). In thinking about how best to apply the planned change process to post-Apartheid South Africa, in which a developmental approach to social work is noted as ideal, van Breda (2018) considers two major critiques. First, the planned change process “gives primacy to the economic vulnerability of society, and this commitment must be evident in casework for it to be regarded as ‘developmental’” (p. 77). Second, in proposing needed changes to the planned change process, van Breda (2018) calls for such a process to lift up the rights of clients while fostering the agency of clients in both their own living context and in their relationship with social workers and other helping professionals. This author suggests that change can be accomplished by “fostering a highly democratic and participatory helping process; placing the person and the development of the person, rather than the problem, at the centre of the helping process...and promoting resilience, independence, self-sufficiency, and community-connectedness, rather than dependency and worker-centredness” (van Breda, 2018, p. 77). While van Breda’s (2018) writing is focused on the South African experience, these critiques have applicability to practice in the United States as well.

Despite these limitations, the planned change process has some utility in working with clients and client systems. Our adaptation of the planned change process addresses some of the aforementioned limitations by applying a critical lens and employing concepts related to disability-positive social work practice.

## Critical Perspective

The critical perspective, which stems from the work of social philosophers linked to the [Frankfurt School](#), evolved as a response to both totalitarian and positivist thinking gaining popularity in post-WWI Western Europe (Salas et al., 2010). Since then, the critical perspective has been applied to various fields and areas of study. In social work, the critical perspective is both a lens through which we interrogate our practice within complex social structures and a guide for reflexive engagement with individuals, groups, communities, and systems.

A critical approach to social work, prompts us to examine the methods, structures, beliefs, and knowledge that inform our professional practice. This critical approach also leads us to grapple with the simultaneous roles of social work as an agent of social control and a threat to the status quo. The profession of social work, like most culturally and socially bound institutions, defaults to a position of maintaining, often unintentionally,

systems of privilege and oppression. However, with intentional and ongoing critical awareness and action, social workers can act against, instead of in concert with, oppressive processes and outcomes.

## Theoretical Perspectives

We highlight three theoretical perspectives that are informed by the critical perspective and are useful for disability social work practice: critical cultural competence; intersectionality; and anti-oppressive practice. These complementary perspectives emerged in social work in temporal (the 1970s and 1980s) and geographical (the United States and Canada) proximity to one another.



### Critical Cultural Competence

Cultural competence, a precursor to ‘critical cultural competence’ (which we define below), originated in social work as a response to the increased focus on multiculturalism that emerged in the 1980s (Nadan, 2014). Cross, Bazron, Dennis, and Isaacs (1989), Green (1982), and Solomon (1976) are acknowledged as the progenitors of cultural competence, which has become one of the most prominent constructs in social work education, practice, and research (Danso, 2018; Garran & Werkmeister-Rozas, 2013; Nadan, 2014). Cultural competence is defined as a “set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals and enable that system, agency, or those professionals to work effectively in cross-cultural situations” (Cross et al., 1989, p. 3). Cultural competence is also a process by which individuals and systems respond respectfully and effectively to people of all cultures...in a manner that recognizes, affirms, and values the worth of individuals, families, and communities and protects and preserves the dignity of each (National Association of Social Workers (NASW), 2015).

Recently, a more critical approach to cultural competence, ‘critical cultural competence,’ has emerged with the argument that “awareness, knowledge, and skills alone are inadequate for culturally empowering social work research [and practice]; they should be harnessed for social change” (Danso, 2015, p. 574). Critical cultural competence refers to “social workers’ ability to engage in high-level action-oriented, change-inducing analyses of culture and diversity-related phenomena” (Danso, 2015, p. 574). This concept also recognizes issues such as intersectionality, power differentials in the worker-client relationship, and examination of one’s [social location](#) or social position held in society based on social characteristics (Lusk et al., 2017).

Keenan (2004) further expands on the importance of infusing a critical lens into cultural competence through the idea of informed not-knowing, which, while attesting to the importance of lifelong learning, can guard against [essentialism](#) or overgeneralization. There is recognition that “knowledge is always partial, perspectival, and constructed through the lens of understanding, meaning, and interests of one’s social position” (p. 543). Using a critical lens in the practice of cultural competence includes the practice of cultural

humility, which incorporates an ongoing commitment to self-evaluation and self-critique as a way of maintaining an engaged learning and an other-oriented stance (Hook et al., 2013; Tervalon & Murray-Garcia, 1998).

Almutairi, Dahinten, and Rodney (2015) developed a Critical Cultural Competence model “comprised of four key components: critical awareness, critical knowledge, critical skills, and critical empowerment that fall into a number of conceptual domains: cognitive (critical awareness and critical knowledge), behavioral (critical skills) and affective (critical empowerment)” (p. 318). Critical awareness encompasses awareness of cultural differences—between and within groups—and self-awareness. Critical knowledge focuses on learning with an understanding of the dynamic nature of culture. Both critical awareness and critical knowledge underpin the use of critical skills in intercultural interactions. Finally, critical empowerment attends to power imbalances in relationships and the environment. The Critical Cultural Competence model was developed with specific attention to multicultural healthcare environments but has potential for use in a variety of areas.



Components of Critical Cultural Competence

## Application to Disability Social Work Practice

As Dupré (2012) notes, “the disabled people’s movement...affirms and celebrates the existence of disability culture as characterized by several agreed-upon assumptions: disability culture is cross-cultural; it emerged out of a disability arts movement and its positive portrayal of **disabled people** it is not just a shared experience of oppression but includes art, humor, history, evolving language and beliefs, values, and strategies for surviving and thriving” (p. 168). Critical cultural competence supports recognition of the personal and positive elements of disability culture while aligning with the social model of disability in its critique of ableist social, political, and economic systems. In working with individuals and families, this construct brings attention to the power dynamics inherent in many service systems, especially those engaged in involuntarily. It also helps practitioners develop competence in reflective processes related to engaging across cultures, contexts, identities, and experiences. Furthermore, critical cultural competence prompts the self-reflection and critical examination

necessary to recognize one's own biases, perspectives, and position within cultural and social systems. Finally, this construct helps us avoid essentializing disability experiences, identities, and contexts.

## Limitations of this Framework for Disability Social Work Practice

There is much less application of cultural competence or critical cultural competence to disability in the literature than to other identities, experiences, and practice areas. One reason for this, as Dupré (2012) notes, is that the field of social work has not embraced an understanding of disability culture. Cultural competence and intercultural practice are most often addressed as related to race, ethnicity, language, and religion. Therefore, there are fewer theoretical and empirical explorations of critical cultural competence in disability social work to inform practice. Also, though we have seen a highlighting of disability culture by disabled people's movements, it remains that disability is not uniformly or universally viewed as a social/cultural identity. This has implications for how identity- and culture-bound perspectives are applied when working with disabled people who do not hold disability as a cultural identity. Finally, though the 'critical' element of critical cultural competence attends to the notion of practitioners adopting an expert stance regarding culture, there remain concerns that the element of 'competence' in the construct lends itself to essentialism (Dupré, 2012; Nadan, 2014), especially as related to disability "types".

### Intersectionality

The history and development of intersectionality is not static and continue to shift. Kimberlé Crenshaw, an American lawyer and scholar, is credited with naming the term intersectionality. The idea and conceptualization of intersectionality, however, may be traced back further. Guy-Sheftall (2009) notes the contributions of [Anna J.H. Cooper](#) (1858-1964) to Black feminism and intersectionality, as evident through Cooper's writings on the racism and sexism experienced by Black women in the Southern United States. Hancock (2005) outlines how [W.E.B. Du Bois](#) (1868-1963) wrote about race and class as well as race and gender, developing early ideas on how identities and oppressions existed and operated together in political contexts.

Activism and social movements led by women of color during the 1960s and 1970s further contributed to the development of intersectionality. [Francis Beal](#) and [Toni Cade Bambara](#) published work examining the interconnected impacts of racism, sexism, classism, and capitalism in the lives of Black women (Collins & Bilge, 2016). The [Combahee River Collective](#), through their advocacy and activism, brought attention to the multiple oppressions – racism, sexism, classism, and heterosexism – experienced by their members and communities (Collins & Bilge, 2016). During the 1980s, contributions to intersectionality are linked to a number of activists, writers, and scholars including (but not limited to): [Gloria Anzaldúa](#), [Angela Davis](#), [bell](#)



[hooks](#), [Akasha Gloria Hull](#), [June Jordan](#), [Audre Lorde](#), [Trinh Minh-ha](#), and [Cherríe Moraga](#) (Bubar et al., 2016; Collins, 2015; Collins & Bilge, 2016; Hulko, 2009; Mehrotra, 2010).

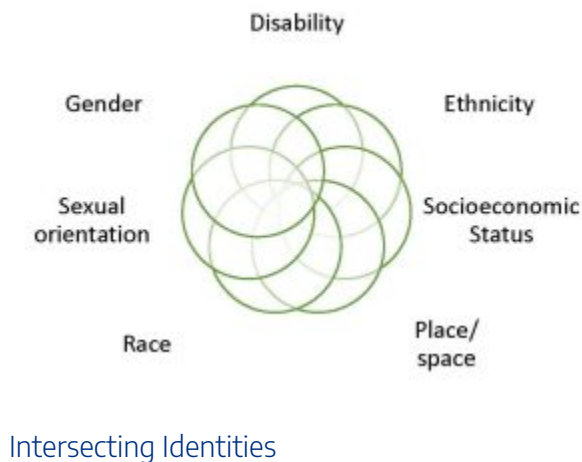
[Kimberlé Crenshaw](#) was instrumental in bringing the term intersectionality to the forefront. Crenshaw (1989) argued that Black women experience racism and sexism in the legal system and shifted these terms to include women of color. At the time, in the legal system, racism was commonly understood in reference to men of color and sexism in connection to White women. Crenshaw (1989, 1991) brought forward that these forms of oppression were not mutually exclusive and operated together in distinct ways for women of color. [Patricia Hill Collins](#) has also contributed immensely to the theorizing and conceptualization of intersectionality. Collins (1990, 2000) proposed interlocking models of oppression versus additive models, in which multiple oppressions are not viewed in binaries (i.e., Black or White, female or male, etc.) and, instead, are considered to function together. Collins (1990, 2000), for example, highlighted the racism, sexism, and classism experienced by African American women, yet acknowledged that these oppressions also impact many other groups. In this view, using the interlocking model, oppressions exist interdependently.

While the roots of intersectionality remain in activism, social movements, and scholarship by women of color, intersectionality has expanded considerably and is now found across disciplines (Collins, 2019). Intersectionality has also developed in definition, meaning, and application over the decades (Cho et al., 2013; Collins, 2015; Collins, 2019). Broadly, Collins and Bilge (2016) describe intersectionality as an “analytic tool” and a “way of understanding and analyzing the complexity in the world, in people, and in human experience” (p. 11). Intersectionality, as Collins and Bilge (2016) note, considers “social inequality, power, relationality, social context, complexity, and social justice” (p. 53). They emphasize intersectionality in praxis, its belonging to social movements, and its connections to transformation and social justice (Collins & Bilge, 2016). Given the significance of these ideas to social work, scholars and practitioners have contributed to the understanding and applications of intersectionality within the social work profession (see, for example, Bubar et al., 2016; Hulko, 2009; Joseph, 2015; Mattsson, 2012; Mehrotra, 2010; Pease, 2010). Contemporary social work has generally integrated intersectionality as a broad term that encompasses all forms of oppression and groups of people. Not always are the key contributors and developments of intersectionality fully recognized in social work. Current and future social workers may not have an appreciation or give credit to the feminists and activists of color who brought this theorizing and work forward. Thus, an acknowledgment of how intersectionality came to be before being incorporated into social work is intentionally included in this article.

## Oppression and Privilege

People accessing services and social workers alike have various personal and social identities that position them as oppressed and privileged. How one defines and understands themselves signifies their personal identity, whereas how others define and view them refers to their social identity (Hulko, 2009). Collins and Bilge (2016) emphasize that identity is a “starting point for intersectional inquiry and praxis and not an end in itself” (p. 101). They explain that identity can be a way to form coalitions, collective action, and transformative

movements (Collins & Bilge, 2016). Coming to know and understand how identity may impact people and communities is imperative to social work practice. Oppression and privilege experienced as a result of specific identities, for instance, gender, sexual orientation, race, class, age, or disability, denotes one's social location (Hulko, 2009). Interlocking systems of oppression, for example, racism, sexism, and ableism, position and marginalize one's social location (Hulko, 2004). Awareness and analysis of how identities are privileged and marginalized, in addition to the interconnectedness between interlocking systems of oppression and social location, are a central component of social work practice. Ranking oppressions is often a concern that arises when future or current social workers are learning about intersectionality. Fellows and Razack (1998) describe that competing oppressions cannot be deemed hierarchical and being marginalized does not make one exempt from being implicated in the oppression of others. Fellows and Razack (1998) refer to the latter as the "race to innocence" (p. 339). Razack (1998) further explains that addressing one aspect of marginalization cannot be separated from challenging all forms of oppression, whether one is impacted by specific subordinations or not. Given the saliency of certain issues in society, it is crucial to consider the historic and current contexts of oppression.



## Application to Disability Social Work Practice

Intersectionality in disability social work practice allows for a more comprehensive appreciation and understanding of a person's and community's experiences. A disabled person has personal and social identities, which impact their daily life and realities. Their social location further determines opportunities that may or not be available to them. Interlocking systems of oppression, such as the ableism, racism, and sexism they may experience, often exclude them from many facets of society.

While significant, the disability or disabilities people live with are not their entire being and are connected to other aspects of who they are (MacDonald, 2016). For instance, they may also be a student, a parent, a member of a faith community, and hold a particular job title or role. However, disabled persons are often defined by



others through an ableist lens, placing this disability's social identity at the forefront (Touchie et al., 2016). Using an intersectional lens, social workers may view the entirety of a person's experience.

## Limitations of this Framework for Disability Social Work Practice

Intersectional social work practice and scholarship, with a focus on disability, is an emerging area (see, for example, Johnson et al., 2020; MacDonald, 2016; Wehbi & Lakkis, 2010). Despite a recent growth in interest in disability and intersectionality, it is a limitation that there is not extensive literature to draw on to inform our work. Numerous social workers already apply an intersectionality lens in practice, and many future social workers will certainly bring considerations of intersectionality and disability to their work and contribute to this evolving area.



### Anti-Oppressive Practice

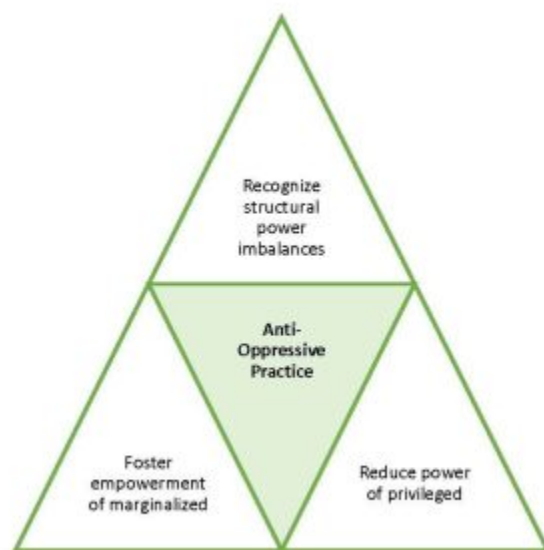
With a more recent introduction in the United States (Morgaine & Capous-Desyllas, 2015), anti-oppressive social work practice traces its development from radical and structural social work in Canada (Baines, 2007; Sakamoto & Pitner, 2005), critical social work in Australia (Fook, 2002; Ife, 1997; Healy, 2005, 2014) and anti-racism and anti-discriminatory social work practice in Britain (Dumbrill & Yee, 2019; Macey & Moxon, 1996; Williams, 1999). Anti-oppressive practice, as Dumbrill and Yee (2019) outline, is an “umbrella of theories and perspectives” (p. 230). As it has evolved, anti-oppressive practice has expanded to draw on additional theories, which include: feminist, Marxist, post-modernist, Indigenous, post-structuralist, critical constructionist, anti-colonial, and anti-racist (Baines, 2007, 2011; Brown, 2012) with queer and disability perspectives more recently added (Baines, 2017). By building on numerous progressive frameworks, anti-oppressive practice is positioned as a transformative approach to social work (Lai, 2017).

Anti-oppressive practice centers on recognizing and challenging power and oppression, seeking equity, inclusion, and social justice for oppressed persons, groups, and communities, while emphasizing broader political, systemic, and structural understandings and explanations of social work and society (Baines, 2007, 2011, 2017; Dalrymple & Burke, 1995, 2006; Dominelli, 2002; Morgaine & Capous-Desyllas, 2015; Payne, 1997, 2005, 2014). With social work typically focusing on individual practice and the problems of people accessing services (Baines, 2007; Sakamoto & Pitner, 2005), anti-oppressive practice moves beyond this limitation by considering the personal, cultural, and structural levels of oppression experienced by persons and communities (Campbell, 2003; Mullaly, 2010; Mullaly & West, 2018).

Understanding and acknowledging the roles of identity and social location is fundamental to anti-oppressive practice. Baines (2007) explains that identity is how a person is associated or categorized with either dominant or marginalized groups, with social location being how they are situated within the “webs of oppression and privilege” (p. 24). Oppression is rooted in the unacceptance of differences and the prejudice

and discrimination of certain identities and groups (Dumbrill & Yee, 2019; Mullaly, 2010; Mullaly & West, 2018). Examples of such oppressions include ableism, racism, sexism, heterosexism, cissexism, classism, and ageism (Dumbrill & Yee, 2019). Less mentioned in anti-oppressive practice are the impacts of colonization, imperialism, or globalization in creating and shaping the power, privilege, and access to resources inherent among dominant groups (Baskin, 2016; Dumbrill & Yee, 2019; Pon et al., 2011; Pon et al., 2016; Yee & Wagner, 2013).

Critical consciousness-raising, as proposed by Sakamoto and Pitner (2005), is important to anti-oppressive social work practice. This action involves an ongoing process of critical reflection and analysis of the social worker's assumptions, values, biases, and worldview, of the power dynamics in the helping relationship, and shifting this to empower the people and communities the social worker is engaging with, while also addressing broader social injustices (Pitner & Sakamoto, 2005; Sakamoto & Pitner, 2005). Anti-oppressive social workers aim to engage in this process of critical consciousness raising throughout their practice.



Elements of Anti-Oppressive Practice

## Application to Disability Social Work Practice

Anti-oppressive social work, according to Carter, Hanes, and MacDonald (2012), must recognize ableism in discourse and in practice. Ableism prevents the inclusion and participation of disabled persons in society. Recognizing multiple oppressions, including ableism, and working with disabled persons and communities to challenge these oppressions, gives a way for social workers to practice anti-oppressively (Wehbi, 2017). Building on the social model of disability, Carter, Hanes, and MacDonald (2017) propose an anti-oppressive model of disability for social work. This approach deconstructs dominant notions of disability, while centers

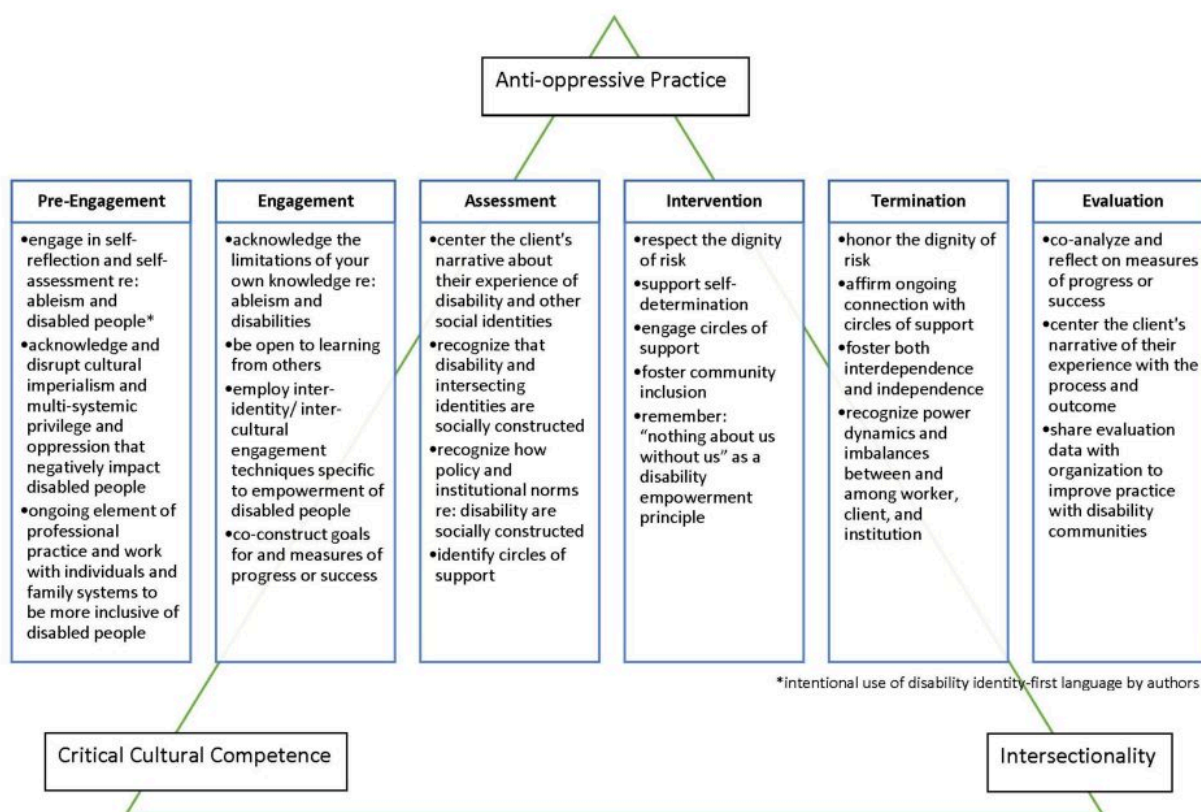
on individual, community, and societal change (Carter et al., 2017). Specific practice skills for working anti-oppressively with disabled persons, as outlined by Carter et al. (2017) include critical consciousness-raising, deconstruction, viewing disabled persons as the experts, empathy, addressing grief and loss, reframing, advocacy, mediation, peer support, and community engagement (pp. 160-162). Anti-oppressive social work practice, according to Sandys (2017), addresses the barriers disabled persons experience when seeking social roles of importance to them, whether this is being a post-secondary student, gaining employment, volunteering, or participating in the community. Anti-oppressive social workers recognize and emphasize the valuable place disabled persons and communities have in society (Carter et al., 2017; Sandys, 2017; Wehbi, 2017).

## Limitations of this Framework for Disability Social Work Practice

Anti-oppressive practice with a focus on disability is less explored in the literature despite the relevance and application of this approach in working with people with disabilities (Sandys, 2017). However, social workers seeking to practice anti-oppressively should not be limited by this lack of information. Anti-oppressive practice literature, including that centered on disability, offers ideas and ways to work alongside disabled persons and communities (Carter et al., 2017; Sandys, 2017; Wehbi, 2017). Social workers seeking to practice anti-oppressively must be up for the challenges of doing social justice social work in an ethical and meaningful way.

## Introducing a Model for Social Work Practice with the Disability Communities

Our model views the planned change process through the lenses of the tripartite theoretical frameworks presented above, with disability-specific applications in each stage of the process.



An interactive H5P element has been excluded from this version of the text. You can view it online here:

<https://rotel.pressbooks.pub/disabilitysocialwork/?p=22#h5p-2>

## Pre-Engagement

Pre-engagement is a step not explicitly found in other iterations of the planned change process, which typically

begin with engagement. We added pre-engagement as a key initial step to highlight the importance of engaging in reflective and reflexive practice regarding one's positionality (with special attention to intersectionalities), assessment of cultural competence, practice of cultural humility, and preparedness to engage in anti-oppressive practice.

The tenets of anti-oppressive practice call for social workers to engage in reflectivity and reflexivity about who we are as social workers, and what and how we do things (Baines, 2017). Central to that process is a consideration of practitioners' social identities and how they may lead to privileged or oppressed positions. Considering this 'positionality' is vital for social workers to engage in prior to meeting clients who may have different positionalities. Reflectivity is about unearthing the actual truth embedded in what professionals do, versus just what they say they do (Schön, 1983, 1987). Reflexivity, by contrast, is the ability to look inwards and outwards to recognize how society and culture impact practice as well as how we ourselves influence practice. The reflective and reflexive social work practitioner will want to ask, "How do I create and influence the knowledge about my practice that I use to make decisions?" In embracing reflectivity and reflexivity, social workers move beyond 'just knowing' how well practice is going, which is a form of implicit evaluation that is subjective by nature.

Reflexivity and reflectivity tie especially well to the concept of critical cultural competence described above. Critical cultural competence posits that awareness, knowledge, and skills are not enough for doing empowerment-oriented, anti-oppressive practice (Danso, 2015). Social work practice without the use of a critical cultural competence lens may affect ineffective or low-quality services (Casado et al., 2012) and may deepen marginalization in traditionally oppressed communities, such as the disability community (Danso, 2015). The four key components of critical cultural competence are especially useful and necessary at the pre-engagement step of the planned change process, critical awareness and critical knowledge (Almutairi et al., 2015).

When thinking about critical awareness, acknowledging sociocultural differences, especially as they relate to our clients' disability identity, is vital. Recognizing disability identities links back to our need to take an intersectional approach to understanding ourselves in relation to our clients – which is in turn part of anti-oppressive practice. Assessing our individual attitudes and values is important, along with recognizing or watching out for the potential challenges associated with cross-cultural interactions as there are a range of disability cultures present in the United States. Being able to have awareness of disability-related cultural differences is vital to the self-awareness required for social work practice with disabled people (Almutairi et al., 2015).

In particular, social workers need to be aware of the potential consequences of disability cultural diversity while also recognizing the social determinants of intersectional power relations based on disability and other social identities (Almutairi et al., 2015). With respect to the gathering and use of critical knowledge, the authors are focused on developing a conceptualization of any disability culture our client might identify with as well as gathering information about any potential communication challenges during cross-cultural interactions (which may often be between disabled and non-disabled people, for example) (Almutairi et al.,

2015). At this stage, it is also vital for social workers to question their connection to and operation within the political state as it relates to disability justice (Baines, 2017).

While this pre-engagement step is framed as the initial step in the process of work with a client, the above-described types of reflective and reflexive considerations need to be engaged in on an ongoing basis as case dynamics shift and evolve by continually employing a critical lens to examine one's own perspectives and practices as well as the structures and systems with which the client is interfacing. Also, maintaining a stance of informed not-knowing, recognizing the limitations of current knowledge and the need to engage in ongoing learning is important (Keenan, 2004).

Now, to move from the theoretical to the applied, social workers can engage in a range of considerations in the pre-engagement step as an act to disrupt cultural imperialism in the form of mainstream, non-disability justice-oriented practice (Baines, 2017). For example, the social worker should consider their varying social identities and resultant world views in a consideration of how those views might impact their work with the specific client in question. Questions to consider might include "How will my social identities impact client engagement?" "How might my world views get in the way of seeing things from my client's point of view?" or "What social welfare system-cultural norms do I practice that might get in the way of a fair, client-specific assessment?" By engaging in this form of reflexive and reflective practice, social workers can work towards subverting dominant cultural paradigms (about who needs and deserves help and in what ways) that may, when subconsciously implemented, oppress clients (Baines, 2017).

As noted above, the planned change process in general, and the model for social work practice with the disability community in particular, may be implemented at multiple levels of practice. To demonstrate how the critical theoretical perspectives informing the model could be applied to a micro/mezzo-level social work practice situation, a multi-part case example is offered below. Though the case study primarily focuses on micro- and mezzo-levels of practice, the influence of macro-level issues is acknowledged as part of the narrative.

## Example

Josie, a licensed clinical social worker, receives a referral to work with a new client, Regina. Based in an outpatient mental health center, Josie is tasked with providing Regina with counseling to address challenges she is facing with family members and work colleagues. Given that much of the agency's current work with clients is occurring remotely due to the COVID-19 pandemic, Josie will need to utilize a telehealth platform or phone to connect with Regina.

The case file Josie reviews includes an intake form filled out by the client and records from the agency's previous involvement in Regina's life. Josie notes that Regina identifies as a Black woman and that she grew up in a rural area in western Massachusetts where her family has lived for generations. Josie reads that Regina is a high school graduate who tries to maintain a balance between being able to engage in meaningful work that does not put receipt of her health care benefits at risk in order to manage the care she needs for her disability,



which is identified as autism. Before reaching out to Regina, Josie spends time considering how her own presence as a White, middle-class social worker from the suburbs of a major city (who also does not identify as disabled) might impact the process of building a relationship with Regina. Further, she considers how her worldview and values relate to messages she received while growing up and how this may impact her future work with Regina.

Acknowledging that history and language are powerful influencers of perspectives and practices, Josie takes time to consider the history of mainstream social work with various Black communities, which, when involved, was often oppressive. She also learns about the historical roots of formal and informal mutual social aid in Black communities that addressed the needs and fostered the resilience of community members prior to the advent of mainstream social work and in response to instances of exclusion from or harm done by dominant systems. Given what she learns about history and language influencing practice, Josie notes that it will be important to ask Regina about how she describes herself with regard to race, ethnicity, disability, and other identities, and how she understands her own experiences with service systems. Additionally, Josie happens across an article that explores the complexities of written expressions of identity, specifically whether or not to capitalize the racial identity categories of Black and White. Josie researches this further and finds that there is no definitive standard and that it is most important to be engaging in thinking about these issues and in practice to follow the lead of the client.

Josie also seeks to learn more about various disability perspectives and experiences among Black Americans. Reflecting on her learning, Josie reminds herself that while book learning is important, her client, Regina, will be her best guide in understanding her culture and any other factors that play out in her life. Josie recognizes that in practice, cross-cultural considerations could go unaddressed. She prepares herself for working with Regina by thinking about how she can bring up their different and shared social identities and how she and Regina might be able to build a bridge to co-construct goals, objectives, and an intervention plan for their work together. Another aspect of Josie's pre-engagement work will involve considering how Regina prefers to refer to her race or ethnicity (as well as other social identities) in written documentation.

## Engagement

The engagement phase is a prime opportunity to learn from a client more about their disability culture (if any) and any other cultures the client is affiliated with. This first step is also the time to learn about the client's experience of disability and other oppressions as well as privileges (Danso, 2015). While doing this work, social workers will utilize the knowledge they have gained during pre-engagement, while simultaneously acknowledging the potential limitations of that knowledge. Central to anti-oppressive practice is the idea that social workers must see disabled people not only as clients, but partners who are also as allies, advocates, and activists who can teach us about their cultures and realities (Baines, 2017). Also important is the ability to add to that knowledge by centering the personal expertise of clients on their life, while being open to learning from others. This is an evolving and shifting process.

Regardless of the social worker's own disability identity, a key part of the engagement process in practice with disabled people is understanding how disability identity does—or does not—fit into their worldview and self-concept. Just because a person has a disability, it does not mean that their disability is the reason they are seeking services. Instead, consider disability as a social identity in an intersectional approach to engagement. This engagement work could include gathering knowledge from the client about how they prefer to refer to themselves, how they prefer to communicate, and how they learn best – on top of identifying their primary concerns and presenting problems. In discussions of how anti-oppressive practice works, social workers have acknowledged that language is a force in political struggles – especially when it comes to disabled people (Baines, 2017).

## Example

As she is about to meet Regina, social worker Josie grounds herself and reflects on the pre-engagement work she did. Josie turned to literature authored by Black American women who have shared their experiences with disability and mental health services. Other readings focused on learning more about autism, rural communities, and related topics, but ultimately she will look to Regina as the expert in her own life, from whom she can learn.

Josie and Regina meet virtually on video via a telehealth platform. Josie begins by introducing herself, explaining confidentiality and agency policies related to their work together, including their current need to meet remotely due to the COVID-19 pandemic. Josie aims to ‘start where the client is’ and asks Regina to share more about herself, beyond what is in the case file. Josie also asks Regina what she would like to work on. Josie thoughtfully moves into a conversation about what it might be like for Regina to be working with someone with different social identities than herself. Josie mentions that she recognizes that there might be things that a White, suburban woman who is not disabled might not understand or know to focus on, but that she is open to being pointed in the right direction. Josie's action is demonstrative of a power-sharing approach that attempts to narrow the potentially hierarchical gap between social worker and client. Regina explains that she identifies as a Black woman who has more recently embraced her own disability. Regina tells Josie that she is very involved in the [Autistic Self Advocacy Network](#) (ASAN), and Josie makes a note to learn more about this organization in order to understand Regina's worldview better. She asks Regina to talk about how various parts of her identity (e.g., her gender, her race, her disability) interact and influence her life experiences. For example, she asks about Regina's experience as a female with autism given that the dominant narrative of the autistic experience appears to be male. By directly bringing up these topics, Josie is working to be transparent about working towards creating a positive relationship with Regina, one in which she will feel supported. As the engagement process goes on beyond the first meeting, Josie is sure to demonstrate what she has learned from Regina in her second, third, and fourth meetings—and beyond—by taking a culturally responsive approach that ideally helps Regina to feel heard and seen, such as sharing what she has learned from reading about the ASAN.



Josie recognizes that it is also important to honor and implement the three theoretical frameworks that guide this model of social work practice with the disability community in her documentation work as well as other aspects of client-centered practice. This includes utilizing a critical cultural competence lens in thinking about how she writes about Regina in her case notes—for example, considering how she will document in a way that respects how Regina wants to be referred to (e.g., capitalizing Black) while meeting agency or professional documentation requirements.

## Assessment

As the assessment step launches, social workers should be drawing on the critical skills discussed as part of critical cultural competence as well as the reflective and reflexive skills associated with anti-oppressive practice. Considerations of intersectionality in client assessment dovetail with both approaches. Recall that intersectionality is a tool for contextual analysis and action in the form of assessing in the practice of social work (Cho et al., 2013; Collins & Bilge, 2016; Crenshaw, 1995). This framework posits that “people simultaneously occupy multiple positions (positionalities within the socio-political and structural fabric of society” (Ortega & Faller, 2011, p. 31). Using this lens, we consider how potential inequities that clients experience are not caused or maintained by a single factor alone (such as racism, sexism, ableism). Instead, inequities may be created and may continue due to the interactions between multiple manifestations of privilege and oppression. Systems of advantage based on social identities are enacted and enforced internally (within individual people), interpersonally (between individuals and groups), institutionally (within organizations), and structurally (among institutions, across society) (Lawrence & Keleher, 2004). These separate systems work together to organize and justify both privilege and oppression (Collins & Bilge, 2016; Connor, 2006).

A social worker’s embrace of an intersectional framework with the skills of anti-oppressive practice and critical cultural competence includes a focus on a social worker’s actions toward enacting key aspects of critical awareness and knowledge during cross-cultural interactions with clients and their identified circles of support. This process includes the need for social workers to create space during assessment meetings to negotiate and establish disability culture-specific meanings related to presenting problems and modes of operation. Recognizing any intersectionalities and social constructions of disability identity as well as other intersecting identities should be central to this negotiation. This process of negotiation will help social workers determine a culturally appropriate approach to practice and care planning that centers the client’s narrative of their strengths and needs (Almutairi et al., 2015). In addition to the interpersonal aspects of the engagement step, social workers must also work to recognize the social construction of policy and institutional norms that are related to disability or the disability community.

Centering the client’s narrative in the assessment phase can also include embracing the disability rights concept of “[nothing about us without us](#)” in co-deciding what presenting problems are—and are not! Another way this has been conceptualized is “about us, by us,” according to the late Massachusetts-based disability rights advocate John Winske (Disability Policy Consortium, 2020). This links to the aspect of critical cultural

competence referred to as critical empowerment. Critical empowerment goes beyond the social worker's recognition of cultural differences, thinking about how the perception of power imbalance functions in the client's social, historical, and political contexts (Almutairi et al., 2015). For example, a social worker could share their assessment of the client with the client in order to obtain feedback and allow the client to have some agency in how presenting challenges are categorized and framed. In situations where the social worker is present due to legal sanctions, the picture is muddled and requires even more of an attempt to offset the power relations inherent in that situation.

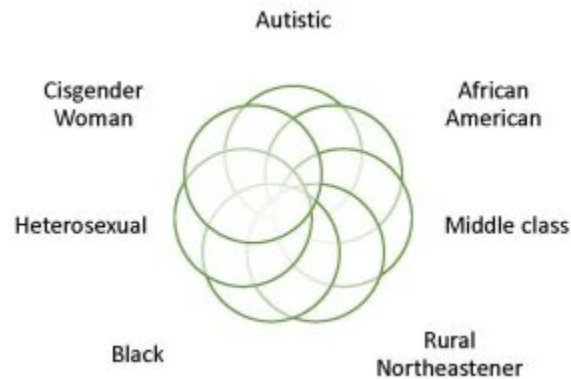
Social workers also need to focus on identifying areas where they can respect the [dignity of risk](#), or the right of disabled people to be able to learn and grow from access to everyday risk. As goals and objectives are being identified by the social worker and client, the social worker should assess for areas in which they might be able to allow clients the dignity of risk. For example, a young mother with an intellectual disability is noted by social workers and nurses in the hospital to forget to feed her new baby. Upon further exploration, the social worker learns that the young woman can read digital but not analog clocks. Replacing the clock in the hospital room and obtaining a digital watch allow the mother to have an opportunity to meet her baby's needs appropriately. In this scenario, the dignity of risk is allowed for in a safety net context.

## Example

In her first meeting with Regina, Josie was very focused on building rapport in a culturally responsive manner, but she was also beginning to make observations about Regina as part of her assessment process. As Josie uses the agency-mandated clinical assessment tools in her work with Regina, she is mindful of whether or not these tools utilize a culturally-sensitive or culturally-specific lens. She makes sure to integrate critical perspectives with the information gained from the clinical assessment tools. As such, Josie may use additional tools to support collaborative reflection on Regina's experiences (see, for example, this [privilege and oppression matrix](#)). Josie also reflects on the differences between meeting clients virtually on video compared to in-home sessions as it relates to the application of anti-oppressive practice techniques, for example.

In order to create a disability-positive process, Josie thinks about the "nothing about us without us" credo that many disability rights advocates call for (something she has learned about on the ASAN website) and uses it to inspire her approach to assessment. This translates into Josie asking Regina to step outside of herself to describe the person and situation she sees, using her own words to describe both strengths and challenges. She also asks Regina to dialogue with her friends in the ASAN chat room about the challenges she is facing, in order to help Regina build community and develop new perspectives. Using Regina's language for conceptualizing a presenting problem can be an empowering action. For example, Regina describes how her colleagues have a hard time with her "tics." Exploring further, Josie learns that the comment refers to incidents in which Regina is compelled to touch or push someone if they have accidentally bumped into her. This has led to conflict. Josie can also look back to the conversation she had with Regina about their differing social identities in order to ask Regina to reflect on how her social location may impact or inform her presenting

problem/s. Regina says that as a Black woman, she sometimes feels marginalized in ways her autistic friends who are White “just don’t get.” Josie and Regina discuss how the experiences of people within a group can differ due to the interactions between multiple manifestations of privilege and oppression in their lives. The goal of this line of conversation is to co-create a narrative assessment related to the presenting problem/s and plans for work together that include an understanding of both the personal and systemic issues at play.



Regina's Intersecting Identities

## Intervention

Once the social worker and client have co-constructed goals and objectives, a care plan can be developed and the social work interventions can commence in partnership with the client (Baines, 2017). Ideally, the social worker's anti-oppressive intervention should not only focus on integrating the disabled person into society but also address ways that society, in micro form, can be changed (Baines, 2017). These interventions will foster community inclusion, a key disability rights concept focused on access to the community for disabled people. Additionally, self-determination on the part of the client will be respected while inclusion of circles of support will be promoted where appropriate.

## Example

Once Regina and Josie have co-constructed both an assessment as well as goals and objectives for their ongoing video work together (a.k.a. “the intervention”), the nature of the work is chosen, and the work process commences. Ideally, this process will include a conversation about how the pair will know when services are no longer needed (in order to facilitate termination, later). As Regina has had a choice in how the intervention is structured, this conversation will support her engagement with the process. In her work with Regina, Josie will be sure to weave in intervention approaches that recognize both Regina's desire to more fully integrate into

work and family environments in any needed ways and address micro-options for how these environments can be more inclusive for Regina and other disabled people.

Josie approaches her work from multiple fronts. First, she conducts different reality-based role plays with Regina to practice noticing social cues, which will help with Regina's inclusion in her workplace community. Second, regarding the need for structural change, as Regina and Josie work together, Regina feels increasingly more comfortable advocating for herself to her manager around neurodiversity acceptance. At Regina's request, the manager encourages the workplace's diversity committee to take on the challenge of learning more about [neurodiversity](#) and exploring the structures in the workplace that may or may not promote inclusion. This includes recognition of the larger issue of greater potential for law enforcement involvement in situations involving Black disabled people – something that Regina could be at risk of during one of her pushing incidents at work (McCauley, 2017; Thompson, 2021).

Third, Josie also works with Regina's family via the telehealth health platform to identify opportunities to do things differently, in ways that make sense to how Regina likes to operate, in order to address a small way that the family culture can be changed. This might mean, for example, building in a daily time for Regina to share new information about her passion area with her family – endangered species of mammals across the world. Having this time allows Regina to talk about topics she is passionate about with the people she loves, but also do so in a way that does not overwhelm the family, by limiting discussion of the topic to once per day versus experiencing it as a constant topic of conversation. In doing this, Josie is aware of how shared familial and cultural norms intersect with personal identities and experiences and need to be addressed all together using an intersectional perspective. The technical challenges involved in conducting family counseling via video with Regina's family during this time have been particularly difficult, but Josie has used similar strategies of checking in with the family during the telehealth sessions as she uses with Regina.

At various points during their work together, Regina and Josie move their individual sessions onto the telephone due to challenges related to Internet access for the video telehealth platform. This presents a challenge for some of the role-playing that the duo are working on together given the need for Regina to develop skills in the area of identifying visual cues in interpersonal interactions. Josie works to check in with Regina on video and/or telephone to make sure that their process is a fit for Regina's needs. Questions she may ask include: "How are the role plays going for you?" "What are you gaining from these role plays towards your therapeutic goals?" "Is there anything we should change in how we are doing this work together?" This also involves Josie needing to attend to and respond to subtle cues that Regina may share in their interactions virtually or on the telephone.

## Termination

During the termination step of practice, it is vital to recognize power dynamics and imbalances especially as they relate to structural issues of privilege and oppression as well as the social worker's role authority and the client's vulnerability (Baines, 2017). For example, issues of power dynamics can arise during termination

regarding decisions about when and how services and relationships are terminated – especially when the services/relationships are involuntary. Even if mandated involvement is not the case, honoring the client's dignity of risk will be a central concern for an anti-oppressive social work practitioner. Ideally, the co-constructed intervention will have led to changes in the client's life allowing for them to resume life without the support of a social worker and, therefore, allowing for the dignity of risk.

## Example

Regina voluntarily sought out assistance from Josie's outpatient mental health center in order to address her challenges at work and at home. Over time, Regina came to really enjoy her weekly virtual counseling sessions with Josie, even though the work was hard and they sometimes experienced technical difficulties. Josie became an important part of her life. Josie has started to notice that Regina's work life has begun to stabilize, as has her family life. Regina has been able to learn more about how to notice social cues and respond to them appropriately in a way that fosters her community inclusion. She has also started to do a better job of managing her tics in a way that promotes the potential for continued community inclusion. Finally, Regina has developed a greater sense of empowerment related to advocating with her family and employer regarding disability and inclusion.

Using an anti-oppressive practice lens, Josie recognizes that her role as a social worker comes with a certain authority. She reminds herself of Regina's potential vulnerability around the termination of services, given the positive relationship and even potential dependency that has developed. It is important, though, to acknowledge dignity of risk in clients moving on independently with their lives without the support of a therapeutic presence.

Reminding Regina of their conversation about when they thought services would no longer be needed, Josie brings up the topic of termination. As there has been a precursor to this conversation, Regina is more prepared to think about termination than she might have been. Regina agrees that her presenting problems have been well addressed and that she understands the need for termination, but asks to be able to contact Josie for support once in a while if she needs it. Given that Josie's agency allows for this via a specialized aftercare program, she agrees to periodic check-ins, acknowledging that this could be preventative in addressing any challenges Regina may encounter in the future.

## Evaluation

At the assessment stage, the social worker and client co-constructed goals and objectives as well as identified measures of progress or success. These goals and objectives feed directly into how the evaluation step should be accomplished. At the evaluation step, which should be continuous throughout the planned change process, client-approved measures of progress or success should be considered carefully, centering the client's narrative of their experience during the intervention process. This reflection may result in the use of explicit evaluation

techniques that are qualitative in nature as opposed to the use of quantitative data collection instruments that may not be culturally appropriate across a range of social identity categories (Danso, 2015). Even with qualitative inquiry as part of the explicit evaluation process, power differentials should be noticed and balanced in the interview setup (Rubin & Babbie, 2014). For example, Danso (2015) writes “Interview practices that align with the community’s cultural norms could reduce power differentials in the interview process. Interviews should be conducted in ways that acknowledge and respect personal and cultural idiosyncrasies. Using cultural concepts and expressions or inviting participants to suggest ways for conducting interviews within the community would enable participants to feel validated regarding their culture or self-esteem” (p. 581). These considerations extend to the data analysis and data reporting process as well (Danso, 2015).

Consideration of implicit as well as explicit evaluation data should be engaged in – especially with respect to how clients view their experience with the intervention (Danso, 2015). Implicit evaluation is focused on informal discussions and informal observations. Going back to considerations of intersectionality are equally important at this step. Intersectionality as a framework encourages practitioners to move beyond viewing and responding to social inequities through a disability-only or a race-only lens and causes people to understand and respond to these inequities at once (Collins & Bilge, 2016). As there is no singular way to be a person of color or to be a person with a disability, service systems must be envisioned and built with inclusive equity in mind. Intersectionality is an essential conceptual tool as it offers insight into the interactions between various social identities and society, while also offering an opportunity to evaluate, namely, assess, modify, and build services that will reduce or eradicate intersectional inequities. Using an intersectional frame is a form of social action at the evaluation step.

## Example

As Josie begins the process of termination, she reflects that the termination and evaluation phases are closely intertwined. Using an anti-oppressive practice approach, she and Regina began their work by identifying measures of progress or success for use in the continuous evaluation of the intervention process. By touching on these measures during each session through the use of electronic tracking tools, Josie can help Regina document her process on what brought her to seek help. This creates a visual map for Regina to look at and respond to. This also helps Josie to meet the National Association of Social Workers’ *Code of Ethics* (2017) requirement to evaluate all practice. This evaluation interaction lays a foundation both for feedback about how the process of treatment is going – and also for having a conversation about termination when the time is right (based on the outcome data!). This type of data-driven evaluation is known as explicit evaluation. Josie also leads Regina in intersectionality-informed discussions that may be thought of as implicit evaluations, related to how, in the end, Regina feels her intersecting social identities may have played into the intervention process and her approach to addressing her challenges.



## Comparison of the Model for Social Work Practice with Disability Communities to Existing Disability Community-Focused Practice Models

Two disability practice-related frameworks have been identified in the United States context: the independent living model and the disability competent care model. The [independent living model](#) (ILM) is very similar to the social model of disability. The ILM conceptualizes disability as a social construct located in society (i.e., the social model of disability) versus being located in an individual body part (a.k.a. the medical model of disability) (Oliver et al., 2012). The focus of the ILM is advocating for independence for disabled people with the acknowledgement that they are their own experts about what they need and which services are ideal to meet those needs (National Center for Independent Living, 2020). Thought of as driven by ‘consumer control,’ many believe the ILM was initiated by disability civil rights legend Ed Roberts and his group of ‘Rolling Quads’ at the University of California at Berkeley, often thought of as the birthplace of the disability civil rights movement and the independent living movement (McCrary, 2017).

In addition to being heavily influenced by the civil rights movement of the 1960s and 1970s, the ILM was also jump-started by the process of deinstitutionalization. During this time period, people with significant disabilities began to have some opportunities to live in community-based settings as opposed to nursing homes and other institutional settings—although quasi-institutional settings such as group homes and other shared living arrangements sprung up at this time as well. These factors caused disability civil rights advocates to speak out for equal opportunity in figuring out how to live, work, and participate in the community, all of which had major implications for independent living potential. The ILM resulted in the development of many independent living centers nationwide (Oliver et al., 2012).

The shift from institutional to independent living was not coupled with sufficient funding for supporting disabled people in the community (Dunn & Langdon, 2016; Larson, 2016). This lack of funding continues to date, with contemporary social welfare programs often being linked to a person’s ability to obtain paid work (Duffy & Elder-Woodward, 2019). However, disabled persons commonly experience ableism and inaccessibility when seeking work or when already employed, and often have additional expenses increasing their costs of living (Saffer, Nolte, & Duffy, 2018). Until these barriers are addressed or removed, sufficient and specific disability support benefits are needed not only to reduce the poverty levels of disabled people but to ensure a more than adequate standard of living (Saffer et al., 2018).

For social workers practicing under the ILM model, such as those in independent living centers, it is important to resist professionalizing the work “on the basis of an expertise in impairment as a cause of social need” as this would be an oppressive act (Oliver et al., 2012, p. 152; Hiranandani, 2005). Rather, social workers need to commit to the removal of barriers causing disability—in an equal partnership with disabled people. Specifically, “the problems of disabled people, or social workers, are not resolved by the incorporation of empowerment as an instrumental competence” (Oliver et al., 2012, p. 152).

The model for social work practice with the disability community presented above aligns with the ILM model of practice in how it addresses both the personal and social aspects of living with a disability and the need for social workers to defer to the client as an expert on their own needs.

The [disability competent care model](#) (DCC) was developed by The Lewin Group in conjunction with disabled people and service system consultants and adopted by the Council on Social Work Education (CSWE) as a guiding framework for practice (Disability Competent Care Working Group, CSWE, 2019). This DCC model is noted to take a person-centered approach to providing social work that is focused on supporting people with functional limitations in achieving best-possible functionality. This process is conceptualized as including work with an interdisciplinary care group that views and supports clients as unique people versus just a diagnosis or condition per the medical model of disability. In addition to responding to a client's physical and clinical needs, DCC also takes into consideration their social, emotional, intellectual, and spiritual needs. Further, this model supports both self-determination and community inclusion with a focus on providing supports and services that allow for home-based self-sufficiency. There are seven pillars which, taken together, comprise the concept of DCC. These pillars include understanding the DCC model, participant engagement, access, primary care, care coordination, long-term supports, and behavioral health. For more information about this model, see [Resources for Integrated Care](#).

In discussing the DCC, the CSWE calls for “moving away from a medical model of disability perspective to a constructionist or social model approach” (p. 7). However, it does not seem that the DCC model focuses on addressing or removing the barriers experienced by disabled persons and communities (Oliver et al., 2012). The DCC model may also be critiqued for not having an explicit inclusion of disability culture. In her work on disability culture and cultural competency in social work, Marilyn Dupré (2012) writes that social workers need to move beyond an assumption of the possibility of cultural competence, to an embrace of learning about disability culture. The model for social work practice with the disability community builds on the utilitarian DCC model by layering on steps for practice infused with considerations stemming from intersectionality, critical cultural competence, and anti-oppressive practice.

## Conclusion

Keeping in mind the model for social work practice with the disability community as you approach your work with disabled people, think about the ways you can infuse your practice with the theoretical perspectives of critical cultural competence, intersectionality, anti-oppressive practice, and the tenets of disability-positive practice: the dignity of risk; self-determination; circles of support; community inclusion; and the ‘nothing about us without us’ credo. Consider your own personal and social identities, experiences of privilege and oppression, and ways you can be reflexive and reflective in approaching your practice with disabled clients.



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## Footnotes

[1] Debates regarding how to write about identity abound. One article that captures the spirit and scope of these debates as related to race is presented by the Columbia Journalism Review (Perlman, 2015), which

recommends capitalizing Black, but not White. Arguments in favor of capitalizing White are made by Appiah (2020) and the National Association of Black Journalists (2020) who argue for the explicit recognition of White racial identity through capitalization. The language in the present document reflects the wishes of the authors, who choose to capitalize both Black and White when referring to racial identity. When discussing concepts such as whiteness and white supremacy, we do not use capitalization. We encourage the readers of this work to make their own decisions about language use based on a thoughtful review of the literature and based on their contexts.

[2] Debates about the right language to use in talking about disability are ongoing. For many years, “person-first” language has been deemed a respectful approach to describing people with impairments, and for some practitioners and communities, it still is. More recently, many disability rights advocates have rejected person-first language and have embraced disability-first or identity-first language with an unapologetic embrace of disability as a social (and cultural) identity. In this article, we use identity-first language due to the preference of the authors. However, in practice, always take the lead of the person or people you are working with.

3.

# MAJOR DISABILITY POLICIES IN THE UNITED STATES

## Review of Major Disability Policies

Nikki Fordey

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### Learning Objectives:

- To understand how treatment of disabled people under the law has changed in the U.S. since the 1800s
- To understand how relevant disability policies and programs continue to impact the lives of disabled people in America
- To engage in critical policy analysis of passed and proposed legislation affecting disabled people and utilize this information to advocate for improvements in quality of life and expansion of rights for disabled clients

## Why Policy, Analysis, and Advocacy Matter for Social Workers

When I decided to pursue social work as a career and started my MSW program, I knew I wanted to help people. I imagined myself someday with an office of my own, able to counsel people and help them see light where previously there was only darkness and pain. But as I got into the field and started clinical practice, I soon realized that there are limits on what change can be initiated on an individual level. Macro work, policy work, advocacy, community organizing, activism – these pursuits are also so desperately needed to help the people



social workers serve. When working with someone with a disability, it matters if they have access to affordable care and resources. It matters if the government has decided that they have civil rights equal to that of a non-disabled person. It matters if the court of public opinion has been able to recognize its ableism in overlooking the needs of all.

I am a disabled cisgender bisexual white woman. I am also a licensed clinical social worker and substance use disorder clinician. I am a progressive public policy advocate. I am a wife. I am a dog mom. I am so many things. But I list disabled first. Why? Because it is at times the most important thing for someone new to my life to understand. I have a chronic illness that affects multiple systems and will progress with more and more impairment over time. Without many of these disability-related policies, my livelihood, future, and very survival would be in immediate jeopardy.

Therefore, these policies are not just words on a page, laws from long ago that you should memorize for a test and then forget. These policies are the foundation and context in which disabled people fight for survival every day. We must understand where we've come from, and what has and has not worked before if we have any hope to continue to make progress. We have come a long way, but there is still so much more work to do. That's where all of you come in.

If you're sitting there thinking "well this doesn't matter to me, I don't think I'm going to work with someone with a disability", I'm here to tell you that chances are you will. At some point in your career, you will have disabled clients. As we saw in Chapter 1 on disability social work principles and concepts, 27% of the U.S. adult population is disabled. Some disabilities are visible, and you will know. But others are invisible, and it will be your knowledge and ability to connect with genuine empathy and understanding that will support your client in disclosing their disability status and how it impacts their mental and physical health.

As a social worker, you have the responsibility to meet your clients where they are – which in many cases will include a disability of some sort. You will be more effective in your clinical work with an understanding of the barriers that disabled people face in our society and the changes still needed for equity and universal accessible design.

Listen to disabled people. Listen to what they need, what they want, what they desire, where they are struggling, but also where they are thriving! This will be elucidated further in the last chapter of this textbook on disability resistance movements, but you will be well served if you start your general policy analysis from the perspective that it is disabled people who know best what they do and do not need.

The following sections detail key disability-related policies in our history, grouping them as chronologically as possible, by topic. While this chapter, mainly due to space and resource constraints, discusses mainly federal policies, it is important to remember that disability-related policies exist at the federal, state, local, and organizational levels. When policies at different levels are in conflict, it is the policy that provides the most access and is most generous to the disabled person that should be followed (Mid- Atlantic ADA Center, 2012).

## Preoccupation with 'Deserving' Poor and Reliance on

## Segregation as Standard Procedure

In the 1800s, disabled people were mostly kept hidden and separate in institutions, where they were treated like abhorred objects incapable of independent thoughts and desires (Anti-Defamation League, 2022). According to the Anti-Defamation League (2022), “the ‘purification’ and segregation of persons with disability were considered merciful actions, but they ultimately served to keep people with disabilities invisible and hidden from a fearful and biased society” (para. 3). It was not a question of *if* a disabled person would be institutionalized and segregated, but *when* – when the individual’s family and locality (town) was no longer able to provide adequate care and the disabled person became a ward of the state. As disabilities often impact a person’s capacity for traditionally productive work, and being productive was seen as the only measure of one’s use for an interdependent society, it was standard to remove the “undesirables” and keep the freedom for the “able-bodied” or “not-yet disabled”.

However, a cultural shift was afoot when a new group of disabled people had to be reckoned with that had more power and could command a higher quality of treatment due to their perceived sacrifice: Civil War veterans. Quickly after the Civil War began, young people with decades of life left to live were returning to everyday civilian life with significant disabilities acquired on the battlefield or otherwise related to military service. **The General Pension Law** of July 14, 1862 (12 Stat. 566) provided for a monthly benefit to be paid to any veteran who was unable to perform manual labor due to a disease or disability acquired while in service or to the widows and/or other dependents of a deceased veteran (Skocpol, 1993). Logue and Blanck (2008; 2020) have documented, however, the racial discrimination that Civil War veterans and their families from the North faced after the war. Black widows, in particular, faced large hurdles in applying for and being approved for Civil War pensions. These obstacles included low literacy, due to laws forbidding slaves from learning how to read and write, and challenges to the legitimacy of their marriages conducted when both persons were enslaved (Logue & Blanck, 2008). While the pension laws were written race-neutral (i.e. black disabled veterans and surviving families were legislatively entitled to the same financial compensation as white disabled veterans and dependents), the way they were implemented was not. Many black disabled veterans and their dependents faced intrusive questioning and harsh judgment for not conforming to white pension assessors’ biased views of family units and gender roles (Pinheiro, 2021). There are documented cases of black widows losing their benefits retroactively if accused of “inappropriate behavior” such as sex work or having a child out of wedlock (Pinheiro, 2021). Therefore, while the Civil War pension laws were life-changing for many, it is important to remember that not all who deserved the assistance were able to easily access it.

The theme of “deserving” or having to earn financial assistance was at the heart of disabled Civil War veterans’ pensions. According to Handley-Cousins (2016), “the image of the amputee became symbolic of the sacrifice of war.” While those disabled by the war were revered and held in special regard, this did not translate to people with disabilities unrelated to war, and even disabled war veterans did not see societal shifts to include their changed needs and limitations (p. 223). The focus was on finding a way for the disability to be overcome or minimized (such as prosthetics and rehabilitation). If this was not possible, it became acceptable for these

noble heroes to utilize financial support from the government as part of their payment for their sacrifice. They were deemed the “deserving poor,” having lost productive capacity in the name of the greater good – protecting and preserving the republic. The disabilities incurred as a result of war were seen as the literal price of freedom and a future for America (Handley-Cousins, 2016).

There was a more concrete cost for Civil War pensions, particularly as more accurate information was disseminated about the protocol for applying, who was eligible, and the potential amounts that could be recovered. In 1861, prior to the Civil War pensions, the annual cost for war pensions was around \$1 million in today’s dollars, used to support approximately 10,700 veterans and widows of previous conflicts (Skocpol, 1993). However, by 1866 the annual expenditure swelled to \$15.5 million to support 126,722 veterans and/or their families (Skocpol, 1993). Further, the **Pension Arrears Act in 1879** (20 Stat. 469) allowed eligible veterans or their dependents to apply for and receive in one lump sum the entire pension amount they would have been entitled to if they had applied when the disability or death originally occurred. Each year there was a federal government surplus (which existed from 1866 to 1893), the Civil War pensions continued to increase in cost, and eligibility requirements were broadened (Skocpol, 1993). Veterans advocated for more benefits and politicians responded favorably to those who could help garner more votes and facilitate the politicians’ maintaining their station through future electoral periods.

What began as a Civil War pension for the totally disabled or deceased turned into America’s first old-age pension, as the **1890 Dependent and Disability Pension Act** (26 Stat. 182) stated that if you served 90 days or more in the (Union) military with an honorable discharge and became disabled at any point after service and were unable to perform manual labor, you were eligible for a pension, explicitly including old age as a disability (Skocpol, 1993). Therefore, any military veteran became eligible for a pension when they were no longer capable of manual labor, either due to old age or a disabling factor earlier in life. These expansions of eligibility and circumstances deemed worthy of financial payout from the government showed that the U.S. Congress was capable of providing direct financial assistance to those it deemed worthy of support. In this case, it was not the disability identity that reigned supreme, but rather veteran status. Despite the program ballooning to over 40% of the federal government’s annual expenditure in 1893, agreements were kept with payments continuing into recent times to widows and dependents of Civil War veterans who became disabled before death (Skocpol, 1993).

The experience with Civil War pensions influenced many future laws regarding financial support from the government. Significant opposition to direct payments has grown as the U.S. economy slows and the federal government has routinely had to rely on deficit spending and accumulating debt to meet its legislatively mandated obligations (Handley-Cousins, 2016). Scrutiny of applications for assistance has continued to increase, and unsubstantiated claims of widespread fraud have multiplied, all in the shadow of the expensive history of Civil War pensions (Logue & Blanck, 2020). As social workers, it is important to remember that eligibility restrictions and gatekeeping of services, especially financial assistance, have roots that trace directly back to the U.S.’s first widespread pension laws (Skocpol, 1993). The question of who is deserving and who is not continues to plague our social service agencies. Social workers should examine their own biases

about poverty and question if the systems they support are assessing need based on financial distress, moral worthiness, or something in-between. At this time, post-Civil War, many politicians were questioning how to respond to disabled peoples' needs without bankrupting the nation and strategizing ways to minimize the impact of deficiencies on the populace's ability to produce (Skocpol, 1993). Disability was seen as something to cure or eradicate, especially if it could be done inexpensively.

Following World War I, a focus on rehabilitation was strengthened, emphasizing returning disabled war veterans to work in whatever way possible and dis-incentivizing a war pension. According to Logue and Blanck (2020), injured men back from the front lines were directed that their best hope for a future was to overcome their impairment and re-enter the workforce. It is also important to note the overall changes in common employment opportunities that took place between the Civil War and WWI – primarily a shift from farming in rural communities to industrial labor in the cities (Social Security Administration, n.d.). This changed the end goal of rehabilitation from full physical recovery to shades of grey in-between, could a returning soldier be taught some skill, some strength, some way to be productive in a capitalist market? If so, that was his destiny. “However limited in scope the approaches were, the adoption of veteran preference in federal hiring and the offering of separate workshops in soldiers' homes were endorsements of adapting work opportunity to disability rather than the reverse” (Logue & Blanck, 2020, p. 571).

Further, “Comparison of pensions and census-listed disability suggests that disability outweighed the value of benefits in most veterans' occupation reports. Pensioners' inclination to resume working after joblessness implies that disability undermined occupational stability, not the will to work [...] nineteenth-century Americans with disabilities wanted what their twenty-first-century counterparts want—work at a meaningful occupation” (Logue & Blanck, 2020, p. 572). The shift from conceptualizing disability as a medical condition to be pitied or ignored to seeing disability as something that could be fixed or cured was significant. However, both of these perspectives fail to take into account the rights of the individual and perpetuate the segregation of those with disabilities who are unable or unwilling to reintegrate into traditionally-sanctioned productive work styles.

## Focus on Income and Health Benefits for Disabled People

Research by scholars such as Katz (1996), Schlesinger (1957), and Chambers (1963) highlights the shift in America in the 19th century from localized control of poverty relief initiatives to state funding for almshouses and poorhouses to confine the poor and subject them to nearly unbearable conditions in an effort to deter dependency on aid. Advances in technology and changes in available employment and the associated inconsistency of income necessitated a system of relief that recognized the risk of more modern forms of self-sufficiency. Local towns could no longer handle the responsibility of transient persons made poor when industrial sources of income disappeared. The Social Security Administration (n.d.) in an analysis of pre-social

security reform society explains, “in an agricultural society, prosperity could be easily seen to be linked to one’s labor, and anyone willing to work could usually provide at least a bare subsistence for themselves and their family. But when economic income is primarily from wages, one’s economic security can be threatened by factors outside one’s control” (para. 33). The need for insurance against unemployment, including disease or disability that could affect employment opportunities, slowly became recognized by the states. Even prior to the Great Depression, the public was demanding changes in safeguards against becoming destitute.

Before the Social Security Act was implemented, financial assistance to the elderly was available via a haphazard state-level system of welfare accessible only to the most economically impoverished (Katz, 1996). These plans were not sufficient for economic independence and according to an analysis by the Social Security Administration (n.d.), “the most generous plan paid a maximum of \$1 per day” (para. 70). A more uniform federal intervention was needed to provide for a financial safety net in a changing economic landscape.

Initially, people were concerned about unchecked government spending, with the bloat of Civil War pensions not far in the rear view. However, according to Ikenberry and Skocpol (1987), “the Great Depression suddenly expanded the political possibilities for social welfare reforms in the U.S.; welfare capitalism and the minimalist role of the federal government of the 1920s were discredited by the Depression crisis” (p. 404). The public and its politicians were eager for a balanced but effective solution. “With the coming to office of President Roosevelt in 1932, and the introduction of his economic security proposal based on social insurance rather than welfare assistance, the debate changed. It was no longer a choice between radical changes and old approaches that no longer seemed to work. The ‘new’ idea of social insurance, which was already widespread in Europe, would become an innovative alternative” (Social Security Administration, n.d., para. 72).

**The Social Security Act of 1935** (Public Law 74-271; 49 Stat. 620) created an insurance system wherein workers would pay taxes now towards their economic security in the future, particularly after retirement and in old age. A graduated program was created to start helping seniors who did not have the opportunity to pay in before reaching old age, with the intent to phase out these direct grants and instead rely on current workers to fund the needs of current retirees (Social Security Administration, n.d.). Contributions kept people from believing this was welfare or a handout, and instead, there was a practical method to save for the disability none of us can escape if we live long enough: old age. There were provisions left out of the 1935 Act, most important to our discussion would be disability-specific relief, which had to wait for more amendments and revisions. In the end, the passage of the act in 1935 was a necessary but not sufficient step toward financial solvency, if you could contribute (Social Security Administration, n.d.). Further amendments in 1939 added benefit payments for the spouse and minor children of a retired worker and payments to the family in the event of a premature death of an insured worker. According to the Social Security Administration (n.d.), “This change transformed Social Security from a retirement program for workers into a *family-based* economic security program” (para. 100).

**Social Security Disability Insurance (SSDI)** began with an amendment to the Social Security Act in 1956 to grant assistance to disabled workers aged 50-64 and disabled adult children (Kearney, 2005). In 1960,

the disability rules were changed to allow assistance to disabled workers of any age and their dependents (Kearney, 2005). These payments are from a disability trust fund, the person must meet eligibility for a disability, and they must have already been insured by their own payments or their spouse or parents' payments (Social Security Administration, 2020). To receive SSDI payments, you must meet the Social Security Administration's definition of a person with a disability, and you must have already been vested as an insured person in the fund, essentially that you have paid enough from working contributions to now receive payments (Social Security Administration, 2020). The amount of benefit directly corresponds to how much and for how long a worker contributed prior to becoming disabled. Individuals are able to contact the Social Security Administration directly to determine if they have made sufficient payments into the disability trust fund to qualify for benefits (Kearney, 2005).

In the 1970s, the Social Security Administration became responsible for a new program, **Supplemental Security Income (SSI)**. In the original 1935 Social Security Act, programs were introduced for needy aged and blind individuals and, in 1950, financially needy disabled individuals were added (Kearney, 2005). These three programs were known as the 'adult categories' and were administered by state and local governments with partial Federal funding. In 1971, Secretary of Health, Education and Welfare, Elliot Richardson, proposed that Social Security Administration assume responsibility for the 'adult categories.' In the Social Security Amendments of 1972, Congress federalized the 'adult categories' by creating the SSI program and assigned responsibility for it to Social Security Administration (Kearney, 2005).

Payments of SSI are from general tax revenues and beneficiaries must have limited income and resources, including less than \$2,000 in any liquid assets (Social Security Administration, 2020). SSI serves as a needed but not sufficient program to survive financially, and many disabled people struggle to meet monetary obligations despite receiving SSI benefits.

It is important for social workers to understand the differences between SSI and SSDI and be informed enough to assist clients in obtaining the benefits that they are eligible for and could use to improve their quality of life. Social workers can play an important role in facilitating information transfer as well as weighing out the pros and cons of each program available. It can be very confusing to parse through the Social Security Administration's website and time-consuming to get a live person on the phone depending on call volumes at your local or federal office. Properly informed social workers can help clients access accurate information and determine next steps in the process of application, acceptance, and even filing and arguing for an appeal. Income is a necessary, but not sufficient, possession for survival in our capitalist society. Disabled people are also particularly vulnerable due to health needs and complications that can arise from a lack of affordable care. Depending on whether a disabled person is receiving SSI or SSDI, they might be eligible for federal and/or state-run health insurance programs.

**The Medicare and Medicaid Act** (Public Law 89-97, 79 Stat. 286) was signed into law on July 30, 1965, by President Lyndon Johnson. "With the signing of this bill, [the Social Security Administration] became responsible for administering a new social insurance program that extended health coverage to almost all Americans aged 65 or older." (Social Security Administration, n.d., para. 114). The architects of Medicare were



purposeful in modeling the program after Social Security, in which all who paid in during their working years became eligible for coverage at age 65, regardless of income level (Oberlander, 2015). The Medicare policies recognized that while older people are more likely to be in need of medical care, they were also less likely to be able to afford it based on fixed and limited incomes. “Medicare initially provided a limited benefits package focused on protecting the elderly against the acute costs of medical care rather than providing comprehensive insurance for all medical costs or covering care for chronic illness” (Oberlander, 2015, p. 122). Universal coverage for older people with benefits earned via work made for a better-funded and publicly supported program (Oberlander, 2015).

In 1973, Medicare was amended to include coverage for people under 65 if they have received SSDI for 24 months, therefore disabled people younger than 65 can be eligible for Medicare depending on their circumstances. People under age 65 who are diagnosed with end-stage renal disease (ESRD) or amyotrophic lateral sclerosis (ALS) automatically qualify for Medicare upon diagnosis without a waiting period (Cubanski et al., 2016). According to Cubanski et al. (2016), “nearly one quarter (24%) of younger [Medicare] beneficiaries with disabilities had incomes less than \$10,000 per year and two-thirds (67%) had incomes less than \$20,000 per year, compared to 13% and 39%, respectively, of older beneficiaries” (para. 4). In addition, Cubanski et al. (2016) found that of Medicare beneficiaries younger than 65, “nearly 6 in 10 (59%) reported their health status as fair or poor and almost the same share (58%) reported having one or more limitations in their activities of daily living, compared to 20% and 34% of beneficiaries age 65 or older, respectively” (para. 6). It could be beneficial for disabled clients under age 65 to apply for Medicare coverage for at least part of their medical needs, particularly if they are low income and in poor health.

Medicare is comprised of multiple parts. **Medicare Part A**, reflecting the original social insurance vision, covers hospitalization costs and is funded by payroll taxes. **Medicare Part B** covers physician and outpatient services, and its financing comes from a combination of beneficiary premiums and general revenues. **Medicare Part C**, which has been added over time, allows beneficiaries to enroll in insurance plans sponsored by private companies that contract with the federal government – aka Medicare Advantage; Medicare is increasingly a hybrid mixture of public and private insurance that reflects two contrasting political philosophies within the same program (Oberlander, 2015). **Medicare Part D** is a more recent development that assists Medicare beneficiaries with coverage for prescription drugs (Oberlander, 2015).

The **Medicaid** program is a partnership between the federal and state governments to provide access to health care for the poor, with each state operating its own program within federally established guidelines (Center on Budget and Policy Priorities, 2020). According to Oberlander (2015), this program was created alongside Medicare to head off any further attempts at a universal national health insurance. Medicaid as a means-tested program showed that the U.S. recognized some people could not afford to care for their health and needed government intervention, but the strict requirements made sure the message was that most people should pay for their own care and that the ‘average’ person should not expect the government to pay for them. People at the bottom socioeconomic status were provided with an opportunity for care, but would often lose coverage if they somehow did slightly improve their income in an effort to improve their quality of life. Many

people had to choose between extreme poverty with some health coverage or slightly less extreme poverty with no health coverage. Additionally, the quality of the health care available for people with Medicaid is different from that available to people with private insurance plans, with more complexity and nuance on what is covered and when, how to prove need for care and a smaller network of providers. This was significant for disabled people in the U.S. as the correlations between poverty and disability persist. Therefore, many Medicaid recipients are disabled. Medicaid provided a path for some to receive desperately needed care for their health concerns, and the program should not be minimized for its narrow eligibility. As of 2018, one-fifth of Medicaid enrollees are seniors or persons with disabilities, and they account for nearly half of all Medicaid spending due to complex health needs (Center on Budget and Policy Priorities, 2020).

As each state is able to operate its own Medicaid program, requirements and benefits vary greatly across our nation. In order to receive federal funding, there are mandatory populations that must be covered by Medicaid – including children living below 138% of the federal poverty line (\$29,974 for a family of three in 2020), most seniors, and people with disabilities receiving cash assistance via Supplemental Security Income (Center on Budget and Policy Priorities, 2020). States are permitted to widen the criteria for Medicaid to cover more groups of people, but they cannot be required to do so. This can leave disabled people who are not receiving SSI without health care coverage – no matter what their income level. This is the reality in the 14 states that continue today to opt out of Medicaid expansion, despite the federal government covering 90% of expansion coverage costs (Center on Budget and Policy Priorities, 2020).

Depending on a disabled person's circumstances, they could be eligible for Medicare, Medicaid, or both. As social workers, it is important that we understand the differences between these programs as well as the eligibility criteria for each in order to support our clients in whatever combination of coverage works for their individual needs.

**The Patient Protection and Affordable Care Act of 2010** (Public Law 111-148; 124 Stat. 119) served as landmark legislation to improve access to health insurance coverage for all Americans and had particular significance to the disability community. This act served as the first time that insurance companies were prohibited from denying coverage based on a pre-existing condition and from charging disabled people more for treatment (Yee, 2015). Previously it was common practice for disabled people to be denied coverage or only offered extremely expensive coverage they could not afford, despite the fact that having a disability does not necessarily mean someone is in bad health and will need more coverage or be more expensive to cover (Yee, 2015). This legislation offered more protections to disabled people for quality and affordable health care coverage and with the removal of pre-existing conditions people with disabilities were for the first time on equal playing ground with non-disabled people for affordable health insurance plans. People with disabilities are not necessarily at higher risk and therefore deserve equal opportunity for coverage. Further, this legislation eliminated lifetime benefit maximums and other limitations that disproportionately put disabled people at risk, for example, a company arbitrarily saying they paid for enough care and would not cover more even if the person had medical necessity. Now, it is possible to receive individualized and as necessary care instead of constant denials and not covered expensive but needed treatments.



In addition, dependents being able to remain or return to parents' health insurance until age 26 "[...] gives families and young adults with disabilities additional time to prepare for and get through these multiple life transitions while preserving critical medical and mental health provider relationships, as well as better coverage for durable medical equipment, assistive technology, and prescriptions than what may be available through student insurance or the employment insurance offered in one's first few jobs" (Yee, 2015, p.18). The Affordable Care Act protected young adults and uniquely helped disabled young adults navigate difficult life transitions with some extra comfort that they could remain on their parents' insurance plans into young adulthood, minimizing disruptions in care and health.

The Affordable Care Act also codified 10 essential health benefits that all health insurance plans must offer, essentially eliminating so-called 'junk plans' that were not practical or did not cover needed services. These required services are: (1) ambulatory patient services; (2) emergency services; (3) hospitalization; (4) maternity and newborn care; (5) mental health and substance use disorder services including behavioral health treatment; (6) prescription drugs; (7) rehabilitative and habilitative services and devices; (8) laboratory services; (9) preventive and wellness services and chronic disease management; and (10) pediatric services, including oral and vision care (Centers for Medicare & Medicaid Services, n.d., para. 1). These categories of services are important to disabled people, but particularly the recognition of "habilitative services" deserves highlighting as this allows disabled people to receive services to learn skills in the first place, not just "rehabilitative services", which assume prior knowledge or functionality that has been lost and is trying to be regained (Yee, 2015).

Some provisions of the ACA have been struck down over time as opposition has remained constant to expanded coverage and cost. However, disabled people continue to benefit from the ACA's policies that might not have been the focus but give disabled people stronger ground from which to advocate for their health needs. Even though the ACA is a 'newer' development, it represents a more primitive level of policy as it addresses basic health and survival. As we progress further in disability policy, we will see the objectives multiply and flourish – moving from disabled peoples' survival to what helps them thrive and live fuller lives in our shared society.

## Focus on Education and Work Services for the Disability Community

**Head Start** programs have served more than 36 million children since 1965, growing from an eight-week demonstration project to include full-day/full-year services and many program options (U.S. Department of Health and Human Services, 2022). Currently, Head Start grants are administered by the U.S. Department of Health and Human Services, Administration for Children and Families. Head Start programs serve over 1 million children and their families each year in urban, suburban, and rural areas in all 50 states, the District of Columbia, Puerto Rico, and U.S. territories, including American Indian, Alaskan Native, and Migrant and Seasonal communities (U.S. Department of Health and Human Services, 2022). "Head Start programs

deliver services to children and families in core areas of early learning, health, and family well-being while engaging parents as partners every step of the way. [...] Head Start services are delivered nationwide through 1,600 agencies which tailor the federal program to the local needs of families in their service area” (U.S. Department of Health and Human Services, 2021, para. 1). Head Start initially laid the groundwork necessary to conceptualize the importance of providing services directly to pregnant women and families with young children, including disabled children with varying needs. Head Start would become more beneficial to disabled children in the context of legislation passed federally mandating educational services to all children.

**Education of All Handicapped Children Act of 1975 (EAHCA)** (Public Law 94-142; 89 Stat. 773) mandated that all children in the U.S. have access to free and appropriate public education in the least restrictive environment possible (Larson, 1985). This legislation attempted to more fully explain and provide guidance on ‘appropriate’ public education for children with disabilities, and even further define education as more than instruction, more than learning, but also preparation for future stages in life. As explained by Wegner (1985):

Free and appropriate public education includes two programmatic components – special education and related services. Special education is defined as specially designed instruction, at no cost to parents or guardians, to meet the unique needs of a handicapped child including classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions. Related services are defined as such developmental, corrective, and other supportive services as may be required to assist a handicapped child to benefit from special education. (p. 177–178)

EAHCA became necessary as more and more parents of disabled children were suing local school districts for not providing the education that their children needed and not accommodating disabled students’ needs (Wegner, 1985). The rift continued to grow between opportunities and quality of services provided for non-disabled children vs. those available for the disabled. Standards and policy mandates were needed for disabled children to receive an education tailored to their needs.

EAHCA mandated “the development of an IEP for each handicapped child. An IEP is a written statement developed by a representative of the local educational agency, the teacher, the parents, and the child which includes a statement of educational performance, annual goals, and specific educational services to be provided” (Larson, 1985, p. 70). IEPs are a necessary, but not sufficient, tool to ensure adequate education. Rather, “the sufficiency of the child’s educational programming is to be judged by his performance in making incremental progress towards his individual educational goals” (Wegner, 1985, p. 188). The child has to be receiving some educational benefit and making some measurable progress towards the IEP goals in order for the school to meet its legislatively-mandated burden.

Of particular interest to social workers may be Wegner’s (1985) assertion that with EAHCA “[...] Congress’s overall plan [was] to ensure that all children, including seriously emotionally disturbed children in need of the full range of psychotherapeutic services, should receive those services needed to allow them to make at least minimal educational progress” (p. 219). Therefore, children with emotional concerns and mental illness are also protected as people with disabilities, and educational services necessary to treat emotional problems are the

responsibility of the educational institution. This can include residential or group home placement if deemed necessary for educational purposes (Wegner, 1985).

EAHCA has continued to be reauthorized and renewed since the 70s and in 1990 underwent a name change to the **Individuals with Disabilities Education Act (IDEA)**. This shift was to make it clear in the language that educational policy applies to all disabled people, starting at birth (via early intervention services) through young adulthood, and not just conventionally ‘school-aged children.’ IDEA was most recently reauthorized in 2015 via Public Law 114-95, the **Every Student Succeeds Act**. According to the U.S. Department of Education (2022), IDEA authorizes grants to states to provide for special education needs and guidance on what needs are required to be met by programming, and how success (i.e. needs attainment) should be monitored and measured. In addition, more of a spectrum of educational needs is considered, including mandating the inclusion of a plan for transition post-school in students’ IEP. Not only are disabled students entitled by law to services from birth through age 21, but they also must have services aimed at transitioning to adulthood with emphasis on further education, independent living, and other long-term goals (U.S. Department of Education, 2022).

One method of providing services is utilizing the structure and assistance available with Head Start. According to the Head Start Program Performance Standards, “A program must ensure at least 10 percent of its total funded enrollment is filled by children eligible for services under IDEA, unless the responsible [Health and Human Services] official grants a waiver” (U.S. Department of Health and Human Services, 2016, p. 15). Therefore, Head Start is an important program for children with disabilities and it is written into the rules that disabled children have some priority for services and supports. This allows more disabled children to receive the services they need in the least restrictive environment.

**Ticket to Work and Work Incentives Improvement Act of 1999** (Public Law 106-170; 108 Stat. 1464) created a “self-sufficiency program that would allow disability beneficiaries to seek the employment services, vocational rehabilitation services, or other support services needed to regain or maintain employment and reduce their dependence on cash benefits” (Social Security Administration, n.d., para. 134). People receiving disability benefits would receive a “ticket” to vocational rehabilitation and be able to work without losing their benefits eligibility and would also not be subject to disability eligibility reviews during this time (Social Security Administration, n.d.). Employers receive financial incentives to help vocationally rehabilitate disabled people, with a focus on returning to productive work. Participation in the program remains low, administrative costs are high, and there is not a lot of movement of disabled people off benefits as a result of their ticket to work (Social Security Administration, n.d.). However, for some disabled people, this program could be the right combination of supports to help them rehabilitate and rejoin or join the workforce for the first time with a new trade or marketable skill.

**Achieving a Better Life Experience (ABLE) Act of 2013** (Public Law 113-295; 128 Stat. 4010) became law on December 19, 2014. This law aims to ease financial strains faced by individuals with disabilities by making tax-free saving accounts available to cover qualified disability expenses (Social Security Administration, 2022). Disabled people can save money and have assets over the \$2,000 limit (instituted by most benefit

programs) and not risk losing their benefits or health insurance. To qualify, an individual must have acquired a disability prior to age 26. The disabled person has their own single ABLE account and can hold up to \$100k without penalty. For the first time, public policy recognizes the added financial burden of disability and the need to save and have access to more money for disability-related expenses (ABLE National Resource Center, 2022). This can be seen as an accessibility issue when we consider the previous lack of a mechanism to save money and also hold on to monetary gifts with the \$2,000 limit – the ABLE Act of 2013 granted access to savings accounts on a similar playing field for people with disabilities as their non-disabled counterparts. ABLE accounts can receive up to \$16,000 per year from all contribution sources, which is the maximum amount set by tax laws of what can be gifted without having to report the gift to the IRS (Social Security Administration, 2022).

## Accessibility Policy and the Disability Community

The **Architectural Barriers Act of 1968 (ABA)** (Public Law 90-480; 82 Stat. 718; 42 U.S.C. 4151-4157) requires certain federal and federally-funded buildings and other facilities to be designed, constructed, or altered in accordance with standards that ensure accessibility to, and use by, physically handicapped people (Raffa, 1985). Standards for accessibility in design were developed by the newly formed U.S. Access Board. The law was not retroactive. The peculiarities of the law created situations where only the substantially renovated portion of the building had to be accessible, and therefore there were buildings with new accessible bathrooms that still lacked any ramp access out front (Raffa, 1985). The law helped, but enforcement was difficult and time-consuming. Voluntary compliance was low, and people did not want to spend more time and money incorporating accessible standards of design into new and renovated constructions (Raffa, 1985). Only federally-funded buildings were covered by the mandate, leaving many buildings inaccessible as they were not required to be constructed with universal access in mind (Raffa, 1985). The ABA attempted to address part of a growing problem, people with disabilities literally being unable to enter buildings necessary to carry out regular life activities, but more teeth were needed to enforce compliance and mandate that more types of buildings incorporate accessible design standards from the beginning.

Organizations of d/Deaf and hard of hearing individuals began thinking of accessibility in a slightly different way, not physical access – but auditory. People quickly realized that status quo communications technology was not accessible to those with hearing and speech differences, and how telephones being inaccessible kept disabled people from fully participating in public and private spaces. The teletypewriter (TTY) was used by telecommunications companies to transmit text, albeit with limited characters and speed (Strauss, 2006). As computers continued to evolve, the TTY became obsolete for this purpose and telecommunications companies moved on to devices more capable of handling large amounts of data (Strauss, 2006). TTY machines were discarded en masse. At the same time, d/Deaf engineer Robert Weitbrecht was concentrating on improving telephone access for the d/Deaf community and saw the TTY as an opportunity (Strauss, 2006). He was able

to connect a discarded TTY to a modem that enabled the TTY to transmit typed text over existing telephone lines (Strauss, 2006). This allowed d/Deaf people to type their message, have it sent over telephone wires, and be received by another TTY connected to the network. With this success, volunteers took to refurbishing thousands of discarded TTYs and providing to disabled people in need of accommodation in order to have live, real-time communication with others in different places (Strauss, 2006). Volunteers also started acting as relay operators. They would receive the TTY message and convert it from text to speech for a hearing recipient. This allowed d/Deaf individuals to connect to hearing individuals. Other devices were integral for hard-of-hearing people to utilize telephone communication including amplifiers, flashing lights to bring attention to a ringing phone, and phones compatible with hearing aids (Strauss, 2006).

The **Telecommunications for the Disabled Act of 1982 (TDA)** (Public Law 97-410; 96 Stat. 2043) attempted to address some of the concerns from the d/Deaf and hard of hearing communities about access to and the affordability of communication devices (Strauss, 2007). This legislation, while not complete, was significant in the history of disabled people's fight for accessibility. According to Strauss (2006), the TDA was "the first time in America's history [that] statute acknowledged the enormous costs to society of failing to provide telephone access to people with hearing loss, recognized the failure of the marketplace to ensure disability safeguards, and declared the furnishing of this access a national priority" (p. 283).

During the 1970s, advances in technology changed the mechanisms of telephone sets which led to lighter and more tamper-resistant phones, but created an accessibility issue for hearing aid users as the sound transmission coils were not compatible with hearing aid receivers (Strauss, 2006). TDA mandated that telephones deemed essential be compatible with hearing aids, which ultimately fell short of advocates' demands for universal compatibility, but did lay the groundwork needed for future more far-reaching legislation (Strauss, 2006). Essential telephones were determined by the Federal Communications Commission to include: coin-operated telephones, phones designated for emergency use, and phones frequently needed by hearing-impaired people (Strauss, 2006). This resulted in situations such as an individual's workstation including a hearing aid compatible phone, but other phones in a workplace continuing to be incompatible, or hotels only needing 10% of rooms equipped with hearing aid compatible telephones leaving someone hard of hearing not knowing if they would be able to find an accessible phone while traveling. In place of universal compatibility, TDA required that telephone manufacturers clearly indicate on the outside of the packaging if the device was or was not compatible with hearing aids, to allow consumers to make an informed purchase (Strauss, 2006).

TDA also gave local telephone companies the authority to subsidize the rates of telephone services to people with hearing disabilities by utilizing surcharges for all customers (Strauss, 2006). Part of the need for subsidized rates came from the insurmountable fact that calls placed via relay systems or between TTY machines took longer to execute than voice calls due to the technology involved. The disability community was asking for a mechanism to make utilizing the telephone more affordable and argued that charging per unit of time was discriminatory as the calls took longer specifically due to one or both of the callers having a hearing disability (Strauss, 2006). It should be noted that TDA merely allowed telephone companies to choose to subsidize in

this manner; it did not mandate them to do so. Many telephone companies still conceptualized telephone access for the d/Deaf, hard of hearing, and speech impaired to be “charity” and insisted it should be the government’s responsibility to pay for these services (Strauss, 2006). Therefore, TDA set the stage for future action but did not in and of itself result in widespread rate reductions.

For years after the implementation of TDA, “consumers complained that the restricted scope of the existing [hearing aid compatible phone] regulations hindered their ability to lead independent lives and summon help in the event of an emergency” (Strauss, 2006, p. 293). After much advocacy, negotiation, and pressure the **Hearing Aid Compatibility Act of 1988** (Public Law 100-394; 102 Stat. 976) was passed mandating that all telephones manufactured or imported to be used in the U.S. after August 16, 1989, be hearing aid compatible. Technology has continued to evolve and d/Deaf people have many options today to be connected and communicate; however, it is important to know the advocacy it took to get to this point and the legacy of the discrimination faced when one merely was requesting access to what a hearing individual would utilize – in this case, a working telephone.

**The Telecommunications Accessibility Enhancement Act (TAEA) of 1988** (Public Law 100-542; 102 Stat. 2721) created a Federal Relay Service (FRS) within the federal government, mandating that TTY users have the same access to federal government offices and agencies as traditional telephone users (Strauss, 2007). The relay service allowed TTY users to connect with a TTY-compatible operator who could then connect the TTY user to the office or agency desired, the operator acting as a relay of information translating between text and speech (Strauss, 2006). TAEA directed all elected federal officials to obtain TTY machines and create a directory of TTY numbers for all offices and agencies to increase access to the federal government for TTY users (Strauss, 2007). The FRS has grown over time to meet demand, expanding in 1998 to provide 24/7 service and by 2000 had over 100 relay operators fielding tens of thousands of calls each month (Strauss, 2007). While the TAEA was restricted in scope to only the federal government, it did show the high demand for telephone access by persons with hearing and/or speech impairments and the changes possible by providing the accommodations needed.

**The Decoder Circuitry Act of 1990** (Public Law 101-431; 104 Stat. 960) mandated that all television sets manufactured or imported into the United States with screens 13 inches or larger be capable of displaying closed captions (Strauss, 2007). For a decade individual networks and shows had voluntarily utilized closed captions; however, audiences wishing to access the information needed to purchase costly decoders and then be able to integrate the device into the television set (Strauss, 2006). Decoder sales lagged greatly behind predictions given the knowledge of the size of the American d/Deaf and hard-of-hearing population (Strauss, 2006). Even if the program someone wanted to watch happened to be captioned, this crucial information could not be accessed without additional equipment. This led to television – entertainment, but also news, weather, sports, etc. being inaccessible to millions of people. According to Strauss (2007), “The Commission on Education of the Deaf suggested a different solution. It proposed that if all television sets were equipped internally with circuitry that decoded closed captions, the larger audiences that would be able to use this technology would create a strong incentive for the television industry to increase its captioned programming”



(p. 509). After much advocacy and continued pressure on legislators, this was the solution that passed into law. The act made it clear that the majority of Congress supported access to closed captioning for all, but further legislation was needed to make fully accessible television a reality.

By the time the Decoder Circuitry Act went into effect in 1993, most network television programming was closed captioned, but only 5-10% of cable television came with captions available (Strauss, 2006). Advocates realized that the hope of the Commission on Education of the Deaf had not been realized; greater availability of closed caption-ready televisions did not encourage all broadcasts to provide captions. After several years of continuous advocacy and negotiation, **The Telecommunications Act of 1996** (Public Law 104-104; 110 Stat. 56) included “for the first time in our nation’s history, require[ment that] all broadcasters, cable operators, satellite operators, and other television programming distributors to make the vast majority of their programming accessible to deaf and hard of hearing people through closed captions” (Strauss, 2006, p. 257). While the governmental mandate was encouraging, the FCC needed to create regulations to implement the mandate and they were faced with a variety of exemption requests. Nearly every broadcaster not currently providing closed captioning tried to make the case that to do so would be an undue burden on their operations, and arguments ensued about what types and timing of programming were truly of benefit to the D/deaf and hard-of-hearing populations (Strauss, 2006). Instead of focusing on universal access and allowing the individual to decide which program to watch, legislators and industry professionals attempted to whittle down the types of programs that would fall under the mandate (Strauss, 2006). The Act also stipulated that the mandate only applied to programming first created after the effective date of the FCC’s regulations (Strauss, 2007). The FCC issued a complex schedule of deadlines for different percentages of different types of programming to be fully closed captioned, some of these deadlines as far out as 2010 (Strauss, 2006). While Congress issued a mandate, the FCC’s regulations made significant room for exemptions from the mandate, leaving d/Deaf, hard of hearing, and other television viewers who utilized captions (English-language learners, children, and others learning how to read, etc.) without access to a considerable amount of programming. Of note, the FCC’s regulations completely exempted from captioning programs broadcast in languages other than English or Spanish (Strauss, 2007). As social workers, we should recognize the bias in this blanket exemption and the negative effect on people who need captions who also communicate in other languages and would, it would follow, greatly benefit from access to programming in their native language that was captioned. There have been several acts and updates to regulations to improve the quantity of captioning available. however, even in 2022, the quality of captioning can leave a lot to be desired in terms of accuracy, grammar, spelling, and appropriate reading speed. In addition, the availability of captioning on videos in an increasingly digital/online world continues to be far from universal (Espino, 2016). Accessibility difficulties persist for disabled people in online/electronic environments, as will be discussed in more detail toward the end of this chapter.

## Policies Related to Civil Rights for the Disability Community

The first disability civil rights legislation was contained in **Section 504 of the 1973 Rehabilitation Act** (Public Law 93-112; 87 Stat. 355; 29 U.S.C. § 701 et seq). According to Davis (2015):

The spirit of the act was to shift federal assistance away from mere vocational rehabilitation and towards a more encompassing idea of improving not just job training but the overall lives of people with disabilities. Yet its lasting impact [exists permanently] in just four lines of the voluminous act. Like a magic phrase inserted into an incantation, those four lines changed the history of disability rights. In Section 504, the very last section of the last major category, a staffer inserted the following words trying to tie the act to previous civil rights legislation: No otherwise qualified handicapped individual in the United States [...] shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance. (p. 11)

As Rouse (1981) explains, “A qualified handicapped person is one who can perform the essential functions of the job with reasonable accommodation. Essential functions are those that constitute the basic functions of the job. Reasonable accommodation refers to modifications which allow the handicapped employee to perform acceptably the essential duties of his or her job” (p. 201). Reasonable accommodation will be further explained in relation to the Americans with Disabilities Act (ADA), but it is important to note that the Rehabilitation Act was where this concept originated, identifying changes needed to include disabled people and requiring those alterations as a matter of law. Rouse (1981) advocated that people with a wide range of disabilities be directly involved in any renovations or reforms made to comply with Section 504, so that real needs could be asserted, and their point of view could be utilized to identify all possible barriers for disabled people to fully access the federal or federally funded building and participate as an equal in federally funded programs.

Chamusco (2017) explains that the 1973 Rehabilitation Act can trace its origins to laws in the early 1900s focused on vocational rehabilitation for disabled people, “however, these were examples of the **medical model** or social pathology model of disability. Both models are premised on the belief that it was the disabled person—not society or one’s physical environment—who must change” (p. 1287). Section 504 instead focused on society and other people needing to change to accommodate disabled people and recognize disabled people’s inherent civil rights in federally funded spaces and programs. As Mayerson (1991) explained, the Rehabilitation Act “[...] changed the focus away from the limitations imposed by a disability and turned it towards the limitations imposed by society through attitudinal and architectural barriers” (p. 2). Davis (2015) highlights the historical significance of the Act as well as its connection to civil rights, “It was the first federal language that clearly and uncompromisingly guaranteed the civil rights of people with disabilities; it was modeled on Title VI of the Civil Rights Act and Title IX of the Education Amendments Act, both of which never mentioned people with disabilities” (Davis, 2015, p. 11). Mayerson (1992) further explains:

Section 504 was also historic because for the first time people with disabilities were viewed as a class – a



minority group. Previously, public policy had been characterized by addressing the needs of particular disabilities by category based on diagnosis. Each disability group was seen as separate, with differing needs. Section 504 recognized that while there are major physical and mental variations in different disabilities, people with disabilities as a group faced similar discrimination in employment, education and access to society. (para. 7)

Solidarity amongst people with different types of disabilities was key in the passage of the Rehabilitation Act as well as additional advocacy needed to implement its provisions, which will be discussed in the disability resistance movements chapter. The act itself was historic; however, its passage did not immediately impact the lives of disabled people.

Prior to the law going into effect, the government needed to create and declare regulations specifying the criteria for being legally regarded as a disabled person and what circumstances would meet the definition of discrimination in the context of disability (McKeever, 2020). Four years passed without the government publishing the needed regulations and disabled advocates were concerned that this delay would decrease the effectiveness of the approved legislation (McKeever, 2020). “[...] advocates organized protests around the country. In April 1977 they launched a sit-in at a federal building in San Francisco that would last for 28 days—the longest peaceful occupation of a federal building in U.S. history—and result in victory.” (McKeever, 2020, para. 7).

The regulations were finally issued after extreme pressure from disabled people and allies. “Regulations are a detailed set of rules issued by a government [...] indicating how a law is to be interpreted and outlining procedures for enforcement of the law. In other words, they translate Congress’ intent into a detailed set of rules and procedures to assist in compliance” (Rouse, 1981, p. 199). Therefore, the regulations were essential for disabled people to actually be protected by the nondiscrimination mandate. It took four years from Congress’s agreeing that disabled people have civil rights to actually have what was needed for those rights to be recognized, enforced, and federally supported. A more thorough explanation of the advocacy that led to the acceptance of the Section 504 Regulations will be provided later in this textbook within the chapter on disability resistance movements.

Rouse (1981) asserted that “Attitudes about the cost of opening our jobs, programs, and services to disabled people need to change. [...] Economically speaking, we must make the financial commitment in our programs to eliminate the architectural, transportation, communications, and attitudinal barriers that prevent the disabled from assuming their rightful roles and responsibilities in our society. So the basic question is, can we open our minds enough so that we become aware of our attitudes and change them?” (p. 205). Further, what we should not accept is the economic burden of disabled people not being able to fully access and participate in our society, what we all lose when disabled people are excluded. Section 504 was only able to protect disabled peoples’ civil rights in federal buildings and federally funded programming, leaving any private program, and even state or local government buildings and programs, able to continue with the discrimination and exclusion of people with disabilities.

In part due to this lack of comprehensive discrimination protection, advocates in the 1980s collectively decided to focus on universal civil rights legislation for disabled people (McKeever, 2020). According to

McKeever (2020), “The National Council on Disability commissioned a report on the need for such a law, while its vice chair Justin Dart Jr.—who would later become known as the ‘Godfather of the ADA’—embarked on a national tour to discuss disability policy with local officials and gather stories of the discrimination people with disabilities faced” (para. 10). While it was clear to disabled advocates that discrimination was occurring regularly in disabled people’s lives, it was important to gather concrete data supporting their assertions.

Results from the 1986 Harris Survey supported the need for change. The survey’s findings were the results of polls conducted in the early 1980s that found that disabled people are uniquely underprivileged and disadvantaged, poorer, less educated, less social, have less life fulfillment/satisfaction, and that many disabled people reported they wanted to work but weren’t employed (Mayerson, 1991). Disabled respondents reported that employers would not recognize that they were capable of holding a full-time job because of their disability (Mayerson, 1991). Disabled respondents also described discrimination in the job market and educational institutions, social rejection (people shying away or ignoring people with disabilities), lack of accessible transportation, and denial of health and life insurance due to disability (Mayerson, 1991). In addition, there was a push to chip away at the protections offered by Section 504, finding loopholes and exceptions to perpetuate inaccessibility and inequality and singling out particular groups for exclusion. Davis (2015) explains that:

The 1980s saw a continual chipping away at the larger civil rights claims of Section 504. [...] one of the most notable of these erosions was the increasing use of carve outs to restrict 504 from applying to various groups, notably those with conditions that essentially offended the sensibilities of conservative politicians and their constituencies. This meant that people with AIDS or who were HIV positive, along with sexual minorities in the LGBT community, people who were drug or alcohol addicted, and the like, were made personae non gratae when it came to civil rights. (p. 76)

The disability community continued to lack universal protection as well as universal appreciation and understanding of their limitations as well as strengths. Efforts were made to decrease the power of the community and their advocacy efforts by pitting different disability groups against each other and resisting that separation was essential in order to keep civil rights as a focus.

**Fair Housing Amendments Act of 1988 (FHAA)** (Public Law 100-430; 102 Stat. 1619) extended disability civil rights protections to housing in the private sector, independent of the receipt of federal funding by amending Title VIII of the Civil Rights Act of 1968 to prohibit discrimination on the basis of disability in sales, rentals, or financing in housing, representing the first time disability was added to the list of traditionally protected groups (Mayerson, 1991). The United Spinal Association (2004) created an explanation document to assist disabled people with understanding their rights and responsibilities under the FHAA, stating “this law is intended to increase housing opportunities for people with disabilities. However, individual citizens must come forward with concerns, file complaints or sue if they believe their rights have been violated. The government has no other way of detecting discrimination as it occurs” (p. 1). The act mandates that:

Newly constructed multi-family dwellings with four or more units must provide basic accessibility to people

with disabilities if the building was ready for first occupancy on or after March 13, 1991. The design features mentioned apply to all units in buildings with elevators and to ground floor units in multi-level buildings without elevators. Multi-story townhouses are exempt from these requirements. (The United Spinal Association, 2004, p. 7–8)

The accessible design features required of these types of new construction include: at least one entrance must be on an accessible route; all public and common use areas must be accessible; all doors into and within the premises must be wide enough for people who use wheelchairs; there must be an accessible route into and through the unit; all light switches, electrical outlets, thermostats, and environmental controls must be placed in an accessible location; reinforcements in the bathroom walls for installation of grab bars around the toilet, tub, and shower must be provided; kitchens and bathrooms must be constructed so that a person who uses a wheelchair can maneuver about the space (The United Spinal Association, 2004).

The FHAA prohibits: refusing to sell or rent a unit where a genuine offer has been made, imposing different terms and conditions or treating people differently, discouraging an individual from living in a certain neighborhood or community (‘steering’), and advertising or making statements in a way that denies access to an individual, misrepresenting the availability of a unit, and blockbusting by encouraging the sale or rental of a unit by implying that people of a certain protected class are entering the community in large numbers – all on the basis of disability (The United Spinal Association, 2004). The FHAA also made it illegal “[...] for a landlord to refuse to allow a tenant with a disability to make modifications, at the tenant’s expense, which would permit the tenant to fully enjoy the premises. The landlord can, where reasonable, require the tenant to restore the interior of the premises to the condition it was in prior to the modification” (The United Spinal Association, 2004, p. 3). In addition, the FHAA allows tenants to make modifications to public and common spaces such as lobbies, laundry rooms, and parking lots – these are considered reasonable accommodations in structural modifications (The United Spinal Association, 2004). Finally, the “FHAA requires that the housing provider make reasonable modifications in rules, policies, practices or services necessary to give persons with disabilities equal opportunity to use and enjoy the dwelling” (The United Spinal Association, 2004, p. 7). For example, a building with a no-pets policy would be required to allow a person with a disability to have their trained service animal on site.

The FHAA was historic for conceptualizing disabled people as a protected class and enshrining their rights to accessible housing in statute. However, the financial burden of any needed accommodations or modifications in housing built before 1991 remained on the disabled person’s shoulders, leaving many unable to access the available affordable housing in their neighborhoods. Further, it was difficult for people with disabilities to seek relief if a landlord was in violation of FHAA, requiring time, money, and legal resources not widely available to disabled people. The need for comprehensive civil rights legislation remained.

The report commissioned at the direction of Congress in 1986 by the National Council on Disability, an independent federal agency, was entitled *Toward Independence* and listed 35 legislative recommendations based on findings from Justin Dart Jr.’s interviews with disabled people all over the country, including an omnibus Americans with Disabilities Act (Mayerson, 1991). The follow-up report entitled *On the Threshold*

*of Independence* (with a few edits) was the Americans with Disabilities Act as originally introduced in 1988 (Mayerson, 1991). Therefore, many of the reports from disabled people were incorporated directly into the legislation. Davis (2015) explains that:

The proposed ADA was an ambitious and overly idealistic piece of legislation. Many refer to it as the ‘flat earth ADA’ or the ‘flatten the earth ADA.’ The idea was that the legislation would flatten the playing field for people with disabilities by eliminating all barriers and doing so immediately. In this view all buildings new and old would be transformed. All transportation would become accessible. The proposed legislation was about as radical a piece of civil rights legislation as one could imagine, and it was coming from a largely conservative Republican council. (p. 84)

However, there was strong pushback from business-minded individuals as well as some disability advocates that this initial piece of legislation went too far, particularly compliance being expected immediately upon passage of the act. The 1988 version of the ADA languished in committees and died the quiet death of the vast majority of bills introduced into Congress (Davis, 2015).

Nevertheless, the legacy of the 1988 version of ADA legislation should not be understated. As Davis (2015) explains, “ADA sponsors and the disability community used 1988 as an opportunity to publicize the Act, mobilize grassroots support, solicit the endorsement of presidential candidates in the upcoming election, enlist congressional cosponsors, and establish the act as a top priority for the next Congress” (p. 91). It was essential that presidential candidates go on record in support of civil rights for disabled people in order for the newer version of the ADA to gain traction in Congress and have a hope of passing through various committees and both chambers. Some scholars theorize that the disabled vote is what helped Bush Sr. win the election in 1988 as he came out strong in favor of the concept of a civil rights bill for disabled people whereas his opponent Dukakis was silent on the issue (Davis, 2015). Bush’s endorsement of a comprehensive bill of civil rights for the disabled community allowed some Republicans cover to support the bill that would have been more hesitant without the president’s leadership and according to Davis (2015) made the bill bipartisan. A disability subcommittee was formed to transform the 1988 version of the ADA into a piece of legislation that would satisfy concerns about the financial burden placed on businesses, a balancing act between assertion of what disabled people need to fully participate in society and the cost of modifications (Davis, 2015). Multiple teams and advocates from around the country contributed to the new version of the ADA that was introduced into Congress the following year. Mayerson (1992) additionally asserts that:

The ADA owes its birthright not to any one person, or any few, but to the many thousands of people who make up the disability rights movement – people who have worked for years organizing and attending protests, licking envelopes, sending out alerts, drafting legislation, speaking, testifying, negotiating, lobbying, filing lawsuits, being arrested – doing whatever they could for a cause they believed in. There are far too many people whose commitment and hard work contributed to the passage of this historic piece of disability civil rights legislation to be able to give appropriate credit by name. Without the work of so many – without the disability rights movement – there would be no ADA. (para. 2)

The purpose of the **Americans with Disabilities Act of 1990 (ADA)** (Public Law 101-336; 104 Stat. 327) was to: “(1) to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities; (2) to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities; (3) to ensure that the Federal Government plays a central role in enforcing the standards established [...] on behalf of individuals with disabilities; and (4) to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities” (42 U.S.C. § 12101 et seq).

This was directly in response to information provided by disabled people in at times heartbreaking testimony. According to Mayerson (1992):

Members of Congress heard from witnesses who told their stories of discrimination. With each story, the level of consciousness was raised and the level of tolerance to this kind of injustice was lowered. The stories did not end in the hearing room. People with disabilities came from around the country to talk to members of Congress, to advocate for the Bill, to explain why each provision was necessary, to address a very real barrier or form of discrimination. Individuals came in at their own expense, slept on floors by night and visited Congressional offices by day. People who couldn't come to Washington told their stories in letters, attended town meetings and made endless phone calls. (para. 29)

Further, Davis (2015) highlights the significance of testimony from Rep. Major Owens of New York:

As an African-American congressman, [Rep. Owens] used language that linked the civil rights act to previous ones: ‘The Americans with Disabilities Act will go a long way to stopping a problem that should’ve never started. We may have inherited a society that segregates and excludes people with disabilities, but we don’t have to maintain it.’ Owens ended with a sweeping statement of inclusion. He noted that he had recently learned the term ‘temporarily able-bodied’ could be applied to all ‘non-disabled’ people. The phrase indicates that being ‘normal’ is only a temporary state. He went on: ‘When you think about it, our entire country is made up of disabled people and temporarily able-bodied people. The people we are protecting are not a mysterious, distant them, but rather ourselves.’ (p. 94)

Rep. Owens highlighted the need to see disabled people as full members of our society and recognize (and perhaps come to terms with the reality) that civil rights for disabled people actually benefit every person in our country because anyone can become disabled at any time.

Title I of the ADA banned discrimination in employment against qualified individuals because of disability, evoking the pivotal concepts of reasonable accommodation and undue hardship taken from Section 504 of the 1973 Rehabilitation Act. Businesses would be required to provide reasonable accommodations to assist a disabled person to perform the essential functions of the position unless the accommodations needed would create an undue hardship (significant difficulty or expense) for the company (Parry, 1990). The important improvement on previous legislation was that this ban applied to all but the smallest employers, regardless of funding source (there are exceptions to the ADA for small businesses that employ less than 15 people). This was the first time almost all workers had protections against discrimination on the basis of disability in

application, hiring, advancement, and firing practices (Parry, 1990). Social workers need to understand the concept of reasonable accommodation in order to assist disabled clients in problem-solving when barriers exist in obtaining or maintaining employment. Clients may not know they have the right to request accommodations and what kinds of accommodations may be helpful. An excellent resource is the Job Accommodation Network website ([askjan.org](http://askjan.org)) maintained by the U.S. Department of Labor's Office of Disability Employment Policy. Using this reputable data source, job seekers can search for examples of accommodations that have been used to assist others with their condition or diagnosis, amongst numerous other disability employment tools (U.S. Department of Labor Office of Disability Employment Policy, 2022).

There are some limitations and important distinctions made in the Americans with Disabilities Act. Of importance to social workers with clients with substance use disorder, "The Act does not protect an employee when an employer acts based on the employee's use of illegal drugs. It does protect persons with a disability who no longer are using illegal drugs and either have been successfully rehabilitated or are participating in a supervised rehabilitation program" (Parry, 1990, p. 294). Thus, people are protected from discrimination based on prior drug use or participation in drug treatment, but not discrimination or other adverse actions that might occur based on current drug use.

Title II of the ADA banned the exclusion of disabled people from participation in or receiving benefits from services, programs, or activities of public entities (including state and local organizations). This included requirements for all public transportation (excluding airlines) with fixed routes that no new vehicles be purchased or leased that are not accessible, the establishment of paratransit- special transportation for people with disabilities who are unable to utilize available public transit, and that every public entity submit an annual plan to the Secretary of Transportation "detailing how they will provide special services to persons with disabilities" (Parry, 1990, p. 295). In addition, any newly constructed buildings for the purpose of public transportation must be accessible and existing public transportation buildings must make accommodations and modifications to become accessible to the extent possible, provided that at least two-thirds of a system's key stations are accessible and with light rail, rapid transit, and commuter rail/intercity systems only one car in each train must be accessible (Parry, 1990). Various deadlines for different features to be fully accessible were instituted that have all passed as of the date of this writing. Standards for accessibility "must be consistent with or exceed the minimum guidelines issued by the Architectural and Transportation Barriers Compliance Board" (Parry, 1990, p. 296). Social workers can better serve their disabled clients if they understand the rights that exist for accessible transportation in their service areas.

Title III of the ADA stated that no individual may be discriminated against on the basis of disability with regard to the full and equal enjoyment of the goods, services, facilities, or accommodations of any place of public accommodation operated by private entities. This would include most places of lodging, recreation, transportation, education, and dining, along with stores, care providers, and places of public displays. According to Parry (1990), "All public accommodations shall be afforded to an individual with a disability in the most integrated setting appropriate to the needs of the individual" (p. 296). In addition, this title states it is discrimination not to make reasonable modifications, including not providing auxiliary aids and



services to people with disabilities that are needed to fully participate in and receive the benefits of a public service” (Parry, 1990, p. 296). Barriers in existing facilities are required to be removed when removal is “readily achievable” – meaning “easily accomplishable and able to be carried out without much difficulty or expense” (Parry, 1990, p. 296). New facilities are required to be accessible, and when alterations are made to an area of the facility containing a primary function, bathrooms, telephones, and drinking fountains must be made accessible. However, a compromise was struck in which elevators were not required for facilities that are less than three stories or have less than 3,000 sq. ft. per story unless the building is a shopping center, a shopping mall, or the professional office of a health care provider (Parry, 1990). Title III also has exemptions for private clubs and religious organizations that are exempt from coverage under Title II of the Civil Rights Act of 1964 (Parry, 1990). Social workers should not assume that spaces are accessible to all and instead develop a working knowledge of barriers that disabled clients may face, particularly for places where clients are referred. It might increase empathy and understanding to reflect on the difficulty in knowing which locations must be accessible and which are exempt, and the challenge this poses for disabled people on a regular basis.

Title IV of the ADA focused on telecommunications and stated that relay services must be available to the extent possible and in the most efficient manner for d/Deaf and speech-impaired individuals. Major communications companies were given three years to comply with the mandate for offering relay services that adhere to or exceed the FCC standards (Parry, 1990). The passage of the ADA marked the first time in U.S. history that nationwide relay services, that connect telephone users with d/Deaf or hard-of-hearing people, were required (National Association of the Deaf, 2022). Social workers can be better prepared for when relay services are needed by familiarizing themselves with TTY machines and the policies for communication with d/Deaf and hard-of-hearing clients established by their agencies.

Title V of the ADA are miscellaneous provisions regarding legal consistency and reinforces the concept of choice for people with disabilities. As Parry (1990) explains, the ADA signaled a shift in allowing disabled people to determine what was best for themselves:

Years ago, when the concept of integration of persons with disabilities first was proposed, the emphasis was on an objective standard of freedom or liberty which presumed that the most normal or the least institutional situations were best, regardless of the individual’s perspective. The ADA is more subjective, allowing the viewpoint of the person with the disability to predominate. If a person wishes to participate in a separate or different program, that is fine. Society still has an obligation, however, to ensure that the most integrated situations are available, should the individual choose that alternative. (p. 297)

Following the enactment of the ADA, disabled people could not legally be primarily regarded as in need of charity, medically deficient, or a prospect for employment reintegration (Davis, 2015). As Davis (2015) summarized:

Instead, disability would be seen now and forever as a civil rights issue in which aid and redress would not be focused on physical therapy or monetary benefits. Rather, it would be about the right of individuals to have access to the world that everyone else is part of. No longer would a significant portion of our fellow beings be

considered different by virtue of being invisible or pitiable. Instead, they would be citizens of this country and entitled to the rights and privileges of all people. (p. XIII)

The ADA transformed disability activism by centering the disabled experience in America, recognizing the profound inequities and difficulties in asserting basic civil rights as a disabled person, and strengthening political activism to demand those rights (Davis, 2015). McKeever (2020) reiterates the Act's importance:

'It is the world's first declaration of equality for people with disabilities,' [Justin] Dart wrote after the ADA was passed. 'It will proclaim to America and to the world that people with disabilities are fully human; that paternalistic, discriminatory, segregationist attitudes are no longer acceptable; and that henceforth people with disabilities must be accorded the same personal respect and the same social and economic opportunities as other people.' (para. 13)

The ADA may not be perfect, but as Dart wrote in 1990, "it is only the beginning. It is not a solution. Rather, it is an essential foundation on which solutions will be constructed" (as cited in McKeever, 2020, para. 17).

Dart was correct that the 1990 ADA was not a final solution, and there have been threats to the ADA over the years, including multiple Supreme Court decisions that weakened the scope of who was protected under the ADA by interpreting the definition of disability as having or being perceived to have one or more conditions that "substantially limits one or more life areas" to mean "significantly restricted" (Davis, 2015, p. 225). According to the U.S. Equal Employment Opportunity Commission (2008), The **ADA Amendments Act of 2008** (Public Law 110-325; 122 Stat. 3559) reversed these Supreme Court decisions and declared in statute the definition of disability to include as large of a scope as possible, as was the Congress's intent of the original 1990 Act (42 U.S.C. ch. 126 § 12101 et seq).

Unfortunately, efforts to diminish the far-reaching impact of the ADA have continued in more recent times. **The ADA Education and Reform Act of 2017** (H.R. 620) and other similar proposed (but not passed) legislation have attempted to weaken the ADA. As the Disability Rights Education and Defense Fund ([DREDF], n.d.) explains:

H.R. 620 requires a person with a disability who encounters an access barrier to send a written notice specifying in detail the circumstances under which access was denied, including the property address, whether a request for assistance was made, and whether the barrier is permanent or temporary. No other civil rights law permits businesses to discriminate without consequence unless and until the victims of discrimination notify the business that it has violated the law. The ADA should not place the heaviest burden for ending discrimination on the very people the law is there to protect! (para. 4)

The counterargument to bills like H.R. 620 is that businesses have had notice of accessibility requirements since 1990 – and that is over three decades to comply, seemingly plenty of time to plan and execute necessary changes. Businesses currently have incentives to be accessible as they risk being sued for ADA violations. However, if the ADA is amended to require disabled people to notify a business first that they are not in compliance/inaccessible prior to filing a lawsuit, and then the clock starts on a waiting period to allow the business to comply, many businesses will take a wait and see approach rather than be accessible in the first place



– all incentives for accessibility would be removed (DREDF, n.d.). H.R. 620 passed the House in the 115th Congress but died in the Senate and similar bills have been proposed since but have not passed.

Most recently, as of the writing of this chapter, the proposed H.R. 77 – **ADA Compliance for Customer Entry to Stores and Services Act (ACCESS Act)** attempts to revive the notification and additional waiting time period (also known as “notice and cure”) for compliance with the ADA that was mandated in the proposed H.R. 620 (Congressional Research Service, 2021). The so-called ACCESS Act H.R. 77 was introduced into the House in January 2021 and was referred to multiple committees for study and consideration. Despite the favorable and positive name, the ACCESS Act continues to burden the disabled person with initiating a complaint and following up with legal action, instead of the business or entity being required to comply with accessibility standards that have existed for 30+ years (Congressional Research Service, 2021).

The ACCESS Act also states, as reported by the Congressional Research Service (2021), “Based on existing funding, the Disability Rights Section of the Department of Justice shall, in consultation with property owners and representatives of the disability rights community, develop a program to educate State and local governments and property owners on effective and efficient strategies for promoting access to public accommodations for persons with a disability”, which sounds logical on the surface, until you consider that this education and standards have been available for decades and businesses are expected to comply with all sorts of regulations in order to operate legally. As DREDF (n.d.) explains, “Establishing and running a business necessitates compliance with many laws and rules—that is the cost of doing business. It is unthinkable that we would delay or eliminate consequences for businesses that failed to pay taxes or meet health and safety codes. Violating the rights of people with disabilities should be treated no differently” (para. 9).

It is also important to be aware of recent threats to protections against discrimination and disparate impact on disabled people of so-called neutral policies. *CVS Pharmacy, Inc. vs. Doe* was a recent case taken all the way to the Supreme Court. As Roppolo (2021, November 11) summarizes, the case “stemmed from a lawsuit filed against CVS by multiple people who take prescription drugs for HIV/AIDS. The plaintiffs objected to changes to the company’s terms that meant they could not opt out of mail-only delivery or utilize another pharmacy with experience handling their special medication needs. They argued it had a discriminatory impact on them, even if that wasn’t the company’s intent” (para. 4). CVS maintained that the policy was ‘neutral’ and not discriminatory in nature, and that Section 504 protections did not cover ‘disparate impact,’ only ‘intentional discrimination.’ As reported by Roppolo (2021, November 5), “a ruling that Section 504 does not reach ‘unintentional’ discrimination or ‘disparate impact’ discrimination would rip out a central tenet of our disability rights law in key sectors of our society that are covered only by Section 504,” Claudia Center, the legal director at DREDF, told CBS News” (para. 9). The potential impact of this case could not be understated, in which disabled people would have to prove that discrimination was the intent (and not simply the effect or actual experienced result) of a policy in order to seek needed change.

Roppolo (2021, November 11) explains the sequence of events that occurred:

When the case was first heard in trial court, the judge ruled the problems the plaintiffs described did not violate

federal disability laws. But when they appealed, the 9th Circuit Court of Appeals sided with the unnamed plaintiffs. CVS then appealed to the Supreme Court, saying in court filings the ruling would ‘upend insurance plans and skyrocket healthcare costs nationwide.’ The justices agreed to take the case and scheduled arguments for December 7, [2021] but both sides have now asked the court to dismiss the case. (para. 9-10)

After pressure from disability advocates and customers, CVS announced they would withdraw their appeal to the Supreme Court, and instead work with the disability community and prominent organizations to create policies that “protect access to affordable health plan programs that apply equally to all members” (Roppolo, 2021, November 11, para. 3). Therefore, in this circumstance review by the Supreme Court as to whether Section 504, ADA, and the Affordable Care Act (as it also borrows Section 504 language) apply to unintentional discrimination or policies that have disparate impact on disabled people was prevented from happening.

A similar legal argument was made by the Los Angeles Community College District (LACCD) when blind students won their case against their school for failure to provide textbooks and other materials that are compatible (accessible) via screen readers (DREDF, 2021). LACCD reported intent to appeal the case to the Supreme Court, arguing that “the ADA and Section 504 do not prohibit any form of disparate impact discrimination and only protect disabled people from discrimination that is intentional [...] Supreme Court [should] make this the rule for the entire country” (DREDF, 2021, para. 12). Instead of complying with the original decision in favor of the students or the appellant court decision that sided with the students, or claiming that they were either already meeting access needs or that to provide the requested access would be an undue financial burden or a fundamental alteration to services provided, LACCD attorneys decided to argue against disabled peoples’ civil rights legislation’s ability to protect against unintentional discrimination.

Most often, discrimination against disabled people does not stem from a conscious objective to cause harm to disabled people. Instead, it comes from the way in which our shared communities are designed and constructed and not being aware or wanting to include disabled people in establishing protocols and processes (DREDF, 2021). As DREDF (2021) explains, “Some examples include: failing to provide accessible spaces with ramps and elevators; using trains or buses in public transit that are not wheelchair accessible; launching websites and mobile apps that are unusable by blind people and people with other disabilities; and policies that seem neutral but that actually function to exclude people with disabilities” (para. 15). Therefore, disabled people need laws such as the ADA and Section 504 to mandate the government and businesses provide accessibility and comply with civil rights, “regardless of what anyone ‘intended’” (DREDF, 2021, para. 15).

After enormous pressure from disability advocates, the LACCD Board of Trustees voted unanimously at their March 2, 2022 meeting to direct their attorneys to refrain from appealing to the Supreme Court and instead utilize mediation to come to a settlement agreement (LACCD, 2022). While this particular threat to the ADA and other disability civil rights statutes has been neutralized, it is important to understand the continued vulnerability for criticism and concerns that sooner or later a case will make it to the Supreme Court and 50+ years of fighting for disability civil rights will be put in jeopardy. As social workers, it is important to consider the toll of having your civil rights consistently up for debate has on disabled people.

## The Future of Disability Policy in the U.S.

The world has changed considerably since the ADA was originally passed and there have been multiple lower court rulings about its applicability regarding digital and electronic access for disabled people. Federal government agencies' electronic and information technology (including all websites) were required to be accessible for disabled people under **Section 508 of the Rehabilitation Act** (29 U.S.C § 794 (d)) which was passed as part of the Workforce Investment Act of 1998 (General Services Administration, 2022). Accessibility standards were developed by the U.S. Access Board and have been amended as recently as 2017 to “harmonize these requirements with other guidelines and standards both in the U.S. and abroad, including standards issued by the European Commission, and with the World Wide Web Consortium (W3C) Web Content Accessibility Guidelines (WCAG 2.0), a globally recognized voluntary consensus standard for web content” (General Services Administration, 2022, para. 3). Unfortunately, compliance with these requirements has been far from consistent. A study conducted in 2021 by the Information Technology and Innovation Foundation (ITIF) found that 30 percent of the most popular federal government websites did not pass an automated accessibility test for their homepage, and 48 percent failed the test on at least one of their three most popular pages (Johnson & Castro, 2021). ITIF recommends that the Biden Administration prioritize website access for disabled people by supporting the creation of a federal accessibility testing lab responsible for ongoing accessibility testing (and resolution of issues) of all federal websites, acting as a central clearinghouse dedicated to quickly eliminating access barriers (Johnson & Castro, 2021). Social workers might have an opportunity for advocacy in voicing support and providing examples of why the U.S. needs centralized, ongoing, and thorough electronic accessibility testing and problem resolution.

Additionally, a grey area has existed for decades as to how and whether the ADA applies to electronic information and digital access for non-federally funded websites. After considerable delay and pressure from disability rights advocates, the U.S. Department of Justice finally released guidelines for how the ADA applies to web access for disabled people in March 2022 (The U.S. Department of Justice Civil Rights Division, 2022). According to the press release by the U.S. Department of Justice Civil Rights Division (2022), the Department is now maintaining the position that full and equal access to all content and functionality of websites for state/local governments and businesses that are open to the public online is subject to Title II and Title III of the ADA, respectively. Suggestions on how to make websites accessible are available on the Department's website and multiple companies exist solely to work with businesses and governments to ensure accessibility. However, the difficulty remains in enforcement – the burden is on the disabled person to sue if access is unavailable, whether that be a federal or non-federal website (Espino, 2016).

As of the writing of this chapter, there is no proposed legislation to either expand who must provide electronic accessibility or increase enforcement mechanisms for violations/failure to provide access that does not burden the disabled individual. As you have now read the majority of this chapter and better understand the financial limitations facing many disabled people, it should be clear how the court system and resorting to litigation is not possible for many disabled individuals. Historically it has mostly been larger organizations with

philanthropic funding that have sued companies for accessibility, such as the National Federation for the Blind and the National Association of the Deaf (Espino, 2016).

Social workers should advocate for electronic accessibility within their agencies and organizational affiliations as well as the variety of websites and other information technologies that they personally utilize, including social media. We can amplify and highlight both the legal and ethical imperative for disabled people's digital access rights by educating others about the new Department of Justice regulations. There are programs that can perform automatic accessibility testing. However, what can be more accurate is to properly compensate disabled people to attempt to navigate the online content and catalog the accessibility concerns – disabled people know best what they need (Goldstein & Care, 2012). As summarized by Espino (2016), it is far less costly and damaging for an organization to include electronic accessibility from the beginning than to try to rearchitect a website after losing in court. While enforcement and compliance with regulations are lacking, advocacy groups are bringing lawsuits in greater numbers each year (Espino, 2016; Johnson & Castro, 2021). This author hypothesizes that with the new Department of Justice regulations being issued, more suits will be filed and won by disability advocacy groups, utilizing the clear mandate for access in their legal arguments.

**The Disability Integration Act of 2019 (DIA)** (H.R. 555 and identical bill S. 117) was introduced in both House and Senate in January 2019 and did not progress beyond being referred to and discussed in separate committees (Congressional Research Service, 2020). Highly regarded disability advocacy organization ADAPT (2020) explained in a press release at the height of the COVID-19 pandemic:

[DIA is] bipartisan and bicameral legislation, introduced [...] to address the fundamental issue that people who need Long Term Services and Supports (LTSS) can be forced into institutions, losing their basic civil and human rights. [...] the legislation is more important than ever as elderly and Disabled people – particularly Black and brown people with disabilities – unnecessarily die from COVID-19 because they have been warehoused in nursing facilities and other institutions. (para. 2)

The National Center for Disability Rights ([NCDR],2020) created a website [disabilityintegrationact.org](https://disabilityintegrationact.org) to answer frequently asked questions about DIA and assist advocates in understanding and championing the Act for proposed protections for disabled people in need of LTSS. According to the NCDR (2020) fact sheet, DIA:

[...] ensures people with disabilities have a right to live and receive services in their own homes [...] assuring that states and other LTSS insurance providers deliver services in a manner that allows disabled individuals to live in the most integrated setting, have maximum control over their services and supports, and lead an independent life, [...] and] requiring public entities to address the need for affordable, accessible, integrated housing that is independent of service delivery. (para. 3)

Community-based services would be required to be offered to disabled people in need of LTSS prior to institutionalization and institutionalized people would need to be notified regularly of community-based alternatives available to them (Congressional Research Service, 2020). Disability advocates maintain that forced institutionalization is discrimination and that DIA is needed to strengthen the integration mandates of the ADA to specifically include disabled people in need of LTSS and their federally protected right to services

in the community, their freedom, and their liberty. In the 116th Congress (2019-2020), DIA garnered 238 cosponsors in the House and 38 cosponsors in the Senate (Congressional Research Service, 2020). It remains to be seen what support for DIA would look like today, particularly in a world now forever changed by the COVID-19 pandemic. Social workers would be well served to remain vigilant for legislation such as DIA which has the potential to greatly impact the disabled community.

## Conclusion

This chapter demonstrates the evolution of disability-relevant policies in the United States. While disability rights advocates have made some great strides for the disability community, there are still many problems with disability policy formation, implementation, and enforcement. When reviewing any policy in light of a client case, it is important to ask who is included/eligible and who is left out. The hope with this chapter is to introduce you to important disability policies that have shaped how disabled people have been seen in our country over time. The order of the policies as presented is not always linear and progressive but can be used as a loose framework in thinking about the objectives of legislation and statutes that affect disabled people by category. Please refer to the reference list for more information and resources to continue your study of disability policy: past, present, and future. What federal policies are still needed to protect and empower disabled people? What architectural and attitudinal barriers still exist in the everyday lives of disabled Americans? How effective are these disability policies in your clients' lives? How well are these disability policies implemented? How can you contribute to a better policy environment for the disability community?

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## 4.

# HEALTH AND PERSONAL CARE SERVICES FOR THE DISABILITY COMMUNITY

Esther Son

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## Learning Objectives:

- To understand how lack of quality insurance coverage; accessible equipment in medical settings; and challenges in obtaining sexual health education, fertility consultations, and parenting guidance can lead to barriers in access to health care services.
- To learn about disability-related debates in the health care system.
- To identify policy and practice implications for working with people with disabilities with various social identities in the health care system.

This chapter will discuss the ways in which people with disabilities in the United States face barriers in access to care as a result of the quality of their insurance coverage, whether public or private. It will also discuss the need for accessible equipment in a range of medical settings and how this lack of equipment is a barrier to prevention services. A discussion of the challenges in obtaining sexual health education, fertility consultations, and parenting guidance will also be discussed with attention to the biases that some in the medical community have about people with disabilities. This will be followed by a presentation of views from the disability community on the negative effects of prenatal genetic testing and gene editing approaches (such as CRISPR) on future generations of people with disabilities and the ways in which narratives about these services reverberate back to the days of eugenics. The chapter will conclude with a discussion of how personal care services are a key aspect of community inclusion for the disability community. It will review key health-related laws, policies, and programs relevant to people with disabilities in the United States, such as the Medicaid and Medicare programs. This chapter will also conclude with a case study with discussion questions.

# Introduction

People with disabilities have been an unrecognized “health disparity population” due to the health conditions directly linked to their disabilities. While some health conditions associated with disability result in poor health and extensive healthcare needs, others do not (Krahn et al., 2015). National Institutes of Health (NIH) defines “health disparity populations” as “racial and ethnic minority populations, less privileged socioeconomic status (SES) populations, underserved rural populations, sexual and gender minorities (SGM), and any subpopulations that can be characterized by two or more of these descriptions” (National Institute on Minority Health and Health Disparities (NIMHD), n.d). People with disabilities are disproportionately poor, rural, and members of racial and ethnic minority groups, and thus face amplified disparities on multiple fronts and have the exact general healthcare needs, such as preventive and specialty care services, as people without disabilities (Pollack et al., 2021). However, they have less access to healthcare services due to barriers in accessing healthcare and therefore experience unmet healthcare needs. Article 25 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) also warrants the right of persons with disabilities to attain the highest standard of healthcare, without discrimination (United Nations, 2007). However, there are still crucial issues and debates regarding the U.S. ratification of the CRPD. For example, some opponents worry that the term “sexual and reproductive health” in CRPD could be a euphemism for abortion. Supporters note that the word “abortion” is never mentioned in the Convention and claim that no U.S. laws related to abortion would be created due to U.S. ratification (Blanchfield & Brown, 2015).

Over one billion people are estimated to live with some form of disability, corresponding to about 15% of the world’s population (WHO, 2020). In particular, people with significant disabilities, often requiring intensive healthcare services, account for more than 12% of the US population (Krahn et al., 2015). As a group, people with disabilities are more likely to report their physical health and mental health to be fair or poor and to have higher rates of smoking, physical inactivity, obesity, and alcohol use. They experience more barriers to accessing healthcare services than people without disabilities (Singh & Lin, 2013). Furthermore, they are more likely to experience chronic diseases and conditions at earlier ages than their counterparts, and, as a consequence, this group needs to be included in health promotion campaigns (Krahn et al., 2015).

The recent report “Healthy People 2020: An End of Decade Snapshot,” provides a summary of progress made over a decade in meeting the Healthy People 2020 objective targets, showing that rates improved and either met or exceeded the targets (Office of the Assistant Secretary for Health, 2020). The data show a success rate of 47.2% (n = 76 of 161) of trackable objectives with data for persons without disabilities or activity limitations, and a success rate of 32.5% (n = 50 of 154) of trackable objectives with data for persons with disabilities or activity limitations (Office of the Assistant Secretary for Health, 2020). In addition, baseline data of the national health initiative Healthy People 2030 revealed that 37.2 % of adults with disabilities, age 18 years and older, experienced delays in receiving primary and periodic preventive care due to cost issues in 2018 (U.S. Department of Health and Human Services, 2021). These delays can lead to many health problems, including preventable diseases. Specifically, during the COVID-19 pandemic, this vulnerable

population has been excluded consistently in response measures to control the pandemic. As such, this has resulted in people with disabilities being at increased risk with devastating consequences, including the risk of contracting COVID-19, developing severe symptoms from the disease, or dying from it. It also led them to have poor health during and after the pandemic, whether or not they were infected with COVID-19 (WHO, 2020).

Social determinants of health are the conditions in which people are born, grow, live, work, and age, and shape an individual's health (Healthy People, 2020). They include factors like socioeconomic status, education, neighborhood and physical environment, employment, and social support networks, as well as access to healthcare, including health coverage, provider availability, provider linguistic and cultural competency, and quality of care (Artiga & Hinton, 2018). Addressing social determinants of health is fundamental for improving health outcomes and reducing disparities in health and healthcare. To address social determinants of health, there are an increasing number of initiatives within and outside of the healthcare system. For example, there are recent initiatives that address non-medical, social determinants of health within the context of the healthcare delivery system, such as housing and employment support to Medicaid enrollees, including people with disabilities through a range of optional state plans and waiver authorities (Artiga & Hinton, 2018).

## Racial and Ethnic Disparities in Healthcare Access, Use, and Quality of Care for Children with Disabilities

Health disparities refer to “differences in health outcomes at the population level” and “that these differences are linked to a history of social, economic, or environmental disadvantages. Also, these differences are regarded as avoidable and unjust”, which is defined as health inequities by the World Health Organization (WHO) (Krahn et al., 2015, p. 198). There are significant racial and ethnic disparities in healthcare access, use, and quality for children with special healthcare needs (CSHCN), who have high rates of comorbid health conditions and who subsequently require more frequent and more intensive health services than their typically developing peers (Magaña et al., 2012; Parish et al., 2013c; Son et al., 2017). For example, there are racial and ethnic disparities in age at diagnosis of developmental disabilities, including autism, for Black and Latino children, who receive a diagnosis later than their White counterparts (Dababnah et al., 2018; Mandell et al., 2009). These children are also more likely than White CSHCNs to have unmet healthcare needs, including specialty, dental, and mental healthcare (Ngui & Flores, 2007), in addition to encountering delays in accessing needed healthcare (Rosen-Reynoso et al., 2016). Furthermore, low-income parents of CSHCNs, and those who live in states with higher levels of economic inequality, face higher financial costs (Parish et al., 2012).

“Quality of healthcare” focusing on family-centered care can be measured by six outcomes on family perceptions of and satisfaction with their interaction with the provider, including having a personal doctor who listens, spends sufficient time, provides information, treats families as partners, and respects family cultural norms and values (Montes & Halterman, 2011). Studies show significant racial and ethnic disparities

in 5 of 6 quality of healthcare outcomes between Black and White children and Latino and non-Latino White children with autism and other developmental disabilities (Magaña et al., 2012; Parish et al., 2013c). Racial disparities in quality of healthcare were also substantial between Asian and White CSHCNs. Asian parents were significantly less likely than White parents to report that their healthcare provider provided the specific information they needed, helped them feel like a partner in their child's care, and was sensitive to the family's values and customs (Son et al., 2017). In particular, these disparities in quality of healthcare are closely related to cultural and language barriers faced by children with disabilities, whose parents migrated to the United States and have limited proficiency in English (Eneriz-Wiemer et al., 2014; Son et al., 2018).

## Women with Disabilities as a Health Disparity Population

Women with disabilities experience significant disparities in their healthcare utilization, health behaviors, and health status (Mitra et al., 2015a). They are less likely to receive routine preventive healthcare, such as cervical cancer screening, mammography, and dental care, compared to women without disabilities (Brown et al., 2016; Havercamp et al., 2015; Parish et al., 2013a, 2013b; Swaine et al., 2014; Wisdom et al., 2010). There are also disparities in access to reproductive health services, including family planning and contraception, screening for sexually transmitted infections, maternal health services, and fertility services for women with disabilities, including intellectual and developmental disabilities, mental illness, and physical disabilities (Silvers et al., 2016). While women with and without disabilities are equally likely to desire pregnancy, studies show that pregnant women with physical disabilities are less likely to receive adequate prenatal care, experience barriers to accessing healthcare compared to women without disabilities, and face criticism and judgment from those who disapprove of their pregnancy, including their families and healthcare providers (Iezzoni et al., 2015; Lagu et al., 2017; Mitra et al., 2017). Furthermore, pregnant women with disabilities are at elevated risk for stillbirth, preterm birth, low birth weight babies, fetal growth restriction, and cesarean delivery, although risks vary by type of disability (Mitra et al., 2015a; Parish et al., 2015).

It is estimated that 17.8% of women in their childbearing years, ages 15-44, reported that they have a disability (Mosher et al., 2017). A study on pregnancy among women with physical disabilities using a nationally representative dataset suggests that, after adjusting for age, women with chronic physical disabilities (CPD) are as equally likely as their nondisabled peers to be currently pregnant (Iezzoni et al., 2014). Iezzoni and colleagues reported in 2014 that women currently pregnant are in fair or poor general health roughly nine times more often than non-disabled pregnant women. In addition, almost half of the pregnant women with CPD reported two or more health conditions (Iezzoni et al., 2014). Another study, using a U.S.-population-based sample of women with intellectual and developmental disabilities, reported that the rates of adverse pregnancy outcomes were elevated for women with disabilities, including early labor, preterm birth, and

preeclampsia, and that their infants were more likely to have low birth weight compared to women without disabilities, even after adjusting for age, race, ethnicity, and insurance type (Parish et al., 2015).

Previous intersectional analyses have been done about women's health in the disability community, specifically looking at the social identities of race and ethnicity (Ben-Moshe & Magaña, 2014). For example, Bost (2010) challenges the binary of color in racial analyses of disability by reanalyzing Chicana writers' literary accounts of chronic illness, pain, and disability. Those writers wrote about disability experiences as part of their daily lives. Ben-Moshe and Magaña (2014) discussed the irony that those women might not identify themselves as disability studies scholars. Instead, they describe their experiences as an example of how disability identity is experienced differently by persons with disabilities who are not white and middle class. In addition, gender identity among people with disabilities has not been explored significantly beyond binary categories of gender (i.e., Transgender, Non-Binary, and Gender Non-Conforming Identities) despite multiple compounding and marginalizing forces, including discrimination in healthcare and resulting health disparities faced by non-binary individuals with disabilities. There is a lack of focus in the current literature on gender identity among people with disabilities and unmet healthcare needs (Mulcahy et al., 2022).

## Relevant Policies

Medicare and Medicaid were passed to serve as safety nets for the most vulnerable populations in the United States during the last 55 years. Both programs cover about 111 million people, or 1 in 3 Americans, including 10 million dual-eligible people. That number is projected to reach 139 million people by 2025 (Altman & Frist, 2015). Medicare was established in 1965 as a national social insurance program administered by the federal government to insure Americans reaching retirement age. People pay into the program over the course of their lives and, once eligible, are entitled to coverage without regard to income or health status. Since 1973, it has also covered people under age 65 who receive Social Security Disability Insurance (SSDI) benefits. Medicare requires that nonelderly individuals with disabilities receive SSDI benefits for at least 24 months. They must be unable to engage in gainful activity for at least 12 months to qualify for SSDI. People are required to wait five months before receiving disability benefits, so SSDI recipients must wait a total of 29 months before their Medicare coverage begins. People under age 65 who are diagnosed with end-stage renal disease (ESRD) or amyotrophic lateral sclerosis (ALS) automatically qualify for Medicare upon diagnosis without a waiting period (Cubanski et al., 2016; Ulrich, 2014). Thus, the Medicare population includes 46 million older adults and 9 million younger adults with permanent disabilities. Forty-five percent of Medicare beneficiaries have 4 or more chronic conditions, 34% have a functional impairment, 31% have a cognitive or mental impairment, and 26% assess their health as fair or poor (Altman & Frist, 2015).

Medicare provides coverage for inpatient hospital stays; physician, outpatient, and preventive services; post-acute care; and outpatient prescription drugs. However, traditional Medicare has high cost sharing and has no limit on out-of-pocket spending. Medicare also does not cover dental care, hearing aids, or long-term

services and supports, which are critical resources for most of the Medicare population, including seniors and individuals with disabilities. These gaps are filled with supplemental insurance, either purchased or obtained through an employer, Medicaid, or a Medicare Advantage plan (Altman & Frist, 2015). However, even with supplemental insurance, Medicare beneficiaries spend nearly three times more than beneficiaries without Medicare coverage on out-of-pocket health expenses, adding more financial burden for individuals with disabilities and their families (Cubanski et al., 2014).

In contrast, Medicaid is a joint state and federal program. As such, states must contribute some proportion of the cost of Medicaid, ranging from 26% to 50%. This program provides needs-based insurance and serves nearly 70 million people per year or 1 in 5 Americans. Of the almost 70 million people covered by Medicaid, 33 million are children. Medicaid primarily provides coverage to low-income children and adults, but also provides services to people with disabilities and elderly individuals. It is the primary source of public funding for long-term care that is not covered by Medicare for individuals with disabilities and the elderly. As a result, Medicaid covers 1 in 5 Medicare beneficiaries and almost two-thirds of all nursing home residents (Altman & Frist, 2015).

Before the Omnibus Budget Reconciliation Act (OBRA) in 1981, children and adults with long-term healthcare needs were placed primarily in institutional or other restrictive and segregated settings. The OBRA, through Section 1915 of the Social Security Act, made the necessary changes to authorize state administrators to operate Home- and Community-Based Services (HCBS) waivers. The 1915(c) waivers allow states to waive specific Medicaid requirements and make it possible for people with disabilities at risk of being placed in institutions to receive services in their own homes or communities. After the Supreme Court *Olmstead* ruling mandating that individuals with disabilities be offered services in integrated settings (*Olmstead v. L.C. and E.W.*, 1999), waivers became even more appealing to states (Velott et al., 2015).

Yet, even after 55 years of enacting Medicare and Medicaid in 1965, individuals with disabilities continue to be a health disparity population in the United States. This population still experiences health disparities due to cultural incompetence, stigma and misunderstanding, and an inability to create policy changes that cover the population in a comprehensive way and meet their acute and long-term needs (Ulrich, 2014).

The Patient Protection and Affordable Care Act of 2010 (ACA; PubL No. 111-148) contains provisions aimed at tackling some of these barriers to care. Progress has been made in increasing healthcare access via the ACA. The main goal of the ACA is to significantly reduce the number of uninsured by providing a continuum of affordable coverage options through Medicaid and the Health Insurance Marketplaces. The ACA provided improved access to care and a key opportunity to reduce persistent health disparities faced by historically underserved populations.

While coverage gains were generally positive, challenges arose in plan selection and accessing care following enrollment. In other words, there were pre-enrollment challenges such as accessing enrollment resources (e.g., website, helpline) and obtaining detailed plan information, and post-enrollment barriers to needed care due to inadequate provider networks, high co-pays, or visit/service limitations (Lindner et al., 2018). In addition, coverage of the needs of individuals with disabilities has not been rectified (Ulrich, 2014). A combination



of states' rights to implement eligibility criteria, Medicaid being a target for budget cuts, and individuals with disabilities requiring frequent services and involving more costs than any other group has left many disabled persons without much-needed coverage. The ACA originally expanded Medicaid to anyone at 133 percent of the federal poverty line (FPL), but the Supreme Court made this optional following the June 2012 Supreme Court decision. According to the Centers for Medicare & Medicaid Services (CMS) guidance, there is no deadline for states to implement the Medicaid expansion. As of August 2021, 12 states are still not moving forward on the expansion (Kaiser Family Foundation, 2021); therefore, there is an urgent need for advocacy and persuasion to try to limit the force of partisan politics (Ulrich, 2014). Furthermore, coverage alone is not sufficient to improve health outcomes and achieve health equity among this population, who have strong negative social determinants of health, including poverty, poor access to education, unemployment, job insecurity, unhealthy housing, and exposure to general disadvantage. With growing recognition of the importance of social factors in health outcomes, a growing number of initiatives have emerged to address negative social determinants of health. These initiatives have focused attention on improving health outcomes within non-health sectors, as well as recognizing and addressing health-related social needs through the healthcare system (Artiga & Hinton, 2018).

Recently, President Biden's American Jobs Plan includes a historic investment in Medicaid home and community-based services (HCBS). On June 24, 2021, the Better Care Better Jobs Act, S. 2210, was introduced in the United States Senate and referred to the U.S. Senate Committee on Finance. The bill would expand access to home- and community-based services (HCBS) under Medicaid, and for other purposes by providing \$100 million for states to expand access to Medicaid HCBS and strengthen the HCBS workforce, and provide states a 10% increase in the Medicaid Federal Medical Assistance Percentage (FMAP) for HCBS (Clearinghouse, 2021). These critical services would enable the elderly and people with disabilities to remain in their homes, stay active in their communities, and lead independent lives. According to the Better Care Better Jobs Act, S. 2210 (2021), the President's proposal intends to expand access to good-quality care, lead to better pay and benefits for healthcare workers, enhance the quality of life for families, and help create middle-class jobs. This investment in Medicaid HCBS would create enhanced funding to strengthen long-term care today and in the future, building on the \$12.7 billion short-term HCBS funding that passed as part of the American Rescue Plan.

The next step in further improving the quality of care, focusing on patients, is to address the significant challenges faced by individuals with disabilities. For example, disability-specific challenges in accessing healthcare still exist, including lack of quality of insurance coverage and accessible equipment in medical settings, and challenges in obtaining such services as sexual health education, fertility consultations, or parenting guidance.

# Disability-Related Debates in the Healthcare System

## The Lack of Quality of Insurance Coverage as a Barrier to Access to Care

Individuals with disabilities are struggling to have quality access to healthcare. Health insurance coverage is a major determinant of access to healthcare. Being able to afford quality healthcare is a major concern in the disabled community. According to previous studies, there is a high poverty rate among individuals with disabilities, and with the high cost of medication and other services, they are unable to afford this extra expense (Aldersey et al., 2018). In addition, many of this population need far more health services than those without disabilities (Kaye, 2019; Kennedy et al., 2017; National Council on Disability, 2016). Individuals with disabilities are slightly more likely to have health insurance than those without disabilities; however, they are more likely to use public insurance (e.g., Medicaid) and often report problems finding a doctor or other healthcare provider willing to accept Medicaid even when insured than those without disabilities who have private insurance. Furthermore, one in five (i.e., 21%) of those who have ever been on Medicaid say that they have had problems when trying to enroll in the program, although their experiences with the Medicaid program were generally positive (Aldersey et al., 2018; Kaiser Family Foundation, 2011; Kennedy et al., 2017).

There are barriers to accessing quality care depending on the type of insurance coverage one has. There is still no coherent and coordinated health system in the U.S. – it has multiple systems with no coherence due to our society's piecemeal approach to the insurance systems and social welfare. In addition, health insurers control their costs by charging customers out-of-pocket fees, and by limiting the number of service providers covered by the plan. To understand some of the barriers a person with a disability faces, it is important to understand the complexity of the insurance systems, both private and public, and the qualifications of its applications. To be eligible for Medicare/Medicaid insurance coverage, one could be qualified in a variety of ways. Some eligibility is through work history, disability type (temporary or permanent), and/or age. For example, if a person is under the age of 18 and does not qualify for Medicare, there is a program for low-income families where one could obtain the state's Children's Health Insurance (S-CHIP). A person over the age of 65 is automatically eligible for Medicare and could qualify for both Medicare and Medicaid if their income is low. A working adult with disabilities can apply for Social Security Disability Insurance (SSDI) or the Supplemental Security Income (SSI) program to become eligible for Medicare or Medicaid (Kaye, 2019).

A working adult with a disability usually finds it difficult to afford private insurance coverage due to its high cost, as most are not eligible for employer-based group coverage and, in most cases, their condition would be pre-existing, which would exclude them from individual insurance (Kennedy et al., 2017). This was the case pre-ACA but has been changed since the Act was passed in 2010. The enactment of the ACA was to improve access to healthcare through both expanded public health coverage and improved availability and affordability of private insurance (Kaye, 2019). Major provisions of the ACA aimed to reduce high uninsurance rates among

specific populations, including the youngest adults, lower-income families, and people whose preexisting health conditions had made it difficult to obtain affordable, comprehensive private insurance coverage through prohibitions against denying coverage, charging higher premiums, or limiting coverage for people with such conditions (Kaye, 2019).

The application for these insurances is long and tedious, as, in many cases, it could take even years to process. To be eligible as a person with a disability, one must provide medical evidence of impairments listed and accepted by social security. Acquiring these documents requires the person's current medical history for which there are time limits and requirements. Much of the information is over 80 pages long and is complicated even for the average person. For families and caregivers, the process is intimidating, especially for racial/ethnic and immigrant populations, especially those whose English is a second language. For a person with a disability getting medical attention is vital. Kaye and colleagues (2019) have mentioned that an uninsured person is more likely to delay or not seek medical care and thus has a higher risk of being diagnosed with advanced diseases or a higher rate of mortality than a person with insurance.

According to Kennedy and colleagues (2017), working-age adults with disabilities are now more likely to have insurance coverage and less likely to encounter access problems than before the full implementation of the ACA in 2014. However, compared to those without disabilities, this population continues to struggle with high healthcare costs that make it difficult to obtain the services they require. It is also clear that, despite important reforms in the private insurance market, most working-age adults with disabilities continue to rely on public insurance, particularly Medicaid and Medicare. Another study focusing on the impact of the ACA on working-age adults with disabilities, with a particular focus on those not previously eligible for public coverage who would benefit most from having affordable availability of both private and public coverage, found that following the implementation of the ACA, disparities based on disability status persisted, although the ACA improved overall access and reduced some disparities. However, substantial disparities persist. Disability status remains associated with a much greater risk of delayed or forgone care and mental health disability is associated with a greater likelihood of uninsurance (Kaye, 2019).

## The Lack of Accessible Equipment in Medical Settings as a Barrier to Prevention Services

There are significant barriers for women with disabilities (Mitra et al., 2015a). Prenatal care is a case in point. Lack of accessible medical offices, height-adjusting examination tables, lift devices, and scales put women at risk of inadequate monitoring during pregnancy (Iezzoni et al., 2015; Mitra et al., 2017). This results in a lack of necessary examinations, a lack of routine prenatal care, increased safety issues, and possible secondary health issues for the mother and/or baby. Many OB/GYN providers do not have adequate medical devices, such as height-adjusting tables, lift devices, or appropriate scales to properly care for individuals with physical disabilities, despite regulations that mandate them. Research shows that 44% of providers refused medical care to patients who could not self-transfer onto fixed-height examination tables due to the facility's inability

to accommodate them (Lagu et al., 2015). Additionally, a study conducted by Mitra et al. (2017) reported that 60% of women who participated in their study had some level of difficulty trying to transfer onto the examination table unassisted. In a qualitative study performed by Iezzoni et al. (2015), some women with mobility disabilities reported never being weighed at any appointments, and one woman was asked to go to the Post Office to be weighed using a cargo scale. Other studies indicate that providers who did not have height-adjusting examination tables either bypassed a routine examination or inappropriately performed the examination while the person was in their wheelchair (Iezzoni et al., 2015). The participants' narratives in previous studies reveal that the perinatal care system is not set up with women with physical disabilities in mind. In other words, it reflects that the pregnant body is assumed to be a non-disabled body, and the practices and physical space of perinatal care settings are set up according to this assumption (Tarasoff, 2017). These negative and traumatic experiences can adversely affect the women's psychosocial outcomes.

The lack of examination tables that can adjust to height or proper lift devices has become a major physical safety concern for many people. In a study performed by Lagu, et al. (2015), one woman reported being dropped three times during an attempt by office staff to transfer her to a fixed-height examination table. This could have caused significant physical trauma to both mother and baby. Many providers that do accept patients with mobility disabilities do not have height-adjusting examination tables or lift devices. They also expect the patient to either be able to self-transfer or to have someone come with them to assist in transferring them. This is not always a viable or safe option. The patient is also unable to rely on office staff for assistance, as many of them are not trained in physically transferring patients.

The consequences of inadequate healthcare go beyond prenatal care for women with physical disabilities. Secondary issues can be medical, physical, mental, or emotional (Wisdom et al., 2010). Excessive weight gain, particularly in the third trimester can lead to preeclampsia (Lagu et al., 2015). Women with physical disabilities often have the monitoring of their weight overlooked due to the lack of accessible scales. Some women have reported their providers overlooking their weight progress for the duration of their pregnancy (Iezzoni et al., 2015). The exposure to substandard treatment can often result in women with physical disabilities feeling humiliated or emotionally distressed (Lagu et al., 2015). Stress can impact the baby and could impact the mental health of the mother. Additionally, some women have isolated themselves after perceiving negative judgment from physicians (Lagu et al., 2015). This could lead to women withholding reports of health changes or concerns that need attention. Women with physical disabilities may require additional guidance and support from their healthcare providers, particularly when they see specialists like gynecologists or obstetricians. Women with disabilities are at a greater risk of experiencing symptoms of postpartum depression (PPD) than other women (Mitra et al., 2015b). As such, screening for PPD among new mothers with disabilities as well as timely referral of those with a PPD diagnosis is critical to the health of mothers with disabilities and their children (Byrnes & Hickey, 2016; Mitra et al., 2015b).

Beyond prenatal and postnatal care, women require routine reproductive care such as pelvic exams including a Papanicolaou (Pap) smear and mammography examinations. The pelvic examination has proven essential in determining a woman's cervical, ovarian, and uterine health. The Pap smear is vital in detecting

abnormalities including cervical cancer (Kavoussi et al., 2008). The pelvic examination and Pap smear are typically done in a gynecologist's office and require the use of an examination table with stirrups. The mammography examination detects abnormalities or cancer within the breasts and is usually performed at diagnostic imaging centers. It is crucial that all women receive this care. However, studies have found that women with disabilities have a lower likelihood of having preventive screening performed (Wisdom et al., 2010). They are at greater risk for experiencing health disparities, including decreased access to quality care and lower rates of screening for both cervical and breast cancer. For example, women with developmental disabilities also have a lower likelihood of having a recent mammogram and are less likely to have received a recent Pap test, compared to women without disabilities (Havercamp et al., 2004; Parish et al., 2013a, 2013b; Swaine et al., 2014). Also, there is a racial disparity in the receipt of mammography among women with intellectual disabilities. A study using medical record data found that African American women with intellectual disabilities receive mammographies at significantly lower rates than White women with intellectual disabilities, despite the high rates of mortality from breast cancer among African American women (Parish et al., 2013a).

Not adhering to or enforcing regulations and guidelines to mandate accessibility to medical devices often has made women feel disrespected by medical providers and the healthcare system (Lagu et al., 2015). Significantly, 40.3% of women have reported that they believe their provider knew little to nothing about their disability or how their disability could impact their pregnancy (Mitra et al., 2017). Women should be able to have a certain level of comfort with their physicians, particularly those with intimate contacts such as gynecologists and obstetricians. Clients' positive perception of their providers is vital to ensure a collaborative relationship between the patient and doctor. Many women have perceived their physicians as having negative outlooks on women with disabilities bearing children. They were often made to feel that they would be inadequate parents (Mitra et al., 2017). Other women believed that the providers they visited failed to recognize their strengths or their desire for optimal independence (Iezzoni et al., 2015). Both approaches can lead to the patient feeling stripped of their dignity.

All the findings mentioned above can be particularly concerning for those who are considering becoming or are currently pregnant, despite regulations and policies to provide assistance and protection. The Americans with Disabilities Act of 1990 (ADA) provides guidelines for accessibility for individuals with disabilities. Most of these guidelines refer to accessibility by means of elevators, ramps, the width of doorways, adequate bathrooms, etc. (Americans with Disabilities Act, 1990). However, the accessibility of healthcare equipment in provider facilities is not identified in the original publication of the ADA to which most people commonly refer. There was an update in 2010 to the ADA regarding accessible examination facilities, rooms, and devices for individuals with mobility disabilities (Americans with Disabilities Act Accessibility Guidelines, 2010). However, providers do not always comply with these guidelines due to not receiving training on how to best provide hands-on care for those mothers and lack of education about the best strategies for serving patients with disabilities including facilitating physical access (Lagu et al., 2015; Mitra et al., 2016). For example, Section 4302 of the Affordable Care Act requires provider organizations to report on their efforts to

train providers about working with people with disabilities, and Section 5307 requires that providers receive disability cultural competence training. Still, those provisions have not been enforced, and there are no specific training requirements regarding perinatal care for women with disabilities for obstetricians or any nursing specialties (Mitra et al., 2016).

## The Challenges in Obtaining Sexual Health Education, Fertility Consultations, or Parenting Guidance

Women with disabilities struggle with social and environmental barriers related to maintaining health and well-being when compared with women without disabilities. The sexual and reproductive rights of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) have become part of the fundamental human rights in the world (UN, 2007). However, women with disabilities are more prone to experience sexual abuse and victimization as they are considered to be weak and hence easy targets (Rugoho & Maphosa, 2017). The sexual rights of women with disabilities are further compromised by factors such as the negative attitudes of families and society and cruel religious and cultural practices (Rugoho & Maphosa, 2015). There has been historical stigmatization faced by women with disabilities. As shown in the U.S. legal history, women with disabilities have been subject to forced sterilization despite the fact that many disabilities are not heritable. During the eugenics movement in the early 20th Century, many states in the United States passed laws prohibiting women with intellectual and developmental disabilities (IDD) from marrying and procreating (Cepko, 1993). The US Supreme Court's 1927 decision in *Buck v. Bell* endorsed involuntary sterilization on the grounds that it was necessary "to prevent our being swamped with incompetence. It is better for all the world if...society can prevent those who are manifestly unfit from continuing their kind" (*Buck v. Bell*, 1927). Involuntary sterilization, as well as institutionalization, prevented many women with IDD from becoming pregnant during the first half of the 20th Century, resulting in the forced sterilization of at least 60,000 women with IDD (Cepko, 1993) and the denial of their reproductive rights (Parish et al., 2015). The effects of negative attitudes also cascade to a healthcare provider (Silvers et al., 2016; Treacy et al., 2018). Thus, women with disabilities are more likely to have unmet sexual and reproductive health needs than their counterparts.

Of note, those with developmental disabilities or disabilities acquired early in life have been excluded from discussions about sex and reproduction during their school years (Smeltzer et al., 2007). Knowledge regarding sexuality creates a greater ability to protect oneself from harm, including sexual abuse and exploitation, unwanted pregnancies, and sexually transmitted diseases. This knowledge can foster the ability to be cognizant of the sexual boundaries and expectations prevalent within society. However, people with disabilities are often considered asexual by healthcare providers, who, because of this fail to discuss with them issues around safe sex, contraception, pregnancy, and gynecologic care (Smeltzer et al., 2007; Swaine et al., 2014). This can result in a lack of information about reproductive function and pregnancy.

Previous studies indicate that there are barriers to obtaining sexual health education for individuals with



disabilities (Barnard-Brak et al., 2014; Eisenberg et al., 2013; Treacy et al., 2018; Wilkenfeld & Ballan, 2011). Treacy and colleagues (2018) emphasized that these barriers are closely intertwined with sociocultural taboos regarding sexuality. Further, they argued that taboos may suggest that disability and sexuality are deviant and, therefore, inevitably create an additional layer of complexity to each of the barriers such as “lack of teacher training”; “lack of teacher knowledge and confidence resulting in concern, anxiety, and fear”; “parental anxiety and fear”, “ the need for school/teacher and parent partnerships”; “lack of valid and reliable sexual health education”; and “lack of federal funding specifically designed for students with disabilities based on comprehensive sexual health education” (p. 72).

There are disparities in access to reproductive health services, including family planning, contraception, screening for sexually transmitted infections, maternal health services, and fertility services among women with disabilities (Silvers et al., 2016; Mosher et al., 2017). Also, these disparities have intertwined with the socio-economic status of this population. For instance, the most considerable differences in receipt of family planning services by disability status were seen among women with low education, low income, and those who were not working (Mosher et al., 2017). Barriers to obtaining reproductive health services can include the negative attitudes of healthcare providers as well as a lack of physical access (Smeltzer et al., 2007). Healthcare providers could hold false assumptions about the decision-making abilities and the sexual and reproductive interests of individuals with disabilities. For example, clinicians may dismiss the possibility of obtaining informed consent when patients have intellectual or developmental disabilities, or they may be inexperienced in helping patients with disabilities understand complicated medical issues or unwilling to take the time to explain when patients have difficulties in communication. In addition, clinicians could assume that women with disabilities have no sexual or reproductive interests or that they are sexually inactive, celibate, or asexual (Silvers et al., 2016; Swaine et al., 2014). Incorrect assumptions like these may lead to lesser access to medically indicated reproductive care for women with disabilities than other people of similar age and sex. Also, women with physical disabilities have encountered inaccessible clinic rooms and examination tables as well as inaccessible clinic forms and information, all preventing women with sensory disabilities or intellectual and developmental disabilities from obtaining high-quality contraceptive care (Horner-Johnson et al., 2021).

Women with disabilities can face challenges in accessing fertility consultations or parenting guidance due to biases on the part of some in the medical community. For example, clinicians may assume exaggerated or misdirected concerns regarding the risk of pregnancy, a low probability of treatment success regarding fertility services, and incorrect beliefs about parenting ability (Silvers et al., 2016). Specifically, there are judgments about fitness to parent that motivate some medical providers’ reluctance to provide fertility services. As such, these mistaken assumptions and judgments about parenting ability may discourage referrals for fertility therapy. Previous studies reported that women with disabilities who have experienced pregnancy frequently are faced with complaints about their selfishness, based on the assumption that their relatives will have to raise their children or that their children will become burdens to taxpayers (National Council on Disability, 2012). In addition, women with disabilities may also be discouraged from pregnancy out of an improper fear that



their children will in turn have disabilities (Silvers et al., 2016). This reasoning represents both misleading and profoundly biased perspectives that some in the medical community have about women with disabilities.

## The Negative Effects of Prenatal Genetic Testing and Gene Editing Approaches on Future Generations of Disabled People

With the emergence and refinement of reproductive genetic technologies (RGTs), especially gene-editing technologies like CRISPR/Cas9, potential parents could prevent their future children from being born with a disability (Benston, 2016). RGTs have been categorized as either technologies allowing genetic additions, deletions, or modifications that alter an embryo's DNA, or as processes such as selective abortion to eliminate fetuses with unwanted traits or pre-implantation genetic diagnosis (PGD) allowing parents to have children free from genetic abnormalities without directly manipulating DNA (Benston, 2016). Inevitably, such technologies provide potential parents unprecedented control over the characteristics of their future children. In other words, this technology would allow parents to edit out disabilities from their embryos in order to give birth to a “normal” child. For example, this technology could be applied not only to eradicate a genetic disease such as cystic fibrosis but also across the germline to alter heritable traits. The latter application could be used to create so-called “designer babies” with preferred physical and potentially even intellectual and emotional traits. For this reason, many within the disabled community, including disability studies scholars and activists, have pushed back against the use of gene editing (Beitiks, 2013; Benston, 2016). These technologies can lead to a modern-day Eugenics movement, a movement that once allowed society to prevent those who are considered manifestly “unfit” from continuing their kind and preventing children with disabilities from being born (Buck v. Bell, 1927). According to Emily Beitiks (2013), the development of such technologies reflects our society's negative perceptions and attitudes toward people with disabilities and their community, such as “people with disabilities are living a sad, tragic existence, and only through progress in the genetic sciences can we spare their suffering in future people.” In addition, the disability community argues that while our society continues to invest millions of dollars in anything that might help us eliminate disability, people with disabilities are still struggling to make our society more accessible because these social changes are always considered as “too costly.” However, changes to the built environment, as well as cultural changes of discriminatory attitudes would lead to more widely shared impacts. Furthermore, leading scientists also have warned about the risks of using CRISPR/Cas9 gene editing on embryos because the editing has caused unintended changes, such as the loss of entire chromosomes or big chunks of them in more than half of the cases of their experiment (Zuccaro et al., 2020).

## Personal Care Services (PCS) as a Key Aspect of

## Community Inclusion in the Disability Community

Individuals with disabilities need services in place that are necessary for their daily living. One of these essential services is personal care services (PCS) which provide individual assistance to people with disabilities and older adults to facilitate their living independently in the community due to the deinstitutionalization of people with IDD and community living of people with disabilities (Bogenschutz et al., 2014). Direct support professionals (DSPs), often called direct care workers or personal care aides (Hewitt & Lakin, 2001; Hewitt & Larson, 2007), provide PCS. DSPs are critical for the community integration of people with disabilities. They are key to providing and promoting quality care for millions of people in the United States, including individuals with disabilities. Therefore, the lack of DSPs can also keep individuals with disabilities from creating meaningful relationships, maintaining good health, and being integrated into the community (Friedman, 2018).

The DSPs provide a wide and complex range of support and services, such as health and safety, relationships, networking, communication, personal care, transportation, advocacy, financial duties, community living, crisis prevention, household tasks, education on self-care skills, promoting self-determination, and managing finances (Bogenschutz et al., 2014; Friedman, 2018). These services are usually ordered by the client's physician and are based on an evaluation provided by their physicians. This is also based on what their needs are and what is appropriate and cost-effective for service. DSPs are a lifeline for people with disabilities providing for the physical, emotional, mental, chronic, and temporary needs of this population. They work with a cross-section of the population including children and adults with disabilities assisting disabled individuals in completing basic daily routines and work in a variety of settings, including individual's homes, group homes, private and public institutions, nursing homes, and job support programs (Bogenschutz et al., 2014). They are a reinforcement that provides a deeper sense of independence and a better quality of life (Friedman, 2018).

In addition, there are adult residential services for individuals with developmental disabilities that provide a home and offer medical services such as speech therapy; counseling; nursing care; and recreational, transportation, and nutrition services for individuals over 21 years old. These community-based homes provide the opportunity for individuals with developmental disabilities to live as independently as they can and a chance to become an integral part of a community with neighbors, co-workers, and volunteers based on their preferences, interests, and responsibilities. According to each person's individual service plan, supports are provided by highly trained DSPs and clinical professionals who provide services addressing communication and choice, self-advocacy, self-direction and travel, career guidance and development, community participation, and other needs involving speech-language pathology, nursing, psychology, nutrition, and recreation, etc. (Friedman, 2018).

PCS is covered by Medicaid home and community-based services (HCBS). These critical services enable people with disabilities to remain in their homes, stay active in their communities, and lead independent lives. Over 3.5 million older adults and people with disabilities receive Medicaid HCBS. Though all states provide coverage for some HCBS services, eligibility and benefit standards and policies vary by state, which leads to

significant variation and gaps in coverage. Some states cap the number of individuals who may receive services, which has left almost 820,000 Americans on wait lists (Kaiser Family Foundation, 2018). Also, there is a high annual turnover rate for DSPs (Hewitt, 2014; Hewitt & Lakin, 2001) anywhere from 30% to 70% a year (Bogenschutz et al., 2014). Almost this entire turnover is due to DSPs quitting rather than being fired because of increased workload, extremely low wages with lack of benefits, and lack of training (Friedman, 2018).

## Policy and Practice Implications for Working with People with Disabilities in the Healthcare System

First, it is vital to recognize individuals with disabilities as a health disparity population in the healthcare system. Like everyone else, they have the same healthcare needs, such as preventive and specialty care services. However, they are less likely to access healthcare services than individuals without disabilities due to healthcare access barriers. Therefore, they experience unmet healthcare needs that could negatively affect their health outcomes. Disparity status for people with disabilities would allow federal and state governments to actively work to reduce inequities (Krahn et al., 2015). Moreover, healthcare providers, social workers, and public health practitioners' knowledge of these barriers and how a person's various social identities are intertwined with the obstacles can help provide strategies to improve healthcare access and promote the inclusion of people with disabilities in disease prevention and health promotion programs.

Research on disparities in health and healthcare can help identify vulnerable groups, including racial/ethnic minority, immigrant, low-income, and socially disadvantaged groups, who are at high risk of disability, who are uninsured, and who could benefit from public policy and social interventions designed to reduce the impact of disability and uninsurance. For example, a recent policy brief reported characteristics of people in the insurance coverage gap as a major barrier to access to care (Garfield et al., 2021). As of August 2021, 12 states have not adopted the ACA provision to expand Medicaid to adults with incomes below the 138% poverty line (Kaiser Family Foundation, 2021). As a result, 2.2 million people in these states fall in the coverage gap. These people would be eligible for Medicaid if their state adopted the ACA expansion. However, they currently do not qualify for Medicaid and have incomes below the poverty level, which prevents them from being eligible for premium subsidies in the ACA Marketplace (Garfield et al., 2021). People in the coverage gap are disproportionately people of color, nationally, comprising nearly six in ten (59%) people in the coverage gap, and more than one in six (15%) of the population have a functional disability, including people who have serious difficulty with hearing, vision, cognitive functioning, mobility, self-care, or independent living often requiring significant current healthcare needs (Garfield et al., 2021).

Another policy brief examined trends in health coverage by race and ethnicity between 2010 through 2019 using American Community Survey data for the nonelderly population. The findings show that racial/ethnic disparities in coverage have been reduced due to the ACA, but this reduction did not eliminate disparities in health coverage (Artiga et al., 2021). According to this analysis, there were large gains in coverage across all

racial/ethnic groups under the ACA between 2010 and 2016. In particular, the uninsured rate over the period fell from 32.6% to 19.1% among Hispanic people. Despite these gains in coverage, people of color remained more likely to be uninsured than their White counterparts as of 2016. Also, beginning in 2017, coverage gains began reversing, and the number of uninsured increased for three consecutive years, with the largest significant increase in the uninsured rate over this period among nonelderly Hispanic people (Artiga et al., 2021). Moreover, uninsured nonelderly Hispanic and Asian people are less likely than their White counterparts to be eligible for coverage due to their immigrant and/or non-citizenship status. This trend is also mirrored in the disabled community (Magana et al., 2012; Parish et al., 2013c; Rosen-Reynoso et al., 2016).

Thus, beyond insurance coverage, it is important to address inequities across the broad range of other social and economic factors and other inequities within the healthcare system that could lead to poorer quality of care and health outcomes for people with disabilities. Emphasis on race, ethnicity, and socioeconomic factors beyond health insurance coverage is consistent with the national health initiative Healthy People 2030, which has an increased focus on health equity, social determinants of health, and health literacy, with a new focus on well-being (US Department of Health and Human Services, 2021).

Second, strategies to make healthcare more affordable and accessible for people with disabilities are key to improving their health. Studies have found that people with disabilities are less likely to get the preventive healthcare services they need to stay healthy (Marrocco & Krouse, 2017). Increasing access to preventive healthcare such as cancer screenings can prevent both disease and early death among individuals with disabilities. The number of people getting preventive services has increased in recent years, but there are still disparities based on various social identities, including race/ethnicity, gender, immigration status, etc. Specific strategies at the system level, such as providing reduced copays, the system-wide use and funding of interpreters and multilingual tools, the use of community health workers who are members of the immigrant community, and patient navigators may reduce language and cultural barriers to healthcare among immigrant populations through facilitation, education, and advocacy (Linton & Green, 2019; Son et al., 2018). In addition, team-based care can help people with disabilities get recommended preventive care services in a timely manner. As a practice-level strategy, the medical home, emphasizing comprehensive care and enhanced care coordination, can be critical support for immigrant families who have children with disabilities. For example, integrated mental health, nutrition, social work, and patient navigation services allow for ease of access and for a reduction in stigma and barriers (Linton & Green, 2019). Additionally, it is vital to have better coordination between healthcare professionals and professional care staff in residential facilities, such as direct support professionals (DSPs). Professional care staff or DSPs working with people with disabilities need increased training and awareness about health promotion and cancer prevention (Hanna et al., 2011).

Another example of a practice recommendation that might prove beneficial is providing a prenatal care team to help assist and give guidance to women with physical disabilities. According to Byrnes and colleagues (2016), women who have comprehensive and coordinated care teams to assist them often receive more assistance and support than solely working with their practitioner. A care team would consist of a primary health physician (PCP), any specialty practitioners, a social worker, a dietary consultant, an occupational therapist (OT), and

a physical therapist (PT) working closely with the person with a disability. Having the collaboration of these clinicians and healthcare providers, coordinated by a social worker, can ensure adequate, comprehensive, and supportive assistance in obtaining medical devices, tending to specific dietary needs, securing necessary appointments, and advocating for required accessibility. It is also important to note that this coordinated care team can help individuals with disabilities transition from prenatal care to postnatal care. Some individuals with physical disabilities may require certain devices to assist in caring for their newborn baby. Additionally, since women with physical disabilities are more likely to experience postpartum depression (Byrnes et al., 2016), it is beneficial to have access to professionals that can provide resources and guidance on postnatal care. Support persons such as partners and family members of these women should understand the strong desire to become mothers of women with disabilities. It is vital for these women that their desire to become mothers and their motherhood is recognized as normal by their social and family environment (Commodari et al., 2022). Previous studies show that the desire of women with disabilities for normality face many prejudices about disability and their parenting skills based on an idea of perfect physical functioning, particularly for women with disabilities who wish to become mothers (Commodari et al., 2022; Powell et al., 2017).

Lastly, it is also important to note and highlight the strengths and abilities of people with disabilities and to promote their dignity and worth for people with disabilities based on the ethical principles of social workers (NASW, 2021). Social workers are necessary for advocacy efforts to diminish the inequities and barriers currently faced by this vulnerable population. They are also essential in fighting for ethical healthcare services, including ensuring the dignity and worth of people, which is a core social work value (NASW, 2021). For example, many women with disabilities wish to become parents and should be given the right to self-determine their choice. Also, another core social work value, social justice, is affected by social workers who strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision-making for all people (NASW, 2021). Individuals with disabilities, and particularly those individuals who also experience marginalization related to their race or ethnicity, gender identity, culture, or socioeconomic status are especially vulnerable throughout their life course. Social work practitioners and researchers have a crucial role in identifying these vulnerable groups to effectively challenge social injustice (Bishop-Fitzpatrick et al., 2019). The care team option can be essential in providing needed information, services, and resources, implementing assistance, and ensuring the proper standard of care and the right to self-determination. Therefore, it is vital that social workers work closely with individuals with disabilities to ensure that they can perform at optimal independence and are able to self-determine their care plan. This will promote the core ethics of social work, including the dignity and worth of the person and social justice, which every individual deserves.

## Case study

### The Case of Yuna Choi

Scenario: You are a medical social worker and supervisor at a children's hospital. The department of social work in the children's hospital specializes in working closely with patients and family members who are experiencing mental, emotional, family, and/or financial stress due to their or their loved one's medical condition. Your worker comes in for supervision of a new case. Here are the details:

Yuna was born in January 2019 at 31 weeks with a congenital developmental abnormality. Yuna's mom, Hyejin, 35, was born in South Korea and came to the United States with her husband, Hyunsoo. She was 28, he was 31. They have three children. Hyejin's first language is Korean; she speaks very little English, although she can read and understand English. However, Hyunsoo did not see a need for her to learn English and he was very busy with his work.

Yuna spent a total of eight weeks in two different hospitals. Meanwhile, Yuna's father had to change jobs, and the change affected the family's health insurance. Since Yuna was born in January and it was a new insurance year, they had to spend most of their savings to cover the hospital admission costs.

Yuna struggled to gain weight. She was not as active as she should be compared to her siblings, but everyone reassured her parents that she would recover soon. When she came home, Hyejin was still suspicious of things not being right, so she brought Yuna in for frequent check-ups due to her weight gain issues. With the help of her husband, she questioned why her daughter was not doing something when she was supposed to, and the doctors and specialists were saying that she would catch up. According to her cultural tradition involving respect for authority figures, Hyejin had faith in their expertise and care and stopped asking questions about her daughter.

At the age of eight months, Yuna started Early Intervention (EI), and she became eligible for some equipment for her mobility and feeding at home. The home therapists, doctors, and Hyejin and Hyunsoo filled out all the paperwork and sent it to the Early Intervention Office for approval. They waited six months for the approval to come. When Yuna's father called to investigate the delay, the agency told them it was waiting for approval from the Early Intervention Office and there was nothing they could do. However, Yuna needed the equipment right away. Hyejin felt that no one cared, and she got frustrated. Hyunsoo called the agency and found out who was responsible for the approval of the request. He wrote them a long email at night, expressing their frustration and how it made them feel helpless. The next morning, they received an email of approval for the equipment request.

At one year old, Yuna had her first seizure and was diagnosed with progressive epilepsy. Hyejin would take her to her therapy appointments in the city. Many people in the community and online forums recommended applying for a Medicaid Waiver. However, Hyejin wasn't sure if Yuna would be eligible, and it required so much of their family's time and effort to know how to apply for it, that due to her language barrier and



her husband's busy work schedule, they postponed it. At age three, Yuna had a gastrostomy tube placement because of her failure to thrive. As time went on, Yuna began to develop pneumonia, and at age four, she was diagnosed with obstructive lung disease. At this point, Yuna had weekly doctors' appointments and ongoing EI therapy sessions, to which Hyejin took her weekly for outside treatments in the city. Hyejin became a healthcare system navigator, time manager, care coordinator, nurse, and therapist for Yuna. She didn't work, but she was Yuna's assistant, which felt like a full-time job. In addition, she completely relied on her husband's help regarding making doctors' appointments, finding resources, and applying for disability benefits due to her language barrier. In addition, she tried to use an interpreter provided by hospitals to explain Yuna's situation and the family's needs; however, she discovered that she was not receiving clear and effective communication and that the times given for meeting with doctors were too short, so she stopped using the interpreter service.

Between the doctor's appointments, diagnosis, and therapies, Yuna entered another chapter of her life, where she became a child with special healthcare needs (CSHCN). Hyejin had no option but to apply for the Medicaid Waiver since it would benefit Yuna. The process was long and hard. Social Security requested pages of detailed information from each doctor Yuna had seen in each hospital admission she had had in the past. She encountered many barriers, one document missing or one not updated, and hours-long discussions regarding financial eligibility. She went back and forth at least three times, and at the final appointment, she almost begged the officer to give her the Medicaid Waiver Yuna needed. She was told that they would inform her at a later date. Following this appointment, Yuna had a major seizure and ended up in a coma for three weeks. During this devastating time, your worker met with Hyejin and Hyunsoo in the children's hospital and is trying to help the family get the Medicaid Waiver.

## Discussion questions

### In this case...

- 1) How does intersectionality play out in this case?
- 2) How might you use anti-oppressive practice techniques?
- 3) What is the role of critical cultural competence for the social worker in this case?
- 4) How could you apply the guiding principles of disability social work practice (from Chapter 1)?
- 5) In what ways do we see structural ableism, sexism, and consideration of cross-cultural aspects play out?

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## 5.

# DISABILITY JUSTICE IN EDUCATION AND TRANSITION TO ADULTHOOD

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## Learning Objectives:

- To explain how educational services for disabled children are organized in the United States
- To learn about key education-related policies relevant to disabled people in the U.S.
- To explain the process of transitioning from the educational system to adult disability service systems

This chapter will discuss access to education from early childhood, to adolescence and through university. At the earlier end of the age spectrum, we will focus on how disabled children access appropriate educational services. We will also discuss how general education and special education settings do and do not support disabled children, with a focus on the experience of disability stigma and mainstreaming practices. We will provide a discussion of the overrepresentation of disabled students of color in suspension and expulsion cases in elementary, middle and high school settings. The use of residential treatment centers will be addressed, including a discussion of the controversial use of shock/aversive therapy in some settings. A particular focus of this chapter will be the discussion of the often-fraught process of transition from youth service systems to adult service systems. Considerations about the inaccessibility of higher education institutions will also be presented. We will review key education-related laws, policies and programs relevant to disabled people in the U.S. For example, we will discuss the Individuals with Disabilities Education Act which provides a pathway to personalized, accessible services for youth. Additionally, we discuss the Chafee Foster Care Program for Successful Transition to Adulthood (42 U.S. Code § 677) which offers support to foster children, one-third of whom have disabilities.

## Introduction

With over 3 million children and youth under the age of 18 in the U.S. recognized as having a disability (Young & Crankshaw, 2021), one of the main avenues for receiving supports and services for children, youth and their families is through the U.S. public education system. With the enactment of the Individuals with Disabilities Education Act of 1990 (IDEA), all children are entitled to a Free Appropriate Public Education (FAPE, 1975), which serves as a human rights act for disabled children and youth, and their families. Disability services offered through the U.S. public education system are provided regardless of health insurance status, ability to pay or documentation of legal status in the U.S., and free transportation is provided. Therefore, this is one of the most accessible sectors of disability services in the U.S., and all children and youth (either currently disabled or with conditions that have the potential to be disabling) living in the U.S. are entitled to receive the services, such as accommodations, educational supports, and a variety of individualized services and therapies. However, this system is plagued with injustice in several areas, including disproportionate representation of BIPOC (Black, Indigenous, and other People of Color) [\[1\]](#) students in special education services in general and with specific diagnoses, and disciplinary policies (e.g. suspensions and expulsions) and practices that significantly impact students with disabilities with particular intersections with race, ethnicity, gender, and LGBTQ2S (Lesbian, Gay, Bisexual, Transgender, Queer or Questioning, Two-Spirit)[\[2\]](#) status.

## History: Disability (In)Justice in Education Policy

Despite the intended accessibility and entitlement of education and services for children and youth within the public education system, historically, access to education has not been a guaranteed right, nor has the school building been a desirable space for everyone to learn. For example, residential boarding schools (a predecessor of the U.S. education system) were created as a tool to enact removal of Native American children from their communities, force assimilation to colonialist ways, and at times, outright elimination of the Indigenous peoples of North America (Keating, 2020), out of colonialist desires for (and sense of entitlement to) Indigenous lands (Child, 2018). For over 100 years, between the mid-1800s and mid-1900s, Indigenous children were “forcibly removed from their homes and put into Christian and government run schools... with the intention to erase Indian culture and identity [through means of] neglect and verbal, physical, and sexual abuse” (Regents of the University of Minnesota, 2016, Slide 3). This violent and oppressive history did not begin with residential boarding schools, rather in the 1500s with the invasion of European colonizers inflicting white settler colonialism, genocide, and long-lasting transatlantic enslavement of African and Indigenous people (Elliott and Hughes, 2019). There are elements throughout this chapter that highlight how the education system has worked to both uphold and dismantle racist and ableist practices and policies throughout history and today.

This is crucial context for this chapter, as it highlights how deeply our state systems (including the education system) were founded on racist, colonialist, and ableist beliefs. Leah Lakshmi Piepna-Samarasinha, in their book *Care Work: Dreaming Disability Justice*, states that these systems, despite efforts of reform and justice, “will not save us, because [they were] created to kill us” (2018, p.23). There are parallels as well as intersections between systemic racism and ableism due to views of inferiority of both non-white, and non-abled people. Moreover, regarding intersectionality, “associations of race with disability have been used to justify the brutality of slavery, colonialism, and neo-colonialism” throughout history (Erevelles, Minear, 2010, p.132 as cited in Migambi and Neal, 2018, p.3). This oppression was justified through “The Ugly Laws” which spanned from mid-1700’s to 1970, which “stated that many disabled people were ‘too ugly’ to take up space in public” (Lakshmi Piepna-Samarasinha, 2018, p.23) and were identified through “labels as ‘imbeciles’ and ‘idiots’ and used to restrict unwanted immigration through the use of the legal system” (Schwik, 2009 as cited by Migambi and Neal, 2018, p.4). This fueled “mass creation in the 1800’s of hospitals, ‘homes,’ ‘sanitoriums,’ and ‘charitable institutions’ where it was the norm for disabled, sick, mad, and Deaf people to be sequestered from able-bodied ‘normal society’” and these institutions “overlapped with other prison/carceral systems” (Lakshmi Piepna-Samarasinha, 2018, p.23). This relates to the foundation of the U.S. education system in many ways, both obvious and subtle.

The public education system was developed in the context of these racist and ableist practices of control and institutionalization in the 19th century. What was then referred to as “common schools and institutions,” shifted education of children from “private and philanthropic efforts” to state and eventually local district school systems (Richardson and Parker, 1993, p. 363-364). The “passage of compulsory school attendance” greatly affected the meaning, legitimacy, and authority of the school and state control (Richardson and Parker, 1993, p. 363-364). The passage of mandatory school attendance greatly affected the meaning, legitimacy, and authority of the school and of state control over education (Richardson and Parker, 1993). This regulation gave schools the discretion of “specifying physical and mental deviations as grounds for exemption” which vicariously gave the state control over who participated in “residential facilities for exceptional children” versus “common school education” (Richardson and Parker, 1993, p. 364). Schools were then required to meet the parameters of the attendance policy, thus created the “ungraded class” which included the “poor, physically unkept and disorderly children,” which was “most common in urban school systems, and later became the special class for exceptional children” (Richardson and Parker, 1993, p.364).

The school system was industrialized in the late 19th century, where the school system acted as an extension of the state quite similar to the codified ways it does today. Richardson and Parker explain that additionally, “youth who were ‘vicious and immoral’ in character or found begging or frequenting immoral places could be excluded from attendance and committed to the state reform or industrial school” (1993, p. 364). This experience was undoubtedly heightened and targeted for BIPOC, LGBTQ2S and disabled individuals which vastly influenced the experience of being criminalized. The state reform and industrial schools were separated

and segregated from the “normal” schools, eventually leading to the juvenile justice system, in which children with disabilities were, and still are, significantly overrepresented (Nanda, 2019, p.270). The disability community was seen as the “other, [individuals] to be cured, or if they could not be cured, to be isolated [and] institutionalized” (Chamusco, 2017, p.1288). These interrelationships between individuals and state agencies were “reinforced by practices of eugenics, hygiene, and public health” and embraced specifically within schools where these practices were “administered and politicized as a form of social control” (Petrina, 2006, p.503). Over the last few decades, there has definitely been a monumental shift in access, equity, and safety as it relates to those with disabilities being allowed, included, and accepted into the educational community.

During the Civil Rights Era there was a visible shift from custodialism (the state remains custody of the individual) to integrationism (individual is integrated into the mainstream) of what is considered equality in education (TenBroek & Matson, 1966, as cited by Chamusco, 2017). Skiba states that “special education was borne out of, and owes a debt to, the civil rights movement” and yet it is “highly ironic that racial disparities in rates of special education services remain one of the key indicators of inequity in our nation’s education system” (2008, p. 264). Baglieri et al. (2011) states that a “normative center” has been created in schools, in which White, able, and middle-class bodies are considered the standard, and deviations from this are less desirable in the school system. This brings into question, to what degree is the right to education ensured in the United States? Beatty asserts that “the right to a free public education is not guaranteed by constitutional rights, but has come to fruition from case law and state statutes, such as the well-known *Brown v. Board of Education*, that ensured the state to provide equal education for all students regardless of ethnicity, but the focus did not emphasize disability rights explicitly” (2013, p.532). The guarantee of education is founded on assimilation and social control, and is entrenched in equating success with what is considered white-normative behavior (Migambi & Neal, 2018). This exemplifies the intersectionality of race/ethnicity and disability, and also the continuation of white supremacy and colonization within our classrooms.

## Educational Policy Overview

The following summary provides an overview of the development of educational policy in the U.S. as it relates to providing access to education and services for disabled children and youth. It does not delve into the intricacies of the disparities in representation of BIPOC students in special education, nor the magnitude of injustice as it relates to discipline policies, expulsion and suspension rates, and a number of other policies and procedures. Additional discussion of some of these issues and practices will be covered later in the chapter, and resources and links to further information on these injustices will be provided. A deeper dive into some of these policies is provided in Chapter 3: Major Disability Policies. The focus in this section is on educational access and practices.

## Policy: Section 504 of Rehabilitation Act of 1973

Section 504 of The Rehabilitation Act of 1973 is the first civil rights law pertaining to disabilities in the U.S., and has been influential in antidiscrimination policies in employment, education, and the definition of disability. It plays a crucial part in the disability justice policy landscape, and informed the creation of the Americans with Disabilities Act of 1990. Enacted during the disability civil rights movement, the policy prohibits discrimination based on disability or health condition by any programs that receive federal funding. Section 504 considers a person with a disability to have a condition, either physical, mental, emotional that interrupts a “major life activity,” record of such an impairment, or being “regarded as” having an impairment (U.S. Department of Education, 2020). This definition is broader than the one considered for services under IDEA (which is a categorical, medical model) which improves access to services within the education system for some students, however often requires advocacy from the individual or family, often at a point of discrimination or inaccessibility, even though the precedent has been set as standard. Section has 504 reached a wide array of settings to decrease and eliminate discrimination towards persons with disabilities.

Link to policy (Sections, Amendments, etc.): <https://www.eeoc.gov/rehabilitation-act-1973-original-text>

## Policy: Education for All Handicapped Children Act of 1975

The Education for All Handicapped Children Act of 1975 (EAHCA) was the predecessor to the Individuals with Disabilities Education Act of 1990. This federal law required public schools to provide appropriate education services to disabled children aged 3 to 21 years old. This early version of the current educational act was extremely monumental in ensuring access to education for those with disabilities. EAHCA was a larger catalyst than the Rehabilitation Act of 1973, in supporting young people and their rights to equal and free education regardless of disability status. Prior to the enactment of the EAHCA, it was common practice for children to be denied access to public education. According to the U.S. Department of Education, “in 1970, U.S. schools educated only one in five children with disabilities, and many states had laws outright excluding certain students, including children who were deaf, blind, emotionally disturbed, or had an intellectual disability” (2020). These exclusionary practices were inequitable and disturbingly legal. The EAHCA was considered radical and vastly transformative as it was now federal law that “all children with disabilities have a Free Appropriate Public Education that emphasizes special education and related services designed to meet their needs” (U.S. Department of Education, 2020).

Link to Policy (Sections, Amendments, etc.): <https://www.govinfo.gov/content/pkg/STATUTE-89/pdf/STATUTE-89-Pg773.pdf>

## Policy: Individuals with Disabilities Education Act of 1990

The Individuals with Disabilities Education Act (IDEA) was renamed in 1990 from the former Education for All Handicapped Children Act of 1975, with some revamping that enforced more accountability for a Free Appropriate Public Education (FAPE), and stronger mandates and accountability for federal funding. Mandates for services were added for children from birth through age two. Additionally, the individualized family service plan (IFSP) and the individualized education plan (IEP) were established as requirements. Subsequent reauthorizations and amendments have occurred in 1997, 2004, and 2008. Box 5.1 provides a summary of the key components of IDEA.

### Box 5.1

#### Summary of the Individuals with Disabilities Education Act (IDEA)

- *Part A, General Provisions:* Lays the foundation for the rest of the act. Creates the Office of Special Education Programs. Defines terms
- *Part B, Assistance for Education of All Children with Disabilities:* Provides educational guidelines for children ages 3 to 21. States are required to provide education for disabled students. Dictates financial support for districts. Some of the key principles and benefits for disabled children include:
  - *Free appropriate public education (FAPE)*
  - *Identification and evaluation*
  - *Individualized education plans (IEP)*
  - *Least restrictive environment*
  - *Due process safeguards*
  - *Parent/student participation and shared decision making*
- *Part C, Infants and Toddlers with Disabilities:* Provides educational guidelines for services for children ages birth through age 2. States are required to provide services for children and families. Some of the key principles and benefits for disabled children and their families include:
  - *Expansion of requirements for a statewide system, serving young children*
  - *Individualized family service plans (IFSP)*

- *Part D, National Activities to Improve Education of Children with Disabilities:* Describes national activities aimed at improving the lives of children with disabilities as a whole. Includes grants for improvement and transitional activities.

There was an urgent need for the reforms under IDEA, as the history of many individuals with disabilities included “state institutions with restrictive settings with minimal food, clothing, and shelter, and persons with disabilities were often merely accommodated rather than assessed, educated, and rehabilitated” (U.S. Department of Education, 2020). Turnbull posits that IDEA can be categorized as a school reform law, civil rights law, and welfare state reform law, as the breadth of this bill expands across school policy, family involvement, and larger systemic practices (2005).

This policy dramatically transformed the system of special education and disability services as it relates to education, and has positioned the school as a setting of referral for inhouse services as well as state services for individuals with disabilities and their families. The most monumental aspect of the revamping of Education for All Handicapped Children into IDEA is that a young person with a disability cannot be turned away from an education, solely based on their disability. This act ensured that students have guarantee to an individualized education led by the students’ needs and with familial involvement in decision making.

Eligibility criteria. There is difference in the definition of disability across IDEA versus Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, which has been controversial. While Section 504 eligibility more simply requires a condition (based on school or health care provider evaluation) that limits a major life activity, the IDEA requirements are categorical in the diagnosis, and this diagnosis must negatively impact learning. Children must meet these two criteria (again, based on school evaluation) in order to be eligible for services under IDEA:

1. Diagnostic category: 1. Intellectual Disability; 2. Hearing impairment; 3. Visual Impairment; 4. Speech or Language impairment; 5. Emotional disturbance; 6. Orthopedic impairment; 7. Other health impairment; 8. Traumatic brain injury; 9. Deaf-blindness; 10. Specific Learning Disability; 11. Autism; 12. Developmental delay; or 13. Multiple Disabilities. For definitions of these disability categories, please see: <https://sites.ed.gov/idea/regs/b/a/300.8>
2. Has a need for special education and related services (IDEA, 2020).

This stricter and medical definition of disability under IDEA results in some children not being eligible for services, despite their need. The interaction of Section 504 and ADA protections also adds additional layers, definitions, and implementations. These protections vary from state to state, and case by case, which



simultaneously creates broader implementation for some students, while also creating disparities and individual discretion of those most often in positions of power. One benefit of the process established for determining the diagnostic category for services under IDEA is the ability for schools to give diagnoses for service eligibility without use of the medical community outside of the school setting. This removes barriers for families in accessing traditional medical services, including avoiding long waiting lists and lack of insurance. This is commonly referred to as a “school diagnosis” versus a medical diagnosis. The services received under both policies of 504 and IDEA are explored more thoroughly in the section titled “Providing Services for School-Aged Children and Youth” later in this chapter.

Link to Policy (Sections, Amendments, etc.): <https://uscode.house.gov/view.xhtml?path=/prelim@title20/chapter33&edition=prelim>

Concept Check. Explore the following brief video from YourSpecialEducationRights.com that clarifies the differences between 504 and IDEA, including eligibility differences: [IDEA Basics: \(504 Plan\) How is an IEP Different from a 504 Plan?](#)

## Policy: No Child Left Behind, 2001/2002

No Child Left Behind (NCLB) is a controversial policy that has resulted in polarized outcomes for both students and education funding across the nation. The stated intention was to create more assessment measures of effective education and decrease the achievement gap (the disparity between those deemed “successful” and meeting basic standards in school and those not meeting that standard), however it used a coercive strategy of further industrializing education through widespread standardized testing and creating higher and often unattainable standards that resulted in punitive measures for schools, which resulted in further increasing the achievement gap. There were plenty of pitfalls through this legislation that impacted the level of funding, turn over, eventual closure, and functionality of schools for all students, and especially those with disabilities. Lanear and Frattura identify these pitfalls as:

- *Segregating groups of students to remediate for purposes of increased test score performance*
- *Blaming disadvantaged students for low test scores, creating culture of those ‘wanted vs. unwanted’*
- *Testing proficiency vs. pedagogy of passion, awareness, learning, new knowledge, application, and evaluation*
- *Assuming teachers are the source of the achievement gap instead of systemic inequity*
- *Practice of content-based curriculum instead of application of information*
- *Measuring success by test scores does not serve different levels of disability/language skills in comprehension and acquired knowledge*
- *Measuring about grade level as proficiency instead of independence and autonomy*
- *A brief timeframe in which students are required to achieve proficiency (2007, p. 103).*

The tension between the rights given within IDEA and the pressures of NCLB was not conducive to ensuring equitable education to students with disabilities. Unfortunately, the negative implications for a school deemed “failing” by the standardized testing measures of NCLB became a priority to avoid, thus resulting in a conflict between the “one size fits all philosophy” of NCLB, and the “highly individualized” programming under IDEA in meeting the needs of students with disabilities (Moore, 2011, p.525).

Link to Policy (Sections, Amendments, etc.): <https://www.congress.gov/bill/107th-congress/house-bill/1>

## Policy: Every Student Succeeds Act, 2015

The Every Student Succeeds Act (ESSA) replaced No Child Left Behind in 2015, reauthorizing the Elementary and Secondary Education Act, which is committed to educational equity throughout the nation (ESSA, 2020). The provisions proposed within the ESSA include “upholding critical protections for disadvantaged/high-need students, a first-time requirement that all students be taught to high academic standards in efforts for college/career readiness, an assurance that information is provided to the whole community regarding annual statewide assessments that measure students’ progress, help supporting and growing local innovations, sustaining and expanding administrations’ historic investment in high-quality preschool programs, maintaining the expectation of accountability and action to effect positive change in our lowest-performing schools” (ESSA, 2020, <https://www.ed.gov/essa?src=ft> ). This broad terminology intends to uphold accountability without punitive measures but give states more control of their own school systems.

Link to Policy (Sections, Amendments, etc.) – <https://www.ed.gov/essa>

## Services for Disabled Children and Youth in the Education System

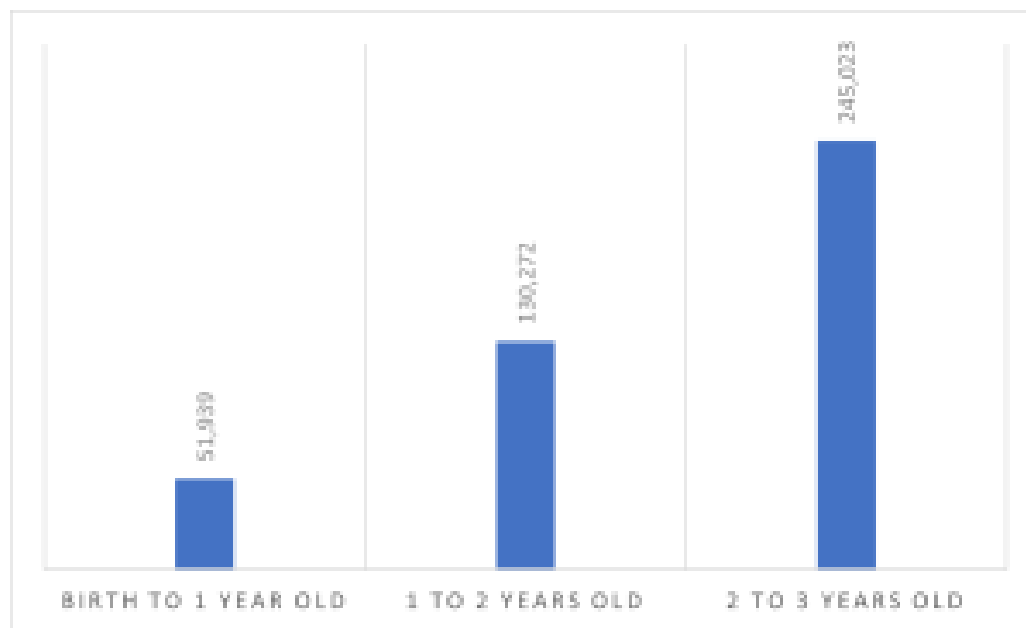
As previously reviewed, the major policy that dictates disability service provision in the education system today is the Individuals with Disabilities Education Act (IDEA) of 1990, with the most recent reauthorization in 2008. Additional students are covered under section 504. The following section will provide an overview of the prevalence of IDEA and 504 usage, disparities in service usage, and further descriptions of services provided in school settings for children ages birth through 21 in the programs of Early Childhood Special Education, services for school-aged children, and Transitions programming. Access to programming at the University level will also be discussed.

## Prevalence

### Birth to Three

Services for children ages birth to three with (or at risk of developing) disabilities receive services under Part C of IDEA, via partnership with local organizations and public education school districts. Some states have their own programs, for example in North Dakota, private agencies are contracted to provide the Early Intervention services by region. Other states participate in a national program titled Help Me Grow, which includes over 100 affiliate localized systems, spanning 29 states and Washington D.C. (Help Me Grow National Center, 2020). In the 2019-2020 academic year, 427,234 children ages birth to three were served in the U.S., with increasing rates of participation as children age (<https://www2.ed.gov/programs/osepidea/618-data/static-tables/index.html>).

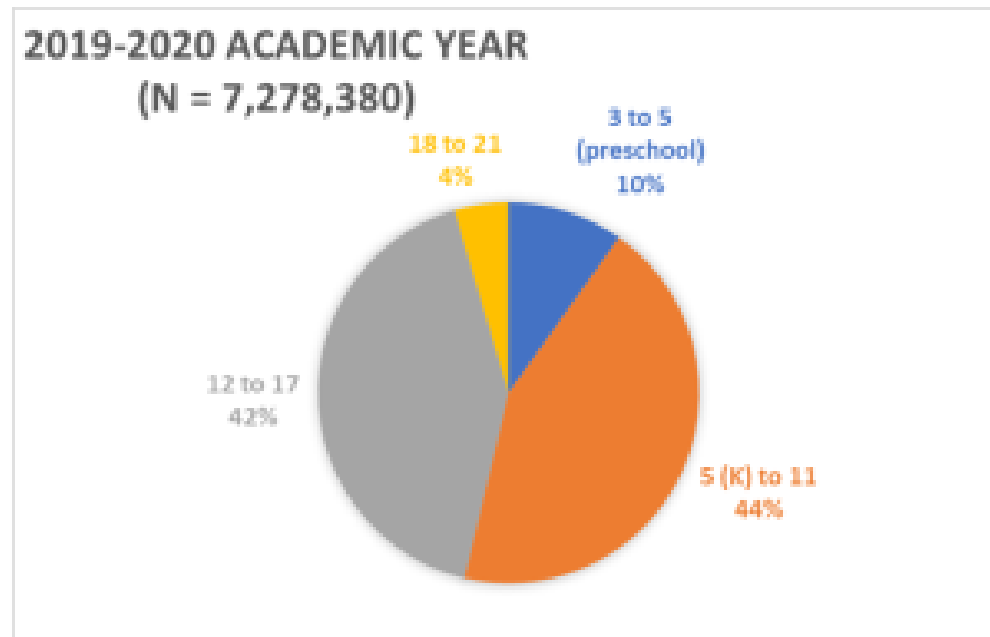
Chart 5.1. Ages of Participants in Part C of IDEA (n=427,234)



### Three to Twenty-one

According to the Office of Special Education Programs (OSEP, 2021), approximately 7.3 million children and youth between the ages of three and 21 received services from the U.S. public education system in the 2019-2020 academic year under Part B of IDEA. While services can begin at birth and extend post-high school through the transitions program, most of the children receiving services are considered “school-age,” beginning at the age of five (in Kindergarten [K]) through age 17 (typically high school graduation). Chart 5.1 shows the distribution of children ages 3 to 21 who participated in the U.S. IDEA Special Education programming in the 2019-2020 academic year.

**Chart 5.2. Ages of Participants in U.S. Special Education (IDEA Part B) in the 2019-2020 Academic Year (n = 7,278,380)**



Some disabled students may not be eligible for services under IDEA and thus would not have an IEP. They may be eligible for a “504 Plan,” which prevents discrimination based on disabling conditions. The 504 plan title is in reference to Section 504 of the Rehabilitation Act. One example is that many students who have been diagnosed with mental or other health conditions may have a 504 plan, indicating they may not need specialized instruction. However, this could include accommodations so that they can be successful in school, such as extra time for taking an exam. Nationally, 2.71% of students in grades K-12 are receiving accommodations solely under a 504-only plan (Zirkel & Gullo, 2021). There is significant state variation in the use of 504 plans, with New Hampshire having the highest usage of 6.32%, while Mississippi has the lowest, with 0.65% (Zirkel & Gullo, 2021). These differences are likely due to significant variations in state and local education policies and practices.

## Demographics and Disparities

Unsurprisingly, there are significant disparities in who has access to special education services. However, the issue of disparities in special education is quite complex. For example, research studies have shown that BIPOC children will have underdiagnosis in some disability categories, such as Autism Spectrum Disorder, as well as overdiagnosis in other categories, such as Emotional Disturbance (OSEP, 2021), with variations across racial/ethnic and disability categories.

National data shows differences in which students are receiving services under the various disability categories by race and ethnicity. The Office of Special Education Programs (OSEP) has compiled several helpful data charts and tables, including highlighting the racial and ethnic differences of children served by

IDEA Part B, among the different disability service categories. This [chart](#) shows that White students have the highest rates of service usage for Traumatic Brain Injury. Hispanic/Latinx students have their highest rates of service receipt under the learning disability category and African American students have their highest rates in the intellectual disability category, which happens to be the lowest category for White students (<https://sites.ed.gov/idea/osep-fast-facts-looks-at-race-and-ethnicity-of-children-with-disabilities-served-under-idea/>). While the OSEP data does indicate that male-identified students have higher rates of Part C participation than female students (4.4 million versus 2.3 million), the data does not further break down by gender regarding specific disability categories. Not surprisingly data is not collected regarding LGBTQ2S status, so comprehensive prevalence rates are difficult to identify for these demographic factors. As many of the diagnoses have at least some biological roots, we can assume that there are many intersectional issues at play regarding child race/ethnicity, gender, and disability category for special education services, including socioeconomic status (Tek and Landa, 2012), and bias in the diagnostic process.

## COVID-19 Pandemic

The long-term effects of COVID-19 and larger implications on students with disabilities are beginning to unfold and will be a consideration going forward in how education supports the community. The pandemic undoubtedly affected the distribution of services for students with disabilities. The immediate school closures left any physical school-based service inaccessible, especially as it related to one-to-one support, group, and peer work. The shift to virtual and distance learning had a range of effects on students, and the lack of reliable, adequate, and accessible technology was a point of disparity. Additionally, the stressors of physical, emotional, financial, and familial health impacted the disability community. [The National Council on Disability report on The Impact of COVID-19 on People with Disabilities](#) provides an in-depth overview of the effect, specifically Chapter 4 and Chapter 7 (2021). The following are examples of some of the findings (2021, p.145 and p. 197):

- *During the shelter-in-place period, many K-12 students with disabilities did not receive FAPE over an extended period of time and went months without essential services and supports that are usually provided in person.*
- *Children with disabilities in low-income households, and particularly children of color with disabilities in low-income households, experienced particularly severe barriers to remote education during the pandemic.*
- *While some students with disabilities flourished in the remote learning environment, many students with disabilities struggled to focus and learn through a computer screen.*
- *Punitive responses to students with disabilities who did not attend or engage in remote education were counterproductive and had particularly dire consequences for students of color with disabilities.*
- *At all levels including K-12 and postsecondary, students who are Deaf, Hard of Hearing, blind, or with other disabilities faced access barriers in digital platforms and related digital documents.*
- *Without access to effective mental health supports, including in-person supports, some children with*

*disabilities experienced mental health crises during the COVID-19 pandemic, ending up in emergency rooms, psychiatric hospitals, residential treatment, and even jail.*

- *Native American students with disabilities served through the BIE received few educational services during the pandemic, effectively losing more than one year of education.*
- *Due to the social isolation caused by remote work, job loss, closed schools, stay-at-home orders, shuttered businesses, and physical distancing, many adults and children experienced new mental health disabilities or exacerbations of existing ones.*
- *Rates of anxiety and depression rose significantly, crisis hotlines saw high call volumes, and more people experienced suicidal thoughts.*

Learning Activity: Explore this OSEP [data](#), and make comparisons across diagnoses, states, and racial categories.

## Providing Services in Early Childhood

Early childhood special education (ECSE) services are provided under both Part C (for children ages birth to three) and Part B (for children ages five through 21) of IDEA. Birth to three services are often provided within the family home, while services for children ages three through five often occur in a preschool setting. In order to be eligible for ECSE, infants and toddlers must meet one of the disability categories as described in IDEA. Many states also include eligibility for young children determined to have a developmental delay, broadening access to crucial early interventions. For example, in Minnesota, young children could either have a diagnosis in one of the IDEA disability categories, or have documentation of a developmental delay score of 1.5 standard deviations from the mean in, cognitive, physical (including vision and hearing), communication, social or emotional, or adaptive development, as determined by a licensed professional ([www.mnlowincidenceprojects.org](http://www.mnlowincidenceprojects.org)). Any professional with a concern about a young child's development can refer the family to their local school district to inquire about developmental screening and to assess for eligibility for ECSE.

## Individualized Family Service Plan

An Individualized Family Service Plan (IFSP) is a document or case plan that lays out the services and supports that will be provided for infants and toddlers receiving services under Part C of IDEA. It also serves as a contract, holding service providers accountable for ensuring access to and provision of needed services for these young children and their families. An IFSP indicates both the types of services that will be provided, the number of services that will be provided, as well as the goals and interventions that will be used. Services included in the IFSP could be speech and language therapy, occupational therapy, physical therapy, case management services, parenting support, and more. IFSPs are required to be evaluated every six months and

are updated at least once per year. A key component of the IFSP is to build off of the strengths of the family, recognizing that young children best receive their growth and development through their families. This differs from an Individualized Education Plan (IEP), as an IEP is a contract for services that will happen in the school setting. Young children receiving special education services in a preschool setting (ages three to five) will have an IEP. More details regarding the IEP are provided later in this chapter. The following is a link to IFSP policy under IDEA: <https://sites.ed.gov/idea/statute-chapter-33/subchapter-iii/1436>

## Advocacy and Justice in Early Childhood Special Education

The broadened eligibility criteria available in some states regarding diagnoses (e.g. a developmental delay category) provide opportunities for crucial early interventions. Scholars from a variety of fields have provided data that shows that early interventions for children with disabilities significantly improve functional and diagnostic outcomes beyond early childhood (Dawson et al., 2010; McConachie & Diggle, 2007; McCormick et al., 1993; Odom & Strain, 2002; Smith et al., 2000). Additionally, services for infants and toddlers are often provided in the home setting, and services for preschoolers typically include transportation to the preschool setting. This reduces transportation barriers present for many families in need of services. Moreover, families do not need access to medical insurance to pay for the interventions, as they are often provided in partnership with the public school system.

Despite this accessibility of services regardless of health insurance status, transportation, and broad eligibility criteria, many young children and their families do not participate in ECSE services. Rosenberg et al. (2008) estimated national IDEA Part C eligibility, based on the Birth Cohort of the Early Childhood Longitudinal Study, and found that approximately 13% of children 24 months of age and younger met the eligibility criteria. However, only 10% of the children eligible were participating in these services. Moreover, it appears that there are extensive disparities in participation rates based on race/ethnicity and socioeconomic status (SES). In an examination of a large representative sample of 4-year-olds in the U.S., Morgan et al. (2012) found that children from families with a low SES, and children living in homes where a language other than English was primarily spoken had lower rates of participation in ECSE. Additionally, studies have found that Black (Morgan et al., 2012; Rosenberg et al., 2008) and Asian (Morgan et al., 2012) children were similarly less likely to participate in ECSE.

Varying explanations for these disparities are found in the research literature. Some authors have highlighted the disparities in diagnoses and participation in early intervention services for children with disabilities who are from families in poverty and children from certain racial and ethnic groups as an accessibility issue, specifically lacking access to health insurance and diagnosis (Liptak et al., 2008). However, other scholars have recognized that many families from racial and ethnic minority groups are aware of their child's diagnosis, but may choose not to participate in mainstream services such as ECSE, in part due to lack of cultural appropriateness, and may also choose family and peer support instead (Garcia et al., 2000; Eiraldi et al, 2006). For example, Eiraldi et al. (2006) developed a “model of help-seeking behavior” based on research evidence that highlights the cultural



factors that contribute to the decision-making of parents from ethnic minority groups regarding service participation for their children with ADHD. This model includes the recognition that cultural norms and values likely carry a stronger weight in service decision-making for families than professional recommendations from outside of the cultural group (Eiraldi et al., 2006).

Due to these known social justice implications of disparities in access and service utilization, social workers and others involved in advocating for families with disabilities should be cognizant of potential issues of systemic racism, classism, sexism, and ableism, and should advocate for historically oppressed groups accordingly. Additionally, since anyone concerned about the development of a young child can refer for developmental screening (including the ability for families to self-refer), early identification and referral to early interventions can significantly improve support for families and potential developmental outcomes.

### Box 5.2. Case example, Part 1: Early Childhood

**Referral:** Maribel Sanchez-Guerrero comes to the attention of the county's Help Me Grow program staff following a recommendation for services from the family's physician. The initial phone call for developmental screening comes in from a woman named Luciana, who states that she is a family resource advocate from a community clinic that works primarily with the undocumented Latine population. She states that she is calling on behalf of a mother who does not speak English very well. Luciana provides the following information:

**Background:** During a well-child visit at the clinic, Carmela Sanchez-Guerrero states that she is concerned about her 2-and-a-half-year-old daughter's growth and her not meeting developmental milestones. Carmela reports that Maribel has barely begun to speak and has delays in many areas. For example, she did not walk until over age two, and while she can walk now, she seems clumsy and uncoordinated. Carmela also reports that Maribel struggles to hold a crayon and a spoon. The physician recommended that Carmela call Help Me Grow and made in-clinic referrals for both a more extensive eye exam and hearing test since Maribel did not pass either of these screenings during the well-child check. Luciana called Carmela at the physician's request to follow up on the status of the referrals and offer assistance. Luciana learned that Carmela followed up on the vision and hearing tests, and Maribel has since been prescribed eyeglasses and has also been diagnosed with a mild hearing impairment and received a referral for a specialty clinic to assess for hearing aids. Carmela tearfully tells Luciana that she has not scheduled the additional hearing test and she did not contact Help Me Grow because they are not documented and she was concerned about being reported and not being able to afford any of the services. Carmela stated that she trusted the community clinic,

but felt very anxious about reaching out to other programs or clinics because she had a cousin who was deported following an attempt to get public benefits. Luciana states that she assured Carmela that the Help Me Grow program was provided in partnership with the public school system (IDEA, Part C), and that seemed to reassure Carmela, as she states that she has an older son who is in the local public school and that it has been a positive experience, and they have felt safe. She asks Luciana for assistance with the calls due to her limited English.

The Sanchez-Guerrero family consists of Jorge Guerrero, age 30, who is employed by his cousin doing home siding and roofing; Carmela Sanchez-Guerrero, age 25, has worked in food service occasionally, but is primarily staying home with the younger children; Diego Sanchez-Guerrero, age 7, attends first grade at the local public school and appears healthy; Maribel Sanchez-Guerrero, age 2 and a half, presents signs of developmental delays in gross motor and fine motor control and speech. She also has a hearing impairment; Mateo Sanchez-Guerrero, age 13 months, appears healthy; Carmela also reports that she is about 5 months pregnant and that the pregnancy is going well. The parents report that they came to the U.S. for work 3 years ago when Carmela was pregnant and Diego was 4. Maribel was born in the U.S. They live in the lower part of a home owned by Jorge's cousin who is his employer. The two families help one another, and it seems to be a stable and supportive, although crowded, living situation.

### **Part 1 Discussion questions:**

- What social justice and disability justice issues are present?
- Apply the practice model from Chapter 2, with an emphasis on
  - The pre-engagement stage: consider issues of anti-oppressive practice, intersectionality, and critical cultural competence.
  - The engagement stage: Which issues and strategies will be important to consider in beginning work with this family?

## **Providing Services for School-Aged Children and Youth**

School-aged children and youth can receive a variety of disability services and supports, in a variety of settings. These supports are not exclusively tied to a classroom or physical location within the school, as services are intended to be highly individualized to each student's needs. There are six main levels of support (see Chart 5.3). Beginning with the lowest level of intervention, "Push-in services" involve a specialist (such as an

occupational therapist or speech and language therapist) coming into the classroom to provide support to the teacher during designated regular instruction times. “Pull-out services” involve pulling the student out of class to work with a specialist individually or with a group for a designated period of time, such as a speech therapy session or social skills group. “Inclusive classrooms” are settings that have a mix of typically developing and disabled peers, with needed services and supports embedded into the classroom. “Exclusive education classrooms” typically involve a smaller classroom that is encompassed of children receiving special education services, with a lower student-to-teacher ratio to provide students with the levels of support that they need. “Specialty schools” are entire school settings that are designed specifically for children with disabilities, and sometimes a specific disability. These specialty schools can be public schools, charter schools, or private. The most restrictive educational settings for children with disabilities are “Residential programs.” These programs are for children who need 24-hour care and services, and who would not have their needs met in a community setting. Due to the intense level of services, we discuss residential programs in more detail later in this chapter, including some of the associated controversial and ethical issues.

Chart 5.3. Levels of Special Education Support



## Individualized Education Plan

Like an IFSP, an Individualized Education Plan (IEP) is a document that dictates the services to be provided, the goals, and methods by which to attain those goals, including the level of services and supports that are to be provided. IEPs hold school districts accountable for providing these services and serve as a contract. An IEP is

required to be reviewed on an annual basis. However, the review can happen more frequently at the caregiver's request. All service providers, parents/caregivers, case managers, teachers, and school district representatives are all invited to attend, as well as the children themselves at the age of 14 and older (by law), with many teams including children at much younger ages. Children are re-evaluated at least once every three years.

While the IEP is intended to be a collaborative process, many times the involved parties do not agree. It is important for social workers to hold true to the professional values of client self-determination, as well as person-centered and family-centered practices. Parents and disabled youth who do not agree with the plans set forth by the school are entitled to “due process” via the IDEA legislation. Families and schools that cannot come to an agreement on their own can enter this mediation process, which needs to be initiated by the parents/caregivers, who file a complaint with their local/state department of education. There are deadlines and specific processes that need to be followed, and social workers who are working with disabled children and their families (whether as school social workers or as advocates) should be aware of this process, and always advocate for the best interests of the child and family. More information on the IDEA legislation in regards to due process complaints can be found at the next website <https://sites.ed.gov/idea/regs/b/e/300.508>, and some helpful information for parents and caregivers regarding their rights and advocacy (including sample forms for requesting a due process hearing) can be found at The PACER Center: <https://www.pacer.org/learning-center/dispute-resolution/due-process-options/due-process-complaints-and-hearing.asp>.

### Box 5.3. Case example, Part 2: Early school-age

Maribel Sanchez-Guerrero is now 9 years old and in third grade. She has been attending the community elementary school that her older brother Diego had attended (who is now 13 and in middle school), as is her brother Mateo (age 7, 1st grade), and brother Marcos (age 5, Kindergarten). Maribel has an IEP, and is in a mainstream classroom with supports, with occasional pull-out to the special education room to complete work. The school social worker has been exploring reports of teacher concerns over this past school year, and is planning assessments for alternative diagnoses, level of care and supports.

**Background:** Following the initial in-home supports and services provided via Help Me Grow, Maribel attended a special education preschool program offered in their school district for children ages 3 – 5 (IDEA, Part B). She attended this program for 2 years prior to entering kindergarten, and did well in the program. She was well-liked by the teacher and aides, and also received several services in the preschool class setting, including speech and language therapy, physical therapy, occupational therapy, and audiology. The audiologist was able to help the family get connected with hearing aids for Maribel, and she gained strength and a lot of gross

and fine motor skills. Maribel thrived on the schedule and routine, and often reminded the teacher of the schedule. She transitioned to kindergarten with ease, as she had grown to love the school routine from her preschool experience. She developed a particular interest in books, which was nurtured and encouraged both at home and at school – especially books about horses! Because of her quiet nature, adherence to routines and schedules, and her love of books, Maribel did well in kindergarten, first and second grade. Her primary diagnosis for her IEP is her hearing impairment, and she is also continuing to receive speech therapy and occupational therapy.

**Current concerns:** Challenges began to arise in the transition to third grade. Teachers and aids have reported that Maribel appears to be struggling to pay attention and seems withdrawn. She has a somewhat flat affect, and only appears to be engaged and interested when it is reading time. While Maribel continues to adhere to the routine and schedule of the day, she seems generally uninterested and has had a few outbursts (screaming, punching the desk or wall, pulling her own hair) when she has been pushed by adults to become more engaged. She does not have many friends, although was well-liked by her classmates up until the more recent challenges. She did have one close friend who has been pulling away from Maribel, stating to the teacher that Maribel is babyish as she still only wants to talk about and play horses instead of tag and soccer with the other kids. School

staff had suggested that Maribel may have ADHD (inattentive type) or perhaps depression, however the school social worker suspected Autism, as they had recently attended a training about Autism in girls, and how it can present differently from boys and often goes hidden and undiagnosed until later than boys. This suspicion proved correct, and Maribel was given a school diagnosis of Autism, with a recommendation for more specialized services.

### **Part 2 Discussion questions:**

- What new disability justice issues have arisen in this case at this stage?
- Where are some of the missed opportunities for service provision? How could things have been done differently/better?
- Apply the practice model from Chapter 2, with an emphasis on
  - The Assessment stage
  - The Intervention stage

## 504 plans

Students covered under IDEA are simultaneously protected by section 504 of the Rehabilitation Act. However, many students who do not qualify for special education services under IDEA still benefit from a 504 plan. Since IDEA requires that students both meet the diagnostic criteria and need special education services, some children who need accommodations but do not meet the IDEA definition standards could fall through the cracks. Students who have health conditions such as diabetes or food allergies, mental health diagnoses, and mild ADHD can receive accommodations via a 504 plan such as allowance of increased breaks or visits to the nurse's office, use of pre-approved fidgets, specific seating arrangements that reduce distractions, and homework and/or testing modifications, as well as protections from discrimination for needing to use these accommodations.

Within over 1.3 million children who receive services solely under a 504 plan, there is evidence that these students are overwhelmingly male, and White (Zirkel & Weathers, 2015). Moreover, there is significant state variation in the use of 504 student protections, ranging from less than 1% to almost 7% (Zirkel & Gullo, 2021). Thus, social workers working with children and youth should advocate for full and equitable access to protections offered by Section 504.

## The controversy of mainstream/inclusion versus disability-centered rooms and schools

Many advocates call for full inclusion of children with disabilities in mainstream educational settings, arguing that it is more socially just to give disabled children access to everything that their non-disabled peers have and to support and encourage full acceptance and inclusion of disabled children into the community. A key point of this viewpoint is that separate schools are segregated schools, which violates the right to a free and appropriate public education in the least restrictive environment as stipulated by IDEA (see the 2018 report by the National Council on Disability titled *The Segregation of Students with Disabilities* here: [https://ncd.gov/sites/default/files/NCD\\_Segregation-SWD\\_508.pdf](https://ncd.gov/sites/default/files/NCD_Segregation-SWD_508.pdf)). However, other advocates counter that *some* children with disabilities thrive best when in an environment designed specifically to meet their needs, versus forcing inclusion within systems that are ableist in their inception and design. Advocates of this approach are generally referring to a specific subgroup of disabled youth who would be considered to have a greater level of impairment from their disability, and thus require a higher level of supports and services. These advocates argue that the term “specialized” education is a better term to use than segregated, as it creates an accepting environment full of services and specialists, which supports disabled students feeling welcomed, wanted, and better able to develop relationships due to the presence of a true community of peers. Read one dad's take on this perspective here: <https://www.disabilityandemployment.net/2019/01/07/why-i-support-segregated-schools/>.

## The role of the school social worker

School social workers are employed by the school district and provide a variety of services within the education setting. School social workers work along the micro-to-macro practice continuum, working directly with students, parents and families, school personnel, and school districts, and connect to resources within the broader community. School social workers provide direct services, including crisis intervention, counseling, social skills groups, assisting families to connect with school and community resources, conducting student assessment, and providing support to staff. They also provide many indirect services, such as participating in IEP meetings, special education case management, planning training programs for school staff (i.e. anti-bullying, suicide screening and prevention), provide consultation regarding school policies, and address attendance concerns (School Social Work Association of America, 2021, [www.sswaa.org](http://www.sswaa.org)).

## Education in Residential Settings (a Deep and Critical Dive)

According to the OSEP data, 13,725 children with disabilities received their education in a residential setting during the 2019-2020 academic year (OSEP, 2021). While this is less than 1% of the total students receiving services in the various education settings, due to the abundance of potential social justice issues, as well as the high likelihood of intersection with social workers, this topic deserves some special attention.

## History of Residential Settings

The inception of residential settings arose from the intersection of several institutions; state government, carceral system, faith-based charities, and education (Richardson and Parker, 1993, p.364). Each of these institutions have upheld a specific framework, i.e. white supremacist/colonist ideology, of who is “worthy” of resources, access, and ultimately deemed a “person.” This ideology holds especially true in the creation, functionality, utility, and treatment of children enrolled in residential schooling. The beginning of these residential school settings occurred in the early 1800’s initially for children, “considered indispensable” who were blind, visually impaired, deaf, hard of hearing and/or hearing impaired, and “were all marked by the common need of specialized guidance and adjusted educational procedures” (Martens, 1940, p.1). These were “welfare institutions designed to give care and training to those with serious handicaps appeared to make institutional care necessary” (Martens, 1940, p.3). It is essential to situate the development of residential schools within the political context as education institutions are typically one of the first spaces to mirror the current circumstances. During this time, the dehumanization of those deemed “disabled” was acceptable and in the 1860’s written into municipal statutes, known as the “Ugly Laws.” This outlawed the appearance of those who “diseased, maimed, mutilated and or deformed, as to be an unsightly or disgusting object” and this



undoubtedly intersected with the education system in the choice to send disabled children away to school, versus inclusion in school with non-disabled children (Wilson, 2015).

Additionally, in the mid-1800's the rise and government implementation of residential boarding schools inflicted a wave of violent assimilation and acts of genocide on Indigenous communities across the country in efforts of "civilization" (Keating, 2016). It wasn't until 1862 that the Emancipation Proclamation prompted the end of slavery, in which Black communities who were enslaved and free were still intentionally excluded from these spaces, unless there was crossover into carceral system specifically referrals to "state reform or industrial schools" (Richardson and Parker, 1993, p.364). Lakshmi Piepzna-Samarashinha provides a larger perspective to the realities that BIPOC communities were experiencing and the means for survival that were not tied to state organized and endorsed systems.

*for many sick and disabled Black, Indigenous, and brown people under transatlantic enslavement, colonial invasion, and forced labor, there was no such thing as state-funded care. Instead if we were too sick or disabled to work, we were often killed, sold, or left to die, because we were not making factory or plantation owners money. Sick, disabled, Mad, Deaf, and neurodivergent people's care and treatment varied according to our race, class, gender, and location, but for the most part, at best, we were able to evade capture and find ways of caring for ourselves or being cared for by our families, nations, or communities — from our Black and brown communities to disabled communities* (2018, p.38).

The historical context here has undoubtedly influenced the structure of residential schooling for those with disabilities or those societally labeled as "disabled" and who have received access to these spaces. Regardless of the societal perspective of residential schooling, the creation and sustained operation of these spaces was the initial step to creating access to education and care for disabled children, who were often outcast from their community, family, and shared spaces. Arguably, these residential settings did provide more community for those with similar experiences, tailored education, and an opportunity not possible before. In addition, residential schools were also created for those "mentally deficient" and "socially maladaptive/juvenile delinquent" (Martens, 1940, p.63, p.83). It is important to note that the use of language here is now outdated. The 18th and 19th century reform movements and medieval church valuing "charity" created "health services for children" which included "orphanages, hospitals, homes, asylums, and later in the early 20th century psychiatric facilities" for those who were "poor, retarded, sick and mentally ill" (Leitchman, 2006). This vastly expanded the variety of residential settings that children, adolescents, and young adults with disabilities encountered when trying to access care, education, or forced to comply with society's expectation of invisibility. It was not until the Education for all Handicapped Children Act of 1975 that instituted a federal mandate for inclusivity, accommodation, and access to education for children with disabilities (see other sections in this chapter and text for more details on this policy). Despite this federal policy, the implementation varied across states, counties, and communities for guaranteeing access to education, fueling disparities and intersystem interactions, i.e. education, carceral, and medical care complexes. This is still quite present today.

## Decision-Making Process

In the 1800s-early 1900s, the process of enrolling or simply sending a young person to these institutions for schooling was fairly straightforward as there were literally no other options. However, access was likely not equal across race and ethnicity. Segregated schools were established, such as the Texas Deaf, Blind, and Orphan School for Colored Youth, which was established in 1887 (Markham, 2020). Yet, the inclusion of disabled students from various racial and ethnic backgrounds in these residential schools may have been more progressive than public schools, as some schools for the Deaf and Blind were integrated, including both White and Black students as early as the beginning of the 20th century. For example, the St. Augustine School for the Deaf and Blind, which opened in 1885, graduated its first Black student in 1914 (African American Registry, 2022).

The shift in policy, political climate, the deinstitutionalization movement, and community activism (see Chapters 9 Behavioral Health Care and Chapter 14 Disability Civil Rights Movement) led to *Wyatt v. Stickney* in 1971, which “decided that people in residential state schools and institutions have a constitutional right to receive such individual treatment as would give them a realistic opportunity to be cured or to improve his or her mental condition. Disabled people could no longer be locked away in institutions without treatment or education” (Southern Adirondack Independent Living, 2018). The shift away from institutionalization especially with those with psychiatric disabilities was “contrary to the original intent of moving people out of institutions, smaller versions of highly supervised, regulated, and to a large extent, segregated residential environments trapped residents in a kind of trans-institutionalization” (Farkas and Coe, 2019, p.2).

There was no clear policy that ensured education in residential settings until 1975 (see the section on the Rehabilitation Act of 1975), and even so, the implementation varied due to state control, which then often referred to the district, then again referred down to the facility themselves. The Department of Education is to be the “governing body,” but the implementation of access was not further solidified until 1990 with the passing of IDEA. These structures are important to consider as it relates to the practice of the school, families, and other systems involved or absent in the placement process. This is a highly debated process, as heavily influenced by individuals or systems, who have the power, authority, and legality to make the serious decision (given the array of services available in the community) of removing a child from a community setting.

These removals were previously “justified on the basis of community protection, child protection and benefits of residential treatment,” (U.S. Surgeon General, 1999, p.170), but lacking research consistent with their effectiveness, even though they were “widely used but empirically unjustified services” (Hoagwood et al., 2001, p.1185). During the 1990s, skepticism arose due to the overuse of residential facilities and proposed that community settings “such as day hospitals, family preservation programs, wraparound services, and multisystemic treatment” were more appropriate, especially as increased medication use reduced some of the more serious symptoms (Baldessarini, 2000, as cited by Magellan Health Services, 2008, p.3). Given this context, the decision-making process has become increasingly important and layered in ensuring the autonomy, independence, health, safety, wellness, and education of the individual. The right to self-

determination, the inherent dignity and worth of a person, as well as a least restrictive environment, are priorities in this process, especially for caregivers and individuals without disabilities who are involved in decision-making with and for minors with disabilities.

Abbott, Morris, and Ward discuss the whole placement process experience from the family and student perspective. Overall, there is a somewhat unclear process in the collaboration between residential-setting and community-education staff, health care providers, assessors, and correctional setting professionals (depending on circumstance) working with families or the young people themselves (2001). See Table 5.1 below, highlighting Abbott, Morris, and Ward’s summary findings about perspectives in the decision-making process (2001).

Table 5.1. Perspectives of Residential Placement, from Abbott, Morris, and Ward’s findings (summary, 2001).

| Negative Perspective                | Ambivalent Perspective  | Positive Perspective                         |
|-------------------------------------|---|--|
| <i>“homesick”</i>                   |   |  |
| <i>“Nervous”</i>                    | <i>“mixed feelings about being placed in residential setting”</i>   |  |
| <i>“uncertainty”</i>                | <i>“delayed timeline for placement”</i>   | <i>“excited to potentially make friends”</i> |
| <i>“avoidant about the process”</i> | <i>“process included those who have no interaction with young person/student”</i>                                       |  |
| <i>“not a preferred option”</i>     | <i>“lack of transparency in the process, regulations, and communication with the child once in residential setting”</i> | <i>“more independence”</i>                   |
| <i>“difficulty decision”</i>        |   |  |

## Overview of Services and Education in Residential Settings

The care received varies based on the specific population, needs, identities, and collective community within the setting. Additionally, the structure, operation, regulation, and funding for these facilities can influence the quality and/or quantity of care and education. Specifically, there is more research available about treatment, care, and education. Generally, “more is known about the behavioral and mental health functioning of children in care. Little research has been conducted on the academic functioning of children in residential care and even less on children with disabilities in this population.” (Trout et al., 2008, p. 126). Additional factors influencing this placement could be “histories of family instability; substance, sexual, and physical abuse; neglect; high-crime neighborhoods; poor social supports; and frequent out-of-home placements. Many of these children present significant behavioral, mental health, and educational problems that require treatment while in care” (Trout et al, 2009, p. 112). These influences also mirror the intersections of the child welfare system, carceral state, and medical complex, with undoubtedly disproportionate and detrimental long-term effects for the disability community.

Residential, congregate, and group care settings are “theoretically intended as a placement of last resort, and as a response to characteristics or psychosocial problems that cannot be addressed in less restrictive family-based settings” while community-based options have more concrete evidence as being an effective form of care, treatment, and education (Barth, 2002 as cited by James, 2012, p.1). There are legitimate risks associated with the placement due to systemic influxes and circumstances such as “staff with often inadequate training and high turnover rates, issues of safety, and potential for abuse as well as negative peer processes” (e.g. Burns et al., 1999; Dishion et al., 1999 as cited by James, 2012, p.2). In addition to decreasing these risks, the following elements are necessary for effective treatment within residential settings : “family involvement (both in the family-centered approach but also close physical proximity to access the residential setting), Placement Stability and Discharge Planning (start at the time of admission, knowing what is needed in community) and Community Involvement and Services (facilitated community connection while in residential treatment and availability, accessibility, and appropriate supports for individual and family)” (Magellan, 2008, p. 6-7). There are circumstances in which these settings are beneficial to individuals and their families, whether a short, interim, or long-term duration. Magellan states there are decades of evidence that demonstrates “there are effective alternative community-based services for those children who can safely be treated at home” (2008, p.2). Additional resources that are alternative to residential settings include “therapeutic foster care, multidimensional treatment foster care, therapeutic group homes, case management, wraparound, multisystemic therapy, assertive community treatment, mentoring” and also community care networks. (Magellan, 2008, p. 8-10). Some of these treatments and supports, children have experienced prior to residential placement and could have been deemed inappropriate at the time. The needs, wants, and trajectory of every individual is continually changing, but it is crucial for resources, opportunities, and choice to reflect that adequately.

## Controversies in Residential Settings

Given the functionality, use, and appropriateness of residential and community settings, there are many controversies, gray areas, and ethical dilemmas that may arise. The following are a few examples to consider when evaluating the intersection of disability, education, social work, and social justice:

- There is a clear balance between upholding two different requirements of IDEA: “the most appropriate setting” and the “least restrictive environment.” The details within these definitions are individualized and based on how that shows up for each child. Additionally, it is reliant upon the resources that are available within the community, and the financial, logistic, and practical accessibility of that resource. Residential settings are often more focused on the disability and the related treatments, responses, and therapies (often prioritized due to heightened needs) than on educational pieces, which is cause for controversy.
- There can be a large difference between considering the power, authority, rights, and wellness of the

- caregiver and the child (which may differ, interfere, or jeopardize the other). This is especially heightened regarding the voluntary or involuntary nature of the residential placement or community-based options.
- The current use of shock and aversive therapy. Opponents of this approach draw attention to practices that are arguably inhumane, including the use of a graduated electronic decelerator (GED), in which electrodes are attached to the child's legs and arms for up to 24 hours a day, with a device in the control of the paraprofessional/medical provider, with the ability to administer a shock to "correct" and "modify" an undesirable behavior (McFadden et al., 2021). There is a plethora of evidence ranging from 2012-2019 of the negligence, inconsistency, and abuse that these devices inflict on students who may have intellectual, developmental, and emotional disabilities that affect their communication, decision-making, and cognition, which certainly amplifies the controversy around this treatment (McFadden et al., 2021). Additionally, these young people may come from histories of abuse, neglect, and physical punishment for their own existence, identity, and disability.
  - Applied Behavioral Analysis (ABA) is a long-standing, widely used, and fairly controversial behavior-based intervention used on children with disabilities. ABA originally founded in 1970 by Ivan Lovah and Robert Koehler, "is a scientific discipline that essentially involves the application of techniques that are based on the principles of changing the behaviors to what is socially acceptable (Understanding ABA, 2019 as cited in Dhawan, 2021, p.381)." The manner in which this is done is heavily focused on the consequences of the behavior and repetitive corrective responses to changing what is deemed as "socially unacceptable." There is a history of punitive and physical forms of "correcting the unwanted behaviors," and there has been a shift in utilizing reward-based systems for behavioral intervention. The following site provides an overview of ABA and the advantages [About ABA – MyABA Today](#). The following video from Chloe Everett, a neurodivergent individual, provides her own perspective on the history and current ramifications of ABA. [The Problem with Applied Behavior Analysis | Chloe Everett | TEDxUNCAsheville – YouTube](#)

## Advocacy and Justice for School-Aged Children and Youth

There are several important social justice issues and concerns for disabled school-aged children and youth in the educational system. While not an exhaustive discussion of all of these issues, some of these topics will be discussed below.

### The disproportionate number of children of color in the U.S. Special Education system

Students from all racial/ethnic groups, other than Asian students, have higher rates of participation in special education than White students. One theory for why this disproportionality occurs is that students of color may actually have higher rates of disabilities than their White peers, due to a variety of factors related to

intersectionality, SES, and Adverse Childhood Experiences (ACEs). Additionally, there is evidence of systemic racial bias, resulting in students of color being identified as disabled in ways that differ from White students (National Center for Learning Disabilities, 2020).

An additional concern is the patterns of disproportionate use of some diagnoses in certain populations, referred to as **diagnostic bias**, for example, assigning African American males with conduct disorder and their White male counterparts with a mood or anxiety disorder for similar behaviors (Mizock & Harkins, 2011). This phenomenon can take place within the U.S. education system as well, and is not a problem with the IDEA policy as it is written, but rather a problem with implementation and systemic racist practices within the diagnostic labeling process.

## Disparities in Discipline Practices

Another significant issue of concern for social workers is the glaring evidence of systemic racism with discipline practices for students with disabilities, and in particular, disabled students of color. Discipline disparities take the form of harsher punishments for similar behaviors, including suspensions and expulsions. While there is evidence that discipline disparities are present for all BIPOC children and youth in the education system, the disparities are even more stark for BIPOC children with disabilities. Research evidence shows that Black males from low SES households who are in special education are suspended at the highest rates of any group. The causes of these disparate practices are layered, intersecting with systemic racism, teacher bias, and SES (National Center for Learning Disabilities, 2020). Additionally, emerging research shows that Black girls are disciplined at rates 6 times that of White girls, and were suspended at rates significantly higher than boys (U.S. Department of Education, 2014). This speaks to the intersections of race, disability, and gender in school discipline practices.

The U.S. Department of Education, Office for Civil Rights (OCR) presented the following Data Collection in June 2021: [Exclusionary discipline practices in public schools, 2017-18 \(PDF\) \(ed.gov\)](#). It is important to note that this data presented is from 2017-2018, which is before the global COVID-19 pandemic, which has undoubtedly affected the education system. The Civil Rights Data Collection includes data on public education ranging from pre-K through 12th grade in all 50 states, D.C. and Puerto Rico. Education settings in this data include: “charter schools, alternative schools, juvenile justice facilities, and special education facilities, and school district data at large” (OCR 2021, Slide 2). The total number of students attending public schools was 50.9 million, and students with disabilities make up over 8.1 million (15.9%) of the total population (OCR, 2021, Slide 3). Overall, there was a 2% decrease in disciplinary actions, but “increased discipline practices of 1) school-related arrests; 2) expulsions with education services, and 3) referrals to law enforcement” (OCR, 2021, Slide 4). This relates to a concept referred to as “the school-to-prison pipeline,” which is discussed below. Students with disabilities who are receiving services under IDEA “represented 13.2% of the total student enrollment and received 23.3% of all expulsions with education services and 14.8% of expulsions without education services” (OCR, 2021, Slide 13). The disparities grow wider as disability intersects with



race and ethnicity, as “Black students served under IDEA accounted for 2.3% of total enrollment, but received 6.2% of one or more in-school suspensions and 8.8% of one or more out-of-school suspensions” (OCR, 2021, Slide 19). Furtado et al. further state that these disparities are of heightened concern because “the way we enforce rules and assign penalties like OSS (out-of-school suspensions) is not effective at preventing future misbehavior, and the cost of discipline gap lies in the billions of dollars in lost education time, increased risk of incarceration which leads to diminished productivity and income long into adulthood” (2019, p.5).

Caregivers of children with disabilities and social workers should be aware of the special rules regarding discipline and children with IEP’s, which differ from children without an IEP in place. Children with IEP’s have some extra protections regarding discipline practices, as many behaviors that rise to the level of requiring discipline are actually manifestations of the disability itself. One example is impulsive behaviors that may be aggressive, yet the child in question is receiving services for Attention Deficit Hyperactivity Disorder, Impulsive Type. Children with IEP’s can still be disciplined and even suspended. However, this generally cannot exceed 10 days in a row (and in some cases within a given school year), or it is viewed as a change of placement. More information on these special rules, including advocacy tips for caregivers can be found at Kidlegal.org: <https://kidslegal.org/special-education-discipline-suspensions-and-expulsions>

## School to Prison Pipeline

This term refers to policies and practices that push children out of school systems and into juvenile justice and criminal justice systems, via police presence in schools (resulting in police intervention for situations that could be handled by the school), zero-tolerance policies (criminalizing minor rule infractions) and other harsh discipline practices (ACLU, 2022). Given the evidence of disparities in discipline practices for students with disabilities, which are heightened when intersected with race and ethnicity, social workers can advocate for and implement a number of strategies that can interrupt the pipeline. A good resource for disrupting the school-to-prison pipeline for students with disabilities is the National Council on Disability report on this topic from 2015. A couple of documented and promising strategies include:

- *Trauma-Informed Schools*. This is an initiative introduced to the U.S. House of Representatives through the Trauma-Informed Schools Act of 2019 [E:\BILLS\H4146.IH \(govinfo.gov\)](https://www.govinfo.gov/bills/116/4146), which is founded on “a shared understanding for all school staff that trauma is common among students and can impact relationships, behavior, and learning” (Bakke Dahl et al., 2021, p.3). This includes not only training and activities for staff, but also a requirement of discipline practices that are centered on “holistic assessments and positive behavioral interventions aimed at addressing the underlying cause of the behavior that avoid harsh, punitive, or exclusionary discipline” (Bakke Dahl et al., 2021, p.3). Here is a toolkit that can help schools achieve a Trauma-Informed approach: *Becoming a Trauma Responsive School Step by Step Toolkit*: <https://www.trepeducator.org/trauma-responsive-school>
- *Restorative Justice Practices*. Restorative practices in schools provide an alternative to discipline, by



having students work collectively to resolve interpersonal conflict and behavioral challenges. The process involves helping individuals who have caused harm to take responsibility, which “requires understanding how the behavior affected others, acknowledging that the behavior was harmful to others, taking action to repair the harm, and making changes necessary to avoid such behavior in the future” (Schott Foundation for Public Education, 2014, p. 2). This is an evidence-based practice, showing improvements in attendance, and reductions in serious behavioral concerns, such as suspensions and expulsions. An example of one district-wide program and outcomes from their shift to restorative practices can be found here: [The Free Legal Right Center work with Minneapolis Public Schools](#) (2013). Additionally, here is a link to a restorative practices guide, put together by Communities for Restorative Justice ([www.C4RJ.com](http://www.C4RJ.com)): <https://www.c4rj.org/images/c4rj-schools-toolkit-revised-2017.pdf>

### Box 5.4. Case example Part 3: Later school-age

Following the school diagnosis of Autism, a recommendation was made for Maribel to change schools to attend a specialized ASD program within the district. Switching to the Autism program in fourth grade proved to be beneficial for Maribel in many ways. She was able to receive services and supports more suited to her needs, such as a friendship skills group, teachers and aides trained in ASD, and an education plan better tailored to her specific presentation of Autism. She also developed some friendships with some of the other children in the Autism program. However, family involvement and communication significantly decreased once Maribel changed schools. The school with the Autism program did not have a strong Latine community as the school in the Sanchez-Guerrero family’s neighborhood. Interpreters were challenging to arrange, and Carmela was often caring for younger children in the family. Lack of family involvement continued to be a challenge for school staff, who often expressed frustration with the family to the school social worker.

#### **Part 3 Discussion questions:**

- What new disability justice issues have arisen in this case at this stage?
- Where are some of the missed opportunities for service provision? How could things have been done differently/better?
- Apply the practice model from Chapter 2.
  - Which stages of the practice model do you feel apply in this situation?
  - Discuss each stage as it applies to the case given the current situation.

## Providing Services for Youth and Young Adults in the Transitions Program

Transition planning is integral to supporting students with disabilities and their families, as services provided can assist in determining the appropriate level of supports and services to enhance community living in adulthood. This planning process begins at age 16 for students with mild to moderate disabilities, and can begin earlier for those with more severe disabilities, with variation based on school district practices. Disabled youth and their families should be actively involved in this process, ensuring that they are knowledgeable about their options and get connected to the services that are needed, which could include additional education or training (i.e. university, trade school, or other training program), employment (independent or supported), and any other services or entitlements that promote successful living in the community after aging out of the education system. The specifics within IDEA 2004 revisions include the following (Sec.602[34])

“(a) Transition services means a coordinated set of activities for a child with a disability that—

(1) Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(2) Is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and includes—

(i) Instruction;

(ii) Related services;

(iii) Community experiences;

(iv) The development of employment and other post-school adult living objectives; and

(v) If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.

(b) Transition services for children with disabilities may be special education, if provided as specially designed instruction, or a related service, if required to assist a child with a disability to benefit from special education” (<https://sites.ed.gov/idea/regs/b/a/300.43>).

## Transition Planning Models

There are a variety of models utilized in the transitional planning process. In their book *Successful Transition Programs: Pathways for Students With Intellectual and Developmental Disabilities*, McDonnell and Hardman (2009) highlight a variety of models used to support this process. Models vary based on which process would best support the individual student’s needs. For example, the Bridges from School to Working Life model focuses primarily on preparing students for paid employment post-high school completion, which include

the use of specific vocational training programs. Alternatively, the Kohler Model emphasizes that transition planning is the foundation of education, versus an add-on service. This model prioritizes student and family involvement, as well as collaboration of services (McDonnell and Hardman, 2009).

Consideration for developing IEP and Transition Planning cooperatively. IEPs and Transition Plans are an integral component to ensuring that students have support, access, accommodations, and resources within a school setting as they serve as contracts for the services and supports to be provided. They can vastly influence the experience and education that the individual students receive, for better or for worse. McDonnell and Hardman (2009) suggest the following elements to be integral to ensuring a collaborative IEP, especially within the transition planning process:

- *Person-Centered Planning* – with the student’s own leadership and expertise in the IEP/Transition process
- *Family Involvement* – including the support system and care network to collaborate with and also share information/education about resources.
- *Cumulatively Developing Student Capacity for Adult Life* – ongoing experience of transition planning, beginning no later than 16 years of age and school courses, experiences, and employment that support this transition planning process
- *Follow Steps for Developing IEP/Transition planning*
  1. Organize the Planning Team – including educators, administration, medical staff, and educational support professionals, families, the student, and outside organizations. Past school personnel may also be consulted in this process.
  2. Conduct Futures Planning – utilize students’ interests and goals to guide this process, and provide connection to resources and path/steps to get there.
  3. Conduct Student/Transition Assessment – determine the “present level of academic and functional performance in home, school, community, and employment settings (a) be valid for the student’s disability and functioning level, (b) be linked to the student’s current and projected postschool environments, (c) be focused on the student’s strengths, and (d) support a person-centered approach to establishing the student’s post-school goals.”
  4. Establish IEP/Transition Priorities – goals and objectives are created from the assessment, including ways to measure goal attainment.
  5. Conduct IEP/Transition Planning Meeting – this is the actual space provided to collaborate with the student, family, and community about all the information collected and developing a plan for next steps for each party
  6. Complete Follow-Up Activities – this includes finalizing the plan, regulatory requirements within the plan, shared with team members, family, and student, along with next steps for ensuring the plan is being implemented (p. 83-98).

## Transition Planning Outside of the School System

In addition to the transition planning services provided under IDEA, many youth with disabilities receive additional services and supports for transitioning to adulthood outside of the U.S. education system. These services and supports can occur within privately funded social service programs, or under services provided by federal and state legislation. The National Youth Transitions Center houses many online resources regarding transition planning and services, and they also provide programming for career exploration and counseling, work-based learning, family education, and support, as well as other services. (<https://thenytc.org/aboutnytc>).

### Chafee Program for Successful Transition to Adulthood

Adolescents and young adults who are aging out of the foster care system and services receive support from two primary programs: the federal foster care program and John H. Chafee Program for Successful Transition to Adulthood program (42 U.S. Code § 677), which is administered by the U.S. Department of Health and Human Services. Specifically, the Chafee program provides support for the adolescent and young adult range of 14-21 years old, and in some cases up to age 23. Given that almost one-third of children in foster care have disabilities according to national foster care data (Slayter, 2016), social workers should pay close attention to students involved in both students, to ensure that they are getting all of the services that support the transition to adulthood that they are eligible for. This program authorizes funds to states and agencies for services that “provid[e] assistance in obtaining a high school diploma, career exploration, training in daily living skills, training in budgeting and financial management skills, and preventive health activities, among other purposes” (Fernandes-Alcantara, Congressional Research Service, 2019). Since enactment in 1999, youth in foster care ages 14 and older have been eligible for services for financial, housing, counseling, employment, and educational support. Former foster youth, ages 18 to 21, and in some cases up to 23, can receive these services with additional support in education and training vouchers, including postsecondary options. Additionally, Chafee-funded services are extended to youth who have left foster care for kinship placements or adoption that occur after the age of 16 (Fernandes-Alcantara, Congressional Research Service, 2019).

#### Box 5.5. Case example Part 4: Transitions Planning

**Background:** Maribel continued in the same Autism program through middle school. The transition to high school was challenging for Maribel due to the change in routine and school. However, her family once again was able to increase their involvement in the school and in Maribel's education. This occurred due to the larger school (which included more of a Latine

population and staff) and closer proximity to the family's home. The school was also familiar to the Sanchez-Guerrero family due to Diego's prior attendance.

18-year-old Maribel Sanchez-Guerrero has recently entered her school district's "Transitions" program for students who have aged out of high school but are still eligible for services under the IDEA. As a goal of this program is to assist in connections to community resources and supports, the school social worker is assisting the family with connecting Maribel to Supplemental Security Income (SSI), as well as planning with the family for what comes next: further education, employment, housing needs, etc.

#### **Part 4 Discussion questions:**

- What new disability justice issues have arisen in this case at this stage?
- Which services and supports for disabled adults may be helpful for Maribel and her family?
- Consider shared decision-making. What strategies might be helpful for centering the perspectives of Maribel and her family?
- Apply the practice model from Chapter 2, thinking specifically about the role of a school social worker in a Transitions program setting.
  - Which stages of the practice model do you feel apply in this situation?
  - Discuss each stage as it applies to the case given the current situation.

## Access to University

Disabled adults are participating in higher education at increasing rates. Over the past few decades, rates of college/university students with disabilities have more than tripled. In 1992, 6.3% of the students reported having a disability (U.S. Department of Education, 2017), while in the 2015-2016 academic year, 19.4% of undergraduate students reported having a disability. Current rates also varied across demographics, with students who were veterans and students over the age of 30 having higher rates of disability than the mean (26% and 23% respectively, U.S. Department of Education, 2021). Additionally, American Indian/Alaskan Native students reported higher disability rates (28%), as did Pacific Islander students (24%), and multiracial students (22%) reported the highest rates of disability, while Asian students (15%) and Black students (17%) had the lowest rates of disability (U.S. Department of Education, 2021). In the same academic year, 12% of graduate students reported a disability (U.S. Department of Education, 2021).

There are two main categories for services and supports for college/university students with disabilities:

Mainstream supports through campus disability services, and special programming and practices. Campus disability services assist students to get needed accommodations in and out of the classroom, and these services are strictly following the ADA. Specialized programming can greatly increase access to higher education for students with disabilities, as services can extend beyond the bare minimum of providing ADA accommodations, to unique educational opportunities designed specifically for disabled students. These programs can be university specific, such as the ASK program at Kirkwood Community College in Cedar Rapids, IA (<https://www.kirkwood.edu/explore/services/learning-services/ask-program>). Other programs are not affiliated with a particular college or university, but rather a specific type of disability and/or demographic (e.g. National Black Deaf Advocates: <https://www.nbda.org/content/college-youth>) or a profession (e.g. Exceptional Nurse: <http://www.exceptionalnurse.com/>).

Additionally, Think College is a “national organization dedicated to developing, expanding, and improving inclusive higher education options for people with intellectual disability.” Explore the interactive map and search function to learn more: [College Search | Think College](#). Browse the National Center for College Students with Disabilities website (<https://www.nccsdonline.org/>) for more statistics and resources, including information about DREAM (Disability Rights, Education, Activism, and Mentoring) which gives disabled students an opportunity to connect with one another for community, advocacy, support and social justice.

### Box 5.6. Case Example Part 5: Closing Activity

Reflect on and discuss future plans for Maribel. Consider person-centered work and shared decision-making as key empowerment concepts to guide your discussion.

Resource: Review this open-access research report, highlighting Autism-Specific support programs for higher education: <https://link.springer.com/article/10.1007/s10803-021-04958-1>

- Is University a good option for her? What supports and services would she benefit from to make that work? What are some potential challenges and barriers, and how might they be overcome?
- What types of employment opportunities are present for Maribel? What supports and services would she benefit from to make that work? What are some potential challenges and barriers, and how might they be overcome?
- What are some considerations for evaluation (the final stage in the practice model) that you would make?

## Summary

In this chapter, we have covered a significant area of services for disabled children, young adults, and their families. These services are informed by a number of federal policies, and span from birth through age 21. These services are plagued by multiple social justice issues: racial/ethnic and gender disparities in accessibility and disciplinary practices; issues of power and control in decision-making; practice systems founded on White supremacy, colonialism, and ableism; among others. Despite these challenges and barriers, disability services provided within the U.S. educational system have the potential to provide beneficial and needed services and supports with fewer barriers (i.e. health insurance status and/or ability to pay, transportation) for access. There is much work for social workers to do, in partnering with disabled children and their families for advocacy, ensuring socially just practices and equal access and treatment for these services.

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[1] The authors have chosen to use the term BIPOC throughout this chapter as it is the term of preference at the time of writing, with humble recognition that this term is not preferred by everyone, and may not be the preferred term at the time that the reader is accessing this chapter. We will update the terminology as new language becomes a common social preference.

[2] The authors have chosen to use the term LGBTQ2S in an attempt to be inclusive of many different identities, recognizing that these are distinct identities and not monolithic. We recognize that this term may not be preferred by everyone. We utilize this acronym with humility, and will update the related terminology in this chapter as new terms become socially preferred.

6.

# AN OVERVIEW OF DISABLED CHILDREN AND PARENTS IN THE FAMILY POLICING SYSTEM

Elsbeth Slayter and Robyn Powell

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## Learning Objectives:

- To explore the ways that ableism and sanism have impacted disabled children and parents in the western context
- To document the ways that ableism and sanism impact parents and children in the family policing system
- To appreciate the voices of disabled children and parents in the family policing system; To understand the evidence-base for parenting education training programs focused on work with disabled parents



## Introduction

This chapter reviews the involvement in and experiences of disabled<sup>1</sup> People in the family policing system<sup>2</sup> – also referred to as the child welfare or child protection system. In the history of the U.S. family policing system, ableism, racism, and other forms of oppression have impacted many children and families involved in the system. The family policing system has long used disability as a criterion for considering a parent as not fit to parent or not capable of parenting. Disabled children are assumed to be at higher risk of abuse and neglect from their parents and other caregivers. As a result, parents and children with disabilities are disproportionately involved with the family policing system. Despite the overrepresentation of the disability community in the family policing system, social workers are often under-prepared for practice with this population, often lacking basic knowledge about the disability community or the various disability service systems. Consequently, families are often not appropriately supported by family policing systems when disability is present. This chapter provides an overview of the key knowledge social workers need in order to approach practice in a way that respects the disability community’s strengths and capacities. We begin with a review of the historical context leading up to present-day practice in this arena. We then address the prevalence of members of the disability community in the family policing system before examining service trends, cultural elements, and relevant policies. We conclude with the voices of the disability community on their experiences with the family policing system as it relates to policy and practice implications before presenting case examples for your consideration.

## History

There is a long history of societal intervention in families where disabled children and parents are present. First, we review what is known about how disabled children were viewed by society. Second, we review how the lives of disabled parents have been controlled over time, including how lives differ based on different social identities, such as race, ethnicity, and class.

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1. In this chapter, the authors use a mix of identity-first disability language and person-first disability language. In keeping with the American Psychological Association’s guidelines, we acknowledge that different members of the disability community may have different choices about how they wish to be referred to, see a discussion here: <https://www.apa.org/pi/disability/resources/choosing-words>.

2. Based on the work of scholar Dorothy Roberts (2022 & 2020), the authors are using the term ‘family policing system’ instead of ‘child welfare system’ or ‘child protection system’ because the authors believe that it most accurately and directly describes the system’s purpose and impact.

## Disabled Children

Negative views of childhood disability are noted across the globe. From early Roman times, disabled children were looked upon as not fully human, and sometimes infants were abandoned to die (Morris, 1986). In the Christian tradition, the bible's New Testament writes about disability as arising from sin and spiritual deficiency, where parents' sins cause blindness or other disabilities. However, other parts of the bible reflect favorably upon disabled people (Mackelprang & Salsgiver, 2015). During the Middle Ages, reformers such as Martin Luther suggested that drowning disabled children could be justified as they might be incarnations of the devil (Blanks & Smith, 2009; Munyi, 2012). Munyi's (2012) analysis of historical accounts of the treatment of disabled children in various parts of Africa in the 19th century reveals a mixed picture. In Benin, at times, disabled children were thought to be protected by supernatural powers, bringing good luck to the community. However, among the Ibo of Nigeria, disabled children were varyingly pampered and totally rejected. In Kenya, children with intellectual disabilities were abandoned in nature so that they could return to 'their own kind,' i.e., animals. In the 1800s and 1900s, disabled children, including racial and ethnic minorities, were often part of 'freak shows' in the United States and Europe (Braddock and Parish, 2001). This time also saw many disabled children of color, especially Black children, in segregated orphanages. Morton (2020) reports

In 1883, 276 of the 353 orphanages across the country excluded black children; 68 institutions, most of them public, admitted a tiny handful; only nine orphanages sheltered black children exclusively. From 1890 to 1933, although the number of orphanages for both white and non-white children increased, the number of racially integrated institutions actually decreased...this prejudicial treatment of black children has been a national phenomenon. (p. 141).

As the 20th century dawned, families with disabled children often kept them at home – often hidden or sometimes sent to an institution due to shame, stigma, and embarrassment. This history of rejection followed disabled children into the 20th century United States. For example, after the rise of the eugenics movement, which lasted into the 20th century, the film *The Black Stork* (1919) depicts the story of a mother of a disabled baby who was convinced to let the baby die. She did this after imagining that the child would be rejected by society, leading the child into a life of crime (Pernick, 1996). The eugenics movement informed immigration policy as it related to both disabled people and people of non-White races and ethnicities, including disabled Asian children, for example (Shin, 2020). Perhaps most famous is the child euthanasia movement spearheaded in Nazi Germany in the late 1930s (Parent & Shevell, 1998). The German government encouraged parents to institutionalize their babies and toddlers with visible disabilities, who were either starved or killed by medical personnel as part of a euthanasia project that resulted in upwards of 10,000 disabled children losing their lives.

During the 20th century in the United States, parents were increasingly encouraged to institutionalize their children or keep them at home (Mackelprang & Salsgiver, 2015). However, for over a century, research has documented the ills of this mode of care, which include “stunted physical, intellectual, emotional, and social development among children separated from family environments and placed in institutions” (Berens

& Nelson, 2015; Human Rights Watch, 2017, 1). Further, regardless of the size of an institution or how it is described, this type of treatment is defined by certain harmful characteristics as they relate to disabled children, such as separation from families and the wider community; confinement to groups homogeneous in age and disability; depersonalization; overcrowding; instability of caregiver relationships; lack of caregiver responsiveness; repetitive, fixed, daily timetables for sleep, eating, and hygiene routines not tailored to children's needs and preferences; and sometimes, insufficient material resources (Human Rights Watch, 2017, p. 1).

Scandals such as those seen at Staten Island, New York's Willowbrook School, involving unacceptable care of institutionalized disabled children led to the community inclusion movement that has shaped the service system we see today (Mackelprang & Salsgiver, 2015). However, if we look at how disabled children of color have been treated vis-a-vis institutionalization, we see that this process has continued. In Morton's (2020) study of Cleveland, Ohio, for example, we see that both private and public sector institutions have provided segregated care for children of color "always unequally, and sometimes punitively" (p. 141). At times, Black children were significantly under-represented in orphanage census numbers compared to the general population prevalence in Cleveland. Morton (2020) tracks this process from the early 1900s through the 1960s. In the Willowbrook era:

Private orphanages that initially accepted small numbers of black children barred them during the 1910s, and dependent black children consequently became the responsibility of public agencies, especially after the Great Depression. Orphanages remained racially segregated until the 1960s, when political and financial imperatives compelled their integration. Racial inequalities remained, however, illustrated by the disproportionate number of black children in an overcrowded, dangerous public detention facility that became a public scandal and a symbol of a child welfare system that institutionalizes and sustains the city's racial inequities (p. 141).

This long negative history of institutionalization related to views of disabled children and encouragement to send them away from society has created a social stigma against having disabled children. Unfortunately, this stigma appears to be paired with a historical record in the literature documenting the increased risk for child maltreatment among disabled children in the 20th century and on to the present. Disabled children are at least three times more likely to be maltreated than their peers (Jones et al., 2012). Further, disabled children are more likely to be seriously harmed as a result of that maltreatment (Sedlak et al., 2010).

Today, common narratives about parenting disabled children often frame it as a tragic and pitiful experience, with little attention to promoting the notions of dignity and worth (Thomas, 2020). More recently, some parents of disabled children have come together "to talk about their children as a reason for celebration and pride, discuss their experiences of convivial community relations and public interactions, and praise evolving configurations of disability in popular media" (Thomas, 2020, 451). Yet despite this, these parents simultaneously talk about their "painful, convoluted and exhausting experiences with institutions (education, healthcare, welfare) as part of what they believe to be a wider (structural) hostility to disability that forces them

into a series of ‘fights’ and ‘battles’ that characterize the experiences of disabled children and their parents’ lives (Thomas, 2020, 451).

## Disabled Parents

The United States has a long and reprehensible history of constraining people with disabilities from living the lives they desire, including implementing policies and practices that hinder people with disabilities from creating and maintaining families (Powell & Stein, 2016). One prominent example is the eugenics movement, which occurred throughout the late 19th and early 20th centuries. Specifically, negative eugenics aimed to restrict procreation by people with disabilities and others considered ‘socially inadequate.’ Based on the idea that these people would produce offspring who would be burdensome to society, more than 30 states legalized compulsory sterilization (Lombardo, 1996; Silver, 2004).

In 1927, involuntary sterilization gained the support of the Supreme Court in the infamous *Buck v. Bell* decision. Carrie Buck, who was considered ‘feeble-minded,’ was raised in a foster home, where she lived until she became pregnant after being raped by a relative of her foster parents (Cohen, 2016). To presumably hide the rape, Carrie was involuntarily institutionalized at the Virginia State Colony for Epileptics and Feeble-minded, where her mother was also committed. Carrie’s daughter, Vivian, was adopted by Carrie’s foster family, and Carrie never saw Vivian again. Subsequently, the institution sought to sterilize Carrie per Virginia’s compulsory sterilization statute. Upholding the state’s sterilization statute on the belief that it served “the best interests of the patient and of society,” Justice Oliver Wendell Holmes, Jr. declared, “Three generations of imbeciles are enough” (*Buck v. Bell*, 1927). Because of these state laws, more than 65,000 Americans (many of whom had disabilities, were people of color, were Indigenous people, or were poor), were forcibly sterilized by 1970 (Lombardo, 2008).

Negative eugenic ideologies also led to state laws forbidding people with disabilities from marrying. In 1974, a study found that nearly 40 states had laws banning people with disabilities, most commonly those with intellectual or psychiatric disabilities, from marrying (President’s Committee on Mental Retardation, 1974). More recently, a 1997 study found that 33 states still had statutes limiting or restricting people with intellectual or psychiatric disabilities from marrying (Pietrzak, 1997). Even today, laws prohibiting people with disabilities from marrying continue in some states (Waterstone, 2014).

## Prevalence of the Disability Community in Family Policing Systems

Data on the extent to which the disability community is represented in the family policing system does exist. These studies draw on medical model approaches to the operationalization of disability, often using case record reviews or secondary data sources to identify disability.

## Prevalence of Disabled Children Involved in the Family Policing System

Disabled children are known to be at increased risk of maltreatment in the form of abuse or neglect (Hughes & Rycus, 1998; Jonson-Reid, Drake, Kim, Porterfield, & Han, 2004; Smith, 2002; Sobsey, 1994; Sullivan & Knutson, 2000; Vig & Kaminer, 2002; Westat, Inc., 1993). Once authorities substantiate maltreatment, disabled children may be placed in the family policing system or may remain with their families under supervision. A recent literature review suggests that, depending on the study, between 14-47% of children involved in the family policing system are disabled (Slayter, 2016). Two population-based studies help us obtain a more specific picture of the prevalence (count) of disabled children in the family policing system. A population-based study helps us obtain an estimate of an entire population of people, allowing us to generalize about what the prevalence of this population may look like in other settings.

First, drawing on data from the Adoption and Foster Care Analysis and Reporting System (AFCARS), an annual data collection system that gathers data from each state and territory, we have information about the prevalence of children included in a national sample (Slayter, 2016). Children were categorized as having one of five conditions: intellectual disability, physical disability, visual or hearing disability, emotional disturbance, or another medical condition. About one-third of children in the family policing system in this study aged 0–18 had an officially diagnosed disability. This means almost a third of all children in that system were disabled. On average, this group was four years older than children without disabilities and very slightly more likely to be identified as having a male gender (gender binary was the approach used in this system). With respect to racial and ethnic identifiers, 57% of the disabled population was Caucasian, 32% was Black or African American, 23% was Hispanic/Latinx, 4% was American Indian/Alaskan Native, and almost 2% was Asian/Pacific Islander. Statistical testing suggested only slight differences between children with and without disabilities. Children with disabilities were 11% and 27% less likely to be categorized as American Indian/Alaskan Native and Caucasian, respectively, than were children without disabilities. Both groups were equally likely to be African American/Black and Asian/Pacific Islander but were 1.27 times more likely to be identified as Hispanic/Latinx (Slayter, 2016). Specific disability prevalence data points were not reported.

Second, Lightfoot, Hill, & LaLiberte (2011) conducted a population-based study looking at Minnesota's family policing system. In this study, over one-fifth of children whose parents or caregivers had substantiated maltreatment cases were labeled as having a disability in administrative records. Further, in the over 5 years old population, more than one-quarter of children, almost 28%, had the disability designation. The study notes that a higher percentage of disabled children were male, at almost 56%, and the gender binary approach was used in this measurement. With respect to race, the majority were Caucasian, at 63%, followed by Black or African American at 22%, American Indian/Alaskan Native at 9%, Asian/Pacific Islander at 1%, and unable to determine at 3%. Disabled children in this population had a range of diagnoses. The most common disability categories were 'emotional disturbance,' at 37%, followed by 'intellectual/developmental disabilities' at 10%, and 'multiple disabilities' at 9%.

As both population-based studies found that roughly one-third of the population was disabled, we can consider this a stable estimate of childhood disability in the population of children in foster care (Lightfoot, Hill, & Laliberte, 2011; Slayter, 2016). Disabled children are notably more likely to be abused or neglected than non-disabled children (Sullivan & Knutson, 1998). They are also more likely to be identified as such by the family policing system (Lightfoot, Hill, & LaLiberte, 2011). This high prevalence rate means that all social workers need to develop disability cultural competence to be effective in their practice. This also means that the likelihood, therefore, that children in foster care transitioning from the family policing system into independent living are also members of the disability community, is high (Hill, Lightfoot, & Kimball, 2010). Social workers in this sector can offer bridges to their clients by connecting disabled children with either mentors or community-based disability organizations and disability culture entities (Lightfoot, 2014).

The research literature also reveals some important basic information about the experiences of disabled children involved in the family policing system that is important for social workers to know. Although the prevalence of failed previous adoptions was small, disabled children in foster care were almost three times more likely to have been adopted previously but then returned to the family policing system, suggesting possible previous family policing system involvement and what is known as an “adoption disruption” (Slayter, 2016). Disabled children were slightly more likely to have entered the system due to a voluntary versus an involuntary placement although the prevalence of this type of entry was low (4.8% of cases) (Slayter, 2016).

Looking at types of child maltreatment experienced in the Slayter (2016) population-based study as measured by reason for removal from the home, neglect emerged as the primary reason children were removed, followed by ‘parental inability to cope,’ which is defined as a situation in which a parent had a “physical or emotional illness or disabling condition adversely affecting the caretaker’s ability to care for the child” (AFCARS, 2007, 3). The third most common removal reason noted in this study was deemed to be the ‘child’s behavior,’ followed by parental drug abuse, and then physical abuse. However, what is notable is that statistical analyses comparing disabled children with children without disabilities revealed only minor differences between groups on the prevalence of these removal types, suggesting no significant differences in removal types between groups.

## Prevalence of Disabled Parents and Caregivers Involved in the Family Policing System

As Lightfoot, Zheng, & DeZelar (2020) note, the literature has focused on the disproportionate rates of involvement in family policing systems among disabled parents although there is “limited evidence that parents with disabilities are more likely to abuse or neglect their children” (583). Additional research on this topic is found in Glaun & Brown (1999) and Oyserman, Mowbray, Meares, et. al. (2000).

Let’s start by looking at the prevalence of disabled parents in the overall U.S. population before looking at their prevalence in the family policing system. Disability advocates contend that disabled parents are prevalent, although documentation is limited. The National Council on Disability (2012) notes that a significant



obstacle to ascertaining the number of parents with disabilities as well as their demographic characteristics, is the absence of data. While some census data provide estimates of the number of people with disabilities or the number of parents within a given locale, almost no regional or national data consider the combination of these two characteristics (p. 31). Further, the structure of existing child protection data sets makes it difficult to track the prevalence of disabled parents involved in the system. Current estimates of the prevalence of disabled parents of children under 18 range from 5% to approximately 10% of U.S. parents (Li, Parish, Mitra, and Nicholson, 2017; Kaye, 2011a; Sonik, Parish, Mitra, and Nicholson, 2018)<sup>3</sup>.

What is troubling is the fact that while just under 10% of parents in the U.S. are disabled, at least one estimate of the number of parents in the U.S. family policing system suggests rates are disproportionately high. Lightfoot and DeZelar (2016) studied the experiences and outcomes of children in foster care removed due to parental disability using the Adoption and Foster Care Reporting System data and found a proxy prevalence rate of 19%. This may be an undercount of the actual prevalence of all disabled parents in the system if some disabilities were hidden or undisclosed and were not involved in the reason for a child's removal. However, a more recent study by the same authors found a lower prevalence rate looking at disability characteristics of parents among all cases, finding a rate at just under 10%. This study drew on data from the National Child Abuse and Neglect Data System (NCANDS), an annual data collection system that partners with states and territories (Lightfoot, Zheng, & DeZelar, 2021). Researchers included data from states with more robust data reporting, ending up with Georgia, Indiana, Minnesota, Mississippi, New Jersey, South Dakota, Texas, and Utah. They looked at over half a million cases, 27% of which were 'substantiated' or approved for further involvement with the family policing system. Within this group of cases, just under 10% had a parent or caregiver who was identified as disabled. However, again, this is likely an undercount of disability because some disabilities are hidden, for example (Lightfoot, Zheng, & DeZelar, 2021).

Given the prevalence of disabled parents in the family policing system, it is clear that child protection workers need to develop disability cultural competence – yet this is often something that falls by the wayside in practice, as is documented in the research literature. This chapter should assist you in becoming more aware as you develop your disability lens for practice!

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3. Kaye (2011b) conducted an analysis that looked at disabled parents by race and ethnicity, documenting significant variation across groups: "13.9 percent of American Indian/Alaska Native parents and 8.8 percent of African American parents have a disability. Further, 6 percent of white, 5.5 percent Latino/Hispanic, and 3.3 percent of Asian/Pacific Islander parents have a disability. Of these parents, 2.8 percent have a mobility disability, 2.3 percent have a cognitive disability, 2.3 percent have a daily activity limitation, 1.4 percent have a hearing disability, and 1.2 percent have a vision disability" (Kaye, 2011a, 10). Lastly, 9% of all children in the country are estimated to have disabled parents, totaling to approximately 6.1 million children (Kaye, 2011b).



## Experience of Services in the Family Policing System

Understanding a bit about the experiences of disabled children in the family policing system is important for social workers involved in this work. The potential traumas of child maltreatment, coupled with the impact of living in foster care, can be detrimental in both the short and long term (Strickler, 2001; Weaver, Keller & Loyek, 2006). Lacking a sense of belonging, experiencing a disrupted family identity, having an attachment disorder, living with emotional distress, and facing the stigma of being children in foster care are all documented risk factors for children in foster care (Barahal, Waterman, & Martin, 1981; Mallon & McCartt Hess, 2006). In addition, youth who spend time living in foster care are less likely to establish lifelong connections that will guide them into adulthood upon ‘aging out’ of foster care (Renne & Mallon, 2005). Together, these experiences may create a cumulative risk for future adverse outcomes, including psychiatric disability, lower levels of education, and limited employment (Pecora, O’Brien, & Hiripi, 2007). Given that disabled children are already at risk for these risk factors, it is possible that they are especially vulnerable to potential socioeconomic and psychological stressors and that these stressors may impede community inclusion.

The population-based Lightfoot, Hill, & LaLiberte (2011) study did examine whether children were kept in the home under supervision or placed out of the home. Regardless of age, disabled children were almost two times more likely to be placed outside of their homes than non-disabled children. So, not only does this population face overrepresentation in the family policing system, but once in care, they are also much more likely to be placed out of their parents’ or caregivers’ homes. In the Slayter (2016) study, we learned more about the placements that disabled children were most likely to experience while in foster care. A child’s foster care placement type can significantly impact their well-being during what is often a time of traumatic transition from regular schedules, habits, and access to circles of support. Ideally, decisions about a child’s placement should be made based on the ‘least restrictive setting’ to meet safety needs, promote placement stability (i.e., the least amount of moving between foster homes and institutional settings as possible), and support possible family reunification (Adoption and Safe Families Act of 1997).

Despite these foster care policy goals, disabled foster youth experienced more of what is known as ‘placement instability’ (a high number of settings in which the youth resided during their current foster care “episode”) than their non-disabled counterparts – between 4-8 placements as compared to between 2-4 placements (Slayter, 2016). We also know that most disabled youth were not placed with their extended family members in what is known as kinship care, a best practice in child protection work. In fact, they were 40% less likely than non-disabled children to be in this placement setting (Slayter, 2016). And while the ideal goal for most children in foster care is family reunification, disabled children were 37% less likely to be placed with their family in a trial home visit than were non-disabled children (Slayter, 2016). Therefore, it was not surprising that disabled children were almost two times more likely to be in a non-kinship “stranger foster care” setting and/or a pre-adoptive foster home (Slayter, 2016). All of this information suggests that while the ideal practices for children in foster care involve maintaining family contact may be less of a reality for disabled children in foster care. In

addition, the literature has noted all of the difficulties that foster parents are challenged with when supporting disabled children. These challenges include difficulty accessing disability care, a dearth of appropriate behavior support, and challenges managing financial strain (Brown & Rodger, 2009).

We also know that while community inclusion is a central policy goal for the disability community, congregate care settings are very prevalent for disabled children in foster care. As you read in Chapter 1 of this textbook, one of the central tenets of empowerment-oriented disability social work practice is community inclusion. Yet, the disability community often has to fight for placement in settings that are community-based and, in the case of child welfare, family-oriented. With respect to congregate care settings, disabled children were almost three times more likely than non-disabled children to be living in an institutional setting and were two times more likely to live in community-based group homes (Slayter, 2016). When it came to independent living placements, although only a small percentage of disabled children were reported to be in this setting, they were 10% less likely to live in this type of placement than their non-disabled counterparts (Slayter, 2016).

Finally, it is essential to consider what is known about the ‘permanency planning goals assigned to disabled children compared to non-disabled children while living in foster care. These goals dictate how social workers approach case planning and placement practice, so they are very important. While the top goal for disabled children with and non-disabled children was reunification with their families, disabled youth had this as their goal at a much lower rate (39% vs. 54%), which translated into being 39% less likely to have this placement (after taking into account age and gender) (Slayter, 2016). Disabled children were also twice as likely to have long-term foster care as their goal compared to non-disabled youth. Long-term foster care is not considered an ideal permanent placement for children in foster care.

## Outcomes of Child Protection Cases

Child protection case outcomes for disabled children also have consistent patterns that social workers practicing in this sector should be aware of. In Slayter’s (2016) population-based study, 64% of all children in foster care remained in care at the end of the year, with the remaining 36% discharged. Disabled children in foster care were 12% less likely to exit foster care than children without a disability. Among all of the children in foster care remaining in the system, about 20% were the subject children in what is referred to as ‘termination of parental rights’ (TPR) cases — and were technically free to be adopted or otherwise placed. There was a higher rate of completed TPRs among disabled children (about 25%) than children without disabilities (about 15%), leading to disabled children being two times more likely to be the subject child in one of these cases. The top five foster care outcomes for disabled children were reunification with a parent/caregiver (48%), adoption (34%), discharge to guardianship (7%), living with another relative (5%), and transfer to another agency (2%).

Research suggests that disabled children have more years of contact with the family policing system than children without disabilities. The impact of a series of intersecting, cumulative risk factors related to disability, child protection involvement, and/or foster care placement may cause disabled children to be at higher risk for negative outcomes. This may occur for several reasons, which may include the trauma of entering foster

care (either once or repeatedly), living away from familiar circles of support and life patterns, the social stigma associated with living in care, and the effects of documented challenges regarding collaboration between disability and child protection agencies (Slayter, 2016).

While this chapter has addressed disabled children and disabled parents separately, there may be an intersection between disabled parents and disabled children involved in the system. There is a potential compounding bias against families that could really be a factor for increased system involvement. In other words, workers might view disabled children as ‘extra vulnerable’ and in need of protection, and disabled parents might be viewed as not capable. Adding those two notions together could certainly lead to increased system involvement as well as increased exposure bias among mandated reporters.

## Challenges with Inter-System Collaboration Between Family Policing and Disability Services

While in care, disabled children and parents alike may not receive optimal care due to the challenges their social workers experience vis-a-vis inter-system collaboration between the family policing and disability service sectors. Disabled children in foster care – especially those facing exit from the system at an older age – are reliant on both systems— systems with very different theoretical approaches to practice. For example, the family policing system is usually an involuntary, time-limited intervention focused on monitoring with the goal of safety, permanence, and well-being. On the contrary, disability services are usually voluntary, focusing on self-determination, independence, and support needed for a lifetime. There is a gap between the underlying theoretical and practice approaches in each sector, suggesting a need to develop collaboration initiatives (Lightfoot, 2014). Unfortunately, despite documented discussions about the needs of disabled children in the family policing system, who are known to be over-represented there, these two systems do not appear to have a favorable history of collaboration, which may be understood in part as a function of their differences (Hill, 2009).

In day-to-day casework, communication between the ‘lead’ caseworker in both the family policing and the disability systems needs to be established to streamline casework planning. At the administrative level, non-governmental collaboratives might be established as a resource exchange and cross-training mechanism (Lightfoot, 2014). An example of an effort of this nature exists in Minnesota. The Disability Child Welfare Collaborative was established in 2011 to convene practitioners and researchers in the areas of child welfare, disability, and education. They work to raise awareness of the needs of disabled children in each sector, acting as a central resource to all three types of providers. In addition, they foster opportunities for dialogue among providers about how to promote positive outcomes for disabled children (Center for the Advanced Study of Child Welfare, 2016). A central focus of their efforts is continual cross-training between sectors to build disability and child protection competence—and the awareness of who to turn to when unanticipated practice questions arise on either side of the aisle. Participants in a collaboration of this nature become the expert in

their own agency, functioning in a consulting capacity with other caseworkers or teachers — who could be encouraged by supervisors to seek help that is specific to the child they are working with (Coyle, 2014).

When social workers in this sector participate in collaborations with disability sector workers, they will develop disability-specific competencies that will allow them to deliver better services to their disabled clients. Social workers working with a disabled child on their caseload need to develop basic disability-related competencies. For example, they should understand that such children will have various needs even if they are in the same diagnostic category. For example, a baby who is diagnosed with failure-to-thrive may need early intervention services that can be provided in foster homes, which will result in training for foster parents regarding the child's care. In contrast, a child with Down Syndrome might have more specialized medical needs, such as cardiac problems. Variations in needs such as these may impact how social workers work with parents/caregivers and disability service systems toward the goal of exit from foster care. Other competencies will relate to the importance of promoting the inclusion of disabled children into everyday community-based life and helping others see such children as valued and unique individuals.

These trainings could also foster the development of social workers' knowledge of communication techniques and the use of assistive and adaptive technologies (Child Welfare League of America, CWLA, 2012). For example, it will be important for social workers to be aware of different perspectives on how disabled parents engage in the process of parenting and/or the use of adaptive equipment. Social workers can view this video on parenting while blind:

<https://ensemble.brandeis.edu/hapi/v1/contents/permalinks/g9KSi48J/view>

...or see this video on maximizing motherhood with technology:

<https://ensemble.brandeis.edu/hapi/v1/contents/permalinks/j4FQd6i2/view>

## Supporting Disabled Parents Involved in the Family Policing System

Just as social workers need to develop disability competence for working with disabled children, they also need to do this for their work with disabled parents. This section highlights the importance of embracing parent-centered planning and the supported parenting approach. It also discusses what is known about the evidence on parenting programs for disabled parents.

Lightfoot & LaLiberte (2011) write about the concept of supported parenting (as opposed to the standard of independent parenting) for disabled parents, an extended discussion of which is instructive in this chapter. This is an important concept to consider because when you think about it, “most parents rely on various formal and informal supports for caregiving” in the childrearing phase (Lightfoot & LaLiberte, 2011, p. 1). When discussing parental support, we are thinking about accommodations, strategies, and techniques that will support people to parent their children successfully. While Lightfoot & LaLiberte's (2011) work was written

with parents with intellectual and developmental disabilities in mind, the concept applies to parents with all types of disabilities.

Let's think about what parental supports can look like in action. We consider these supports to be either technologies, personal assistants, or assistive devices that enhance a person's capacity to function as an individual parent or couple. Further, these supports will make up for aspects of a parent's disability that may affect their capacity to care for their child in some way. Finally, the use of these supports allows disabled parents to fulfill their duties as parents. Lightfoot & LaLiberte (2011) explain:

Technology can include any adaptive equipment that that may assist an individual in parenting, such as adaptive cribs or child care equipment [see [www.disabledparenting.com](http://www.disabledparenting.com)], cooking/feeding equipment, or a smartphone or a Personal Digital Assistant (PDA) that presents step-by-step guidelines for parenting activities...These types of personal supports could include day care services, respite care, a co-parent or parent mentor, in-home parenting training, money management assistance, homework tutoring, housekeeping, safety planning, or even long-term family foster care. (p. 3)

The use of parental supports assists disabled parents in filling gaps between their competencies as parents and the demands of the family environment. This builds on the concept of individual supports used in disability service settings by broadening the lens to one that includes a family focus.

One approach to supported parenting is parent-centered planning (Lightfoot & DeZelar, 2020). This approach draws from the concept of 'person-centered planning,' which is well-known in disability services. This concept is described by Lightfoot & DeZelar (2020) as focused on "develop[ing] a plan for individualized supports through a process that assists people with disabilities and their social networks in planning, by focusing on a person's strengths and preferences rather than on formal assessments or services available" (p. 2). Parent-centered planning is proposed as a way to support disabled parents, their circles of support, and their children in figuring out how someone can engage in positive parenting with their child/children. This would involve using a range of appropriate parental support mechanisms that are individualized to the situation, along with a personalized care plan drawing on those supports. The wishes and desires of both parents and children are part of the planning process in this model, given age appropriateness. Key to this model is using an experienced and trained facilitator who is knowledgeable about the range of support services available in the community. The facilitator will work with the group to make short- and long-term goals for the parent-centered planning process with attention to how various supports will aid in achieving those goals. The process begins with preparation, moves to scheduling and inviting, leads to the actual parent-centered planning meeting, and ends with the transition phase. The details of these phases are described on the following website:

<https://conservancy.umn.edu/handle/11299/213787>

Additional resources on this intervention are also available:

CASCW Practice note: <https://cascw.umn.edu/wp-content/uploads/2020/11/PN36-WEB508.pdf>

1-hour free online training/CEU: <https://cascw.umn.edu/portfolio-items/parent-centered-planning-for-parents-with-disabilities-1-0-hrs/>

Intervention Facilitator's Manual: [https://cascw.umn.edu/wp-content/uploads/2022/01/Parent-Centered-Planning-Facilitator-Manual\\_8.30.21.pdf](https://cascw.umn.edu/wp-content/uploads/2022/01/Parent-Centered-Planning-Facilitator-Manual_8.30.21.pdf)

Podcast: [https://soundcloud.com/user-818593337/parent-centered-planning-for-parents-with-disabilities?utm\\_source=clipboard&utm\\_campaign=wtshare&utm\\_medium=widget&utm\\_content=https%253A%252F%252Fsoundcloud.com%252Fuser-818593337%252Fparent-centered-planning-for-parents-with-disabilities](https://soundcloud.com/user-818593337/parent-centered-planning-for-parents-with-disabilities?utm_source=clipboard&utm_campaign=wtshare&utm_medium=widget&utm_content=https%253A%252F%252Fsoundcloud.com%252Fuser-818593337%252Fparent-centered-planning-for-parents-with-disabilities)

While this model has not undergone empirical evaluation, it is noted to have the potential for use in various ways in the family policing and disability services contexts. As expecting parents plan for the birth of their child/children, for example, disability services workers could use this approach to support parents in developing short- and long-term goals in the context of a care plan. The authors of this plan also argue that social workers could use this approach as a form of an alternative response to alleged child maltreatment or perhaps in situations where voluntary services are requested (Lightfoot & DeZelar, 2020). Further, the authors note clearly that parent-centered planning does not stand in for developing formal support for disabled parents, given the lack of specialty services for many parents within the disability community. For example, there are significant needs for social workers in this sector to build “effective adapted parenting skills training programs, co-housing programs, respite programs, or even the provision of family-focused personal care attendants” (Lightfoot & DeZelar, 2020, p. 4). Rather, it is the goal of parent-centered planning to foster existing informal supports for the parenting effort, akin to what happens in communities that are not disabled, under the principle of interdependence. Key to implementing a supported parenting approach will be the need for social workers to engage in pre-engagement reflective and reflexive practice (see Chapter 2 in this textbook). This is necessary to consider how support or the idea of supportive parenting may also be influenced by other social identities, such as race, ethnicity, and gender identity, among others.

## The Evidence Base for Parenting Education Targeted at the Disability Community

While not every disabled parent needs support or parenting training, social workers need to start by asking disabled parents about their needs. If there are needs, another tool for social workers to consider in case practice with disabled parents may be a referral to a specialized parenting education program. In general, parenting programs are well-established as ways for people to improve their parenting skills, knowledge, and efficacy while also assisting in decreasing their child's/children's disruptive behaviors and their own parenting stress (Radley, Grant, Barlow, & Johns, 2021; Kaplan, Solomon, Salzer, & Brusilovskiy, 2014). Unfortunately, all of the specialized curricula we have found are targeted to either parents with intellectual and developmental disabilities or parents with psychiatric disability without attention to other populations within the disability community. For those not working with either of these populations of parents, it is recommended that parenting education curricula work to become accessible to all members of the community through the use



of a universal design approach. Also, for social workers running parenting education programs either virtually or in-person, reading and acting on one of these simple guides to [website accessibility](#), [accessible social media](#), [meeting accessibility](#), [webinar accessibility](#), or [public event accessibility](#) will go a long way toward engaging the disability community and making the disability community feel welcome!

Social workers unfamiliar with how disabled parents who are, for example, visually impaired or physically disabled engage in the process of parenting and/or use adaptive equipment might benefit from viewing resources about adaptive parenting. For example, one helpful video illustrates the ways that blind parents approach parenting:

<https://ensemble.brandeis.edu/hapi/v1/contents/permalinks/g9KSi48J/view>

...or there is this video that comments on the ways that technology can be harnessed to accomplish parenting tasks:

<https://ensemble.brandeis.edu/hapi/v1/contents/permalinks/j4FQd6i2/view>

## Parents with Intellectual and Developmental Disabilities

For those working in the family policing system, a consideration of the literature base on parenting support programming and parenting training for preventing child maltreatment in this particular population will be helpful (Booth & Booth, 1996; Feldman, 2010; Feldman, Ducharme, & Case, 1999; Garbus & Kennedy, 1999; Llewellyn et al., 2002; Llewellyn & McConnell, 2002). Wilson and colleagues (2014) summarize this research by pointing out that interventions focus on two areas, strengthening social relationships and teaching parenting skills. However, these authors note that while “the evidence for interventions aimed at strengthening social relationships was inconclusive...positive changes were observed” (p. 3), the results had limited generalizability (application) to other populations. Commenting on the evidence for parental skills teaching, Wilson and colleagues (2014) note that “behavioural-based interventions are more effective than less intensive forms such as lesson booklets and the provision of normal services” (p. 1).

While there are a small number of published research studies that evaluate these programs, a recent Cochrane review (a type of rigorous review) has indicated that the existing evidence is limited and has called for more research that uses a more rigorous approach (Coren, Ramsbotham, & Gschwandtner, 2018). These authors note that:

there is some very low-quality evidence that some parents, mainly mothers, with intellectual disabilities are able to provide adequate parenting if they are given appropriate training and support to learn the parenting skills they need. However, there are few studies exploring how interventions might work, for whom and in what circumstances. In particular, there have been few studies that include fathers with intellectual disabilities, or that explore the views of parents themselves. (p. 1)



## Parents with Psychiatric Disability

A significant amount of resources exist for thinking about how to support this population with the parenting process, although the quality of the research on these resources needs improvement (Radley, Grant, Barlow & Johns, 2021). Although it is two decades old, a seminal study in the field documented the types of programs available to support parents with psychiatric disability across the U.S. (Nicholson, Biebel, Hinden, Henry, & Stier, 2001). These diverse programs shared a series of focus areas, namely “addressing basic needs such as housing and financial support, improving parents’ coping and problem-solving skills, improving parenting skills specifically, and enhancing child development. However, as will be discussed below, the relative emphasis on each of these goals, and the particular interventions implemented to achieve these goals, differed across programs” (Nicholson, Biebel, Hinden, Henry, & Stier, 2001, p. 45).

Two examples of these programs are provided in this study. First, one psychoeducational intervention focused on parents of children aged 8-15. The parents had affective disorder diagnoses and had recently experienced hospitalization. The intervention focused on educating parents on the potential effect of their illness on children as well as on methods of building communication skills between parent and child in relation to the topic of psychiatric disability. This program also included an unspecified format for family therapy. These were seen as important tools in fostering resiliency among the children and were found to be effective in follow-up research conducted over time (Nicholson, Biebel, Hinden, Henry, & Stier, 2001, p. 47). Second, a different program created a therapeutic nursery model for children aged 0 – 5 years old with a parent with a psychiatric disability. Interventions included parental coaching as well as milieu therapy for the children in a stimulating environment. Evaluation of the program reported success for children in achieving developmental milestones, with differences in mothers’ clinical characteristics and larger, more supportive family networks (Nicholson, Biebel, Hinden, Henry, & Stier, 2001, p. 47).

Internet-based support, stand-alone parenting education, and peer-support approaches are documented in the clinical literature for parents with psychiatric disability. Internet-based parenting interventions allow disabled parents to build connections with other parents and caregivers, especially at times that work for their schedules. In addition, the flexibility of meeting online allows disabled parents to overcome the challenges of dealing with limited transportation, lack of funds for transportation, childcare for the time they would be in a program, or navigating dangerous neighborhoods (Kaplan, Solomon, Salzer & Brusilovskiy, 2014). One recent study of an internet-based parenting intervention for this population found that parenting and coping skills were enhanced, and parental stress decreased (Kaplan, Solomon, Salzer & Brusilovskiy, 2014). However, it is important to note that this program did not appear to support improved parenting efficacy (Kaplan, Solomon, Salzer & Brusilovskiy, 2014).

One recent study evaluated the Let’s Talk about children psychoeducation-based parenting intervention for parents with psychiatric disability (Mayberry, Goodyear, Reupert, Sheen, Cann, O’Hanlon, & Cuff, 2019). While existing studies focused primarily on the population with affective disorders, this study sought to broaden the scope of the sample, looking at a larger population of parents with a psychiatric disability to

increase generalizability. This program uses a manual throughout 2-3 sessions and is considered a psycho-educational intervention. It is described as aiming to:

...empower the parent, within the context of his or her illness, and provide parents with the skills and confidence to support their family, with the overall goal of impacting positively on family dynamics. Parent empowerment, a core element in LT, is a process whereby parents ‘gain greater influence on their families . . . [and] greater access to networks, resources, and information’ so they are able to better support their children. (Kim & Bryan, 2017, p. 169)

Another focus of this intervention is to center the well-being and healthy development of the children. Although the program focuses on the parent as the primary client, it is framed as a family recovery intervention as it supports the parent in their parenting role. The authors evaluated parents’ self-reported views regarding the impact of the intervention and found improvements in parenting skills and family functioning. Specifically, parents reported better insight, the normalizing of psychiatric disability in the family, changes to how the family communicates, the importance of supporting the parenting role, and awareness of options for additional parenting supports (Mayberry, Goodyear, Reupert, Sheen, Cann, O’Hanlon & Cuff, 2019).

Peer support services are also documented as effective for parents with a psychiatric disability as an adjunctive resource (Kaplan, Solomon, Salzer, & Brusilovskiy, 2014). In general, peer support draws on the notion that those with lived experience of psychiatric disability who are in recovery may be in a unique position to provide support, validation, and even hope to other people with psychiatric disability (Nicholson & Valentine, 2019). Applied to parenting, the idea is that parents with a psychiatric disability “may be less willing to share concerns or request help regarding their role as parents from professionals for fear of losing custody, feeling embarrassed, or feeling inadequate when sharing issues with a non-peer parent” (Kaplan, Solomon, Salzer & Brusilovskiy, 2014, p. 2). Nicholson & Valentine (2019) describe four core program elements of any peer support program engaging the parent, exploring what is going on with the parent, planning with the parent, and accessing and advocating with the parent. These core activities are based on the idea that peer support services should focus on parents’ strengths while being culturally sensitive and trauma-informed. The specific types of actions that parent peer specialists engage in are described as follows:

Parent-peer specialists potentially offer examples of success, serve as role models, reframe deficits and setbacks, normalize parenting experiences, and disclose information about themselves with purpose and intent. The lived experience that peers share also may include expertise in navigating the health care and social service systems as a parent with SMI. For example, they may be aware of community resources or problem-solving strategies that have worked for them. (Nicholson and Valentine, 2019, 2).

While additional research is needed to support evidence-based programming in this area as well, the interventions detailed here provide a sound basis upon which you can begin to think about your case practice with these populations.

## Elements of Disability Culture Related to

## Involvement in the Family Policing System

Disabled parents, especially those involved with the family policing system, are held to ableist notions of what it means to be a good parent outside of the disability community. According to Ora Prilleltensky (2003),

[r]ooted in both patriarchy and ableism is the supposedly clear-cut division between dependence and independence, between those who care and those who are cared for...Thus, parents who are unable to independently fulfill all of the physical tasks of child rearing, are often subjected to skepticism regarding their ability to function as parents. (p. 24)

Interdependence is a critical aspect of disability culture (Gill, 1995). Nonetheless, disabled parents are expected to be able to care for their children without the assistance of others, and interdependence in the form of supported parenting is seen as a deficit (Hayman, 1990). Lightfoot & LaLiberte (2011) explain, “[p]arents have often been assessed based on whether they can independently be responsible for all aspects of caring for their child or children, even though most [non-disabled] parents rely on various formal and informal supports for caregiving.” (390).

Disabled parents also contend with other presumptions about their fitness to raise children. For example, d/Deaf<sup>4</sup> Parents face speculation that their children’s language development will be delayed, while blind parents and those with physical disabilities face assumptions that they cannot safely care for their children (Stein, 1994). Parents with intellectual disabilities are assumed to be unable to care for children and incapable of learning parenting tasks (Powell, 2016). Meanwhile, parents with psychiatric disabilities experience stereotypes that they are a danger to their children (Glennon, 2003). Despite these biases, parents with disabilities often exhibit extraordinary strength and resiliency. In all its forms, participation in family life is part of disability culture.

## Relevant Policies

Although the family policing system is administered primarily by states, the federal government plays an important role in overseeing the system by enacting laws and funding programs. In 1974, Congress passed the Child Abuse Prevention and Treatment Act (CAPTA), which incentivized states to create child maltreatment

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4. According to Carol Padden and Tom Humphries, in *Deaf in America: Voices from a Culture* (1988): “We use the lowercase deaf when referring to the audiological condition of not hearing, and the uppercase Deaf when referring to a particular group of deaf people who share a language – American Sign Language (ASL) – and a culture. The members of this group have inherited their sign language, use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society. We distinguish them from, for example, those who find themselves losing their hearing because of illness, trauma, or age; although these people share the condition of not hearing, they do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people.”

reporting systems to systematically track and respond to child abuse and neglect allegations. CAPTA allocated federal funding to states for child maltreatment, assessment, investigation, prosecution, and treatment activities, as well as grants to state and local government agencies and nonprofit organizations for demonstration programs and projects. CAPTA also set forth a minimum definition of child abuse and neglect. Notably, many believe that CAPTA's definition of neglect is often conflated with poverty. For parents with disabilities, who are much more likely than others to be poor, the framing of poverty as neglect has led to many families being unnecessarily subjected to the family policing system.

In 1978, Congress passed the Indian Child Welfare Act (ICWA) to establish standards for the placement of Native American children in foster and adoptive homes and deter the breakup of Indian families. ICWA was passed in response to the staggering rates of child removal among Native American children and growing concerns that these removals could have adverse cultural consequences. ICWA requires agencies to provide active efforts to the family and actively involve the child's tribe in all family preservation and reunification activities. ICWA is especially important to consider when working with disabled parents, as disability is more prevalent among Indigenous populations.

To address the increasing number of children in the foster care system, Congress enacted the Adoption Assistance and Child Welfare Act (AACWA) in 1980. AACWA had two primary goals: (1) fund child protection services to prevent the removal of children from their families, and (2) create a federal adoption assistance program. Rather than only reimbursing states for the cost of foster care, thereby incentivizing removal, AACWA allocated funding for preservation services, intended to prevent the removal of children, and reunification services, intended to aid the return of children to their families. Further, AACWA required states to make reasonable efforts to prevent the removal of children from their homes and reasonable efforts to reunify children who have been separated from their parents.

Also included in AACWA was the establishment of funds for both financial and medical help that would promote adoptions of children living in foster care, as well as reduce the financial barriers to completing adoption, as well as assist adoptive families in meeting the needs of their adopted children (Buckles, 2013). Framed as subsidies, this help "is available for children who meet certain eligibility requirements, including that the child is deemed as having special needs due to their physical, mental, or developmental disabilities or because there are other factors that may make it harder to find an adoptive family" (Children's Bureau, 2020, 1). Research suggests that these subsidies have increased rates of adoption of children in foster care by foster parents (Buckles, 2013).

Nearly two decades later, in 1997, Congress passed the Adoption and Safe Families Act (ASFA). ASFA amended AACWA by expanding and clarifying some provisions of the earlier law and modifying other provisions. ASFA reaffirmed the family policing system's goal of permanency originally established with AACWA but stated that permanence would best be achieved through the adoption of children in foster care, not family preservation or reunification. ASFA established definitive time limits on family reunification efforts and authorized states to begin to terminate parental rights proceedings for children who have been in foster care for fifteen of the most recent twenty-two months (commonly known as the "15/22 rule"). These

strict timelines can be difficult for parents with disabilities to comply with because obtaining appropriate and accessible supports can take a great deal of time (National Council on Disability, 2012).

However, it is important to note that the 15/22 rule includes exceptions when reasonable efforts have not been provided. Thus, child protection agencies should offer disabled parents additional time when needed. ASFA also allows child protection agencies to bypass reasonable efforts and instead terminate parental rights if the child has been subjected to aggravated circumstances, and some states have included parental disability under this broad provision (National Council on Disability, 2012). Additionally, ASFA established concurrent planning as a principal instrument: states are expected to provide reunification services for families with whom it is hoped children can be reunited and concomitantly search for appropriate adoptive families if reunification efforts are determined to have failed. Unfortunately, concurrent planning allows child welfare workers' biases about disabled parents to inform how they work with these families.

Most recently, Congress passed the Family First Prevention Services Act of 2017 (Family First Act). The Family First Act authorizes federal funds for 12 months of in-home parenting skills programs, substance use treatment, and mental health services to keep families intact and children out of foster care. Notably, the Family First Act does not obligate states to provide these services; they must “elect” to do so, and the federal government will match a state's contribution 50% until the year 2026.

In addition to the above mentioned laws, the family policing system must comply with the Americans with Disabilities Act (ADA) and its predecessor, Section 504 of the Rehabilitation Act (Section 504). The ADA is divided into five titles that cover the various protections afforded by the law: Title I (employment); Title II (state and local government); Title III (places of public accommodation); Title IV (telecommunications); and Title V (miscellaneous provisions, such as attorney's fees). Title II of the ADA, which concerns state and local government agencies, applies to all aspects of the family policing system, including termination of parental rights proceedings. Accordingly, the family policing system may not discriminate against parents with disabilities and must provide accessible and individualized assessments, supports, and services, as well as reasonable modifications. In addition, the Department of Justice and the U.S. Department of Health and Human Services have addressed the rights of disabled parents through investigations in Massachusetts, Oregon, and New Jersey, setting precedents for the rest of the nation.

## Disability-Related Debates in this Arena/Service System

Although disabled parents are overly referred to the family policing system – often without the appropriate basis (National Council on Disability, 2012) and are separated from their children at disproportionate rates – this has not been a widespread debate within that system until more recently. And this debate has been more visible only in states where investigations have been launched, such as Massachusetts. These debates relate to what appear to be widespread ableist views among social workers, judges, and collateral social service system

workers about the capacity of disabled parents to take care of children. See guidance from the Department of Justice on this matter here:

[https://www.ada.gov/doj\\_hhs\\_ta/child\\_welfare\\_ta.html](https://www.ada.gov/doj_hhs_ta/child_welfare_ta.html)

In the academic literature, researchers have documented that d/Deaf and blind parents, physically disabled parents, and parents with diagnoses of intellectual disabilities or psychiatric disabilities have to contend with significant amounts of stigma, stereotyping, a dearth of individualized parenting assessments, and the general lack of service provision. This discrimination and poor service provision extend to disabled people wishing to become foster and adoptive parents who report experiencing both bias and barriers to connecting with potential children in foster care that could be placed with them as a result of stigma and stereotyping (U.S.D.H.H.S., 2021).

With respect to disabled children, the importance of providing “special needs” adoption subsidies for disabled children was identified by policy advocates, leading, in some cases, to increased rates of adoption for this population over non-disabled children (Johnson, Slayter, & Livingstone, 2020). Whether these subsidies create perverse incentives is unknown. Another issue raised in the context of a child death scandal in the Massachusetts family policing system relates to the challenges of identifying children with disabilities by non-disability-trained social workers, such as was seen after the death of David Almond ([Office of the Child Advocate, 2021](#)). This speaks to the challenges inherent in the breadth of knowledge that child protection workers need to know in order to do their jobs well – and to the challenges of cross-system collaboration.

## Voices/Perspectives of Disabled People Involved in This System

To contextualize our discussion of service systems designed to support disabled children and parents, we want to be sure to elevate the voices of those two constituencies. First, stories about the experiences of disabled children in foster care are not easy to find, but we should seek to listen to their voices and learn from them. This quote depicts one disabled child in foster care’s experience of care that we were able to find. Laura says of her experience:

I spent a lot of my childhood in and out of hospital, in and out of children’s homes, for one reason and another. I had a lot of operations when I was younger, on my legs – it was supposed to help me walk better and I did used to walk but I don’t now. Seems a bit of a waste of time now. I also had speech therapy but then, when I went to a day centre when I was 20 or something, I got this machine which I can use to talk, or print things out. It’s much better. I can’t remember why I first went into a children’s home but later on it was because my mum couldn’t cope. The home I first went to didn’t have any other disabled children but the one I went to when I was 13 did. There were children with mental handicaps as well as physically handicapped. I can remember being hit at my first home. That was bad because my dad used to hit me as well. I thought, well one place is as bad as another. He was horrid to my mum as well. I think they knew, social services, but I don’t know what they did about it. My mum used to ask them to take me in. I came here when I was 18. They had a meeting with my mum and



dad and asked me about my future. I didn't know what was on the cards. They said, there's this new place we're opening up for young people. They turned out not to be so young. There's just me and this other girl, the others are older – I think they all came from a home that had been closed down. (Morris, 1999, p. 100).

Second, we share a series of reflections from and about disabled parents. Reflecting on how society thinks about disability and parenting, Meredith Nicholson, who identifies as Autistic, says “she often encounters disbelief that people with disabilities would engage in romantic and sexual relationships, let alone desire parenting, much as disabled people [also faced disbelief](#) that they would want to pursue higher education, obtain jobs or other life milestones” ([Wang, Suksangium & Sammet Moring, 2020](#), para. 5). She goes on to say “There's still this perception that we're a burden, who would want to date us? Who would love us or want to have sex with us? That we are a liability because we would need so much, instead of that we have so much to give” ([Wang, Suksangium & Sammet Moring, 2020](#), para. 14).

In a recent series highlighting the lives of disabled parents, the focus was on disability as a source of strength and resourcefulness in parenting. One parent is quoted as saying, “In our house, disability is an asset...there are strengths that come from having a disability. And [my daughter] is going to grow up understanding that” ([Wang, Suksangium & Sammet Moring, 2020](#), para. 22). In reflecting on her considerations about whether to become a parent, Nicole, a woman with cerebral palsy, stated, “I was thinking about physically how I would care for a child. I knew I could do it as a person with a disability because I had three younger sisters I had a hand in raising...so I knew I could do it. But I did think long and hard about that” ([Wang, Suksangium & Sammet Moring, 2020](#), para. 25). And even though Nicole had years of experience changing her siblings' diapers, for example, she did not have disabled role models, which made seeing herself as a parent somewhat of a struggle.

On the other hand, one mother reports that “having a disability really prepared me for that big change [of having a baby] because I had already been working my schedule around my disability....I was already used to things taking a bit longer and life having to move at a slower pace...and with Evelyn, that's just a really happy joyous reason” ([Wang, Suksangium & Sammet Moring, 2020](#), para. 27). She goes on to say “having a parent with a disability can be a crash course in empathy and compassion in a way that maybe able-bodied parenting takes a little more effort to teach those lessons. I don't think I'm going to have to take Evelyn to some service project to teach her compassion and empathy. I think she's going to see it here” ([Wang, Suksangium & Sammet Moring, 2020](#), para. 29).

The impact of intersectionality was not lost on disabled parents in this essay. “I don't know the road that other people have walked, but for me, disability is something that's made me really sit and think about all of those choices, and my own beliefs, where they were antiquated, where they were downright wrong...And you have to cast out what doesn't work, whether that's ableism, homophobia, trans-antagonism, I'm always learning something new. And that's something that disability has helped me to do” ([Wang, Suksangium & Sammet Moring, 2020](#), para. 31).

But perhaps one of the most well-known disabled parents in the United States was attorney and activist Carrie Ann Lucas. Carrie Ann, who passed away in 2019, was the mother of four adopted children from Colorado (Seelye, 2019). She had a form of muscular dystrophy, which resulted in using a power wheelchair



and ventilator assistance to breathe. Carrie Ann was also hard of hearing and had low vision. She was a single parent, lesbian, and Latina (Wong, 2017). Carrie Ann's children all had disabilities, and two were Black. She was also a foster parent for other children over the years.

Carrie Ann's first encounter with the family policing system occurred more than two decades ago when she sought to adopt her disabled niece in foster care (Powell, 2018). The process took nearly two years because of bias and speculation concerning Carrie Ann's capabilities to care for her niece due to both of their disabilities. In fact, at one point, a judge threatened to place the child welfare worker in contempt of the court if the child was not immediately placed with Carrie Ann. At the time, the child welfare worker told the judge, "There is no way that a handicapped woman can take care of a handicapped child. We're going to be picking up the child within two weeks." Of course, that did not happen, and Carrie Ann went on to adopt three additional children (Powell, 2018).

Carrie Ann's harrowing experience with the family policing system inspired her to attend law school and become a disability rights attorney. Throughout her legal career, Carrie Ann represented many parents with disabilities involved with the family policing system. Although the state deemed Carrie Ann fit to adopt four times, she was referred to the family policing system countless times because of allegations of child maltreatment (Powell, 2018). During one such incident, her daughter's school filed a report with the family policing system because her daughter's ponytail was "too tight." She was also reported to the family policing system for neglecting her children because she wanted them to be independent and autonomous, such as requiring her teenage daughter to drive her own wheelchair from the school bus to the door of their home (Powell, 2018).

Carrie Ann was a tremendous mother and role model for other disabled parents. Her legacy is an important reminder that we must look beyond the ableist notion of what it means to be a good parent. Indeed, her personal experience as a multiply-marginalized disabled parent is precisely what made her an exceptional mother.

Disabled children, too, have views about their experience in the family policing system, and we need to be attentive to what they have to say to inform our social work practice. For example, Carolyn Johnson, who was previously in foster care, notes that:

as a child with a disability, it was hard to have so much uncertainty and change...It would be hard for any child to go through the foster care system, but having a disability made it more difficult for me to understand what was going on in my life. The only time that I really remember my social worker was when she came to my house to take us away. I do not recall a social worker talking with or visiting me in the foster home. It was important to know what was happening in my life. I needed someone to explain the situation to me in a way that I could understand, someone I could trust and talk to about things. Sometimes it felt like the foster homes were just in it for the money. It felt like they did not care about me or that I had a disability. (Johnson, 2006, p. 1)

While in foster care, Johnson became pregnant with a son as a young teenager. As she was both a child in the foster care system and an underage parent, she became a part of the family policing system in a new way. Reflecting on how this impacted her experience, she says, "As a parent, I felt that a lot of things I ran into with

child protection were because I was a young mom with a disability. When child protection looked at me, it seemed to me that they only saw my disability. It felt like they used my disability against me. It seemed that they saw my disability but did not see all of the ways that I was a good mom” (Johnson, 2006, 36). However, Johnson also reflected on the positive experiences she had at a residential school for disabled young people, at which she was placed while in foster care.

This experience changed my life. The staff at [the center] were wonderful. They believed in me and cared about my future. My opinions were important to them. Sometimes the staff even came to me for advice. It was the first time in my life that anyone seemed interested in my opinion. It helped me to feel confident and to see that I had important things to share. Now I love to communicate and give advice. I give them a lot of credit for my success. I also remember a special education teacher named Mrs. Klinefelter. She understood my needs and abilities. We worked together on my school work, and together we built up my self-esteem” (Johnson, 2006, p. 36)

Another child in foster care writes anonymously about his positive experience in foster care as a child with attention deficit hyperactivity disorder, saying,

Up until the 11th grade, school was a struggle. My parents abused me, which made it hard to concentrate, and they never helped or encouraged me in school. Then I went into care, missed a lot of school, and fell behind. Now I need to make a big decision: I’m 19 and only have two more years of financial support from foster care. In October of 11th grade, I was moved into Blanca’s house, where I still live. Blanca was and is the best parent I’ve had. She told me when I got there, “You are going to do well in school because you can.” Partly because she believed in me, I went to my classes every day. That semester, I got B’s in every class” (Anonymous, 2020, p. 1)

These are just a few of the many voices of disabled children and parents involved in the family policing system. As you go forward in your social work practice with this community, it will be important to lift the voice and perspective of your clients at all times to guide your work.

## Policy and Practice Implications for Working with Disabled People in this Arena/Service System

Whether your social work practice is at the micro, mezzo, or macro level in the family policing system, some clear, empowerment-oriented principles you can use to ‘check yourself’ in your work. You can start by adopting some of the core principles of empowerment-oriented social work practice with the disability community discussed in Chapter 1. Then, ask yourself, is this principle reflected in how I am implementing this policy/drafting this policy language/planning this program/designing this case plan? And, of course, always work to bring your intersectional, anti-oppressive, and critically culturally competent lens with you on the journey!

Community inclusion – posits that all people have the right to be respected and appreciated as valuable members of their communities. This includes, for example, a focus on helping people to participate in activities in community settings as opposed to institutional settings and to generally being part of the larger community.

Notably, research suggests disabled people of color may be less likely to experience community inclusion in disability services.

**Self-determination** – This is conceptualized as the process of making something happen in one’s own life. It is the opportunity to make choices, set goals, solve problems, and make decisions for oneself.

**Dignity of risk** – This is the idea that everyone can learn from everyday risks. Central to honoring the dignity of risk is respecting an individual’s autonomy and self-determination to make choices. Also important is the right to make choices even if professionals in the person’s life feel that they could endanger the decision-maker in question. To respect a person’s dignity of risk, one should provide intermittent support even if others do not approve of the unsafe choice. As there is inherent dignity in the experience of everyday risk, this concept suggests that limiting a disabled person’s ability to make a risky choice or limiting their access to the community does not foster overall wellness in the long run.

**Circles of support** – groups of people that can be formal staff, family members, friends, or neighbors who together come around a person to support them.

**Nothing about us without us** – This phrase became the rallying cry of the disability civil rights movement adopted in the 1990s. This phrase communicates the idea that no policy should be decided by any representative without the full and direct participation of those whom the policy affected. These days some have evolved towards saying “about us, by us!”

As you consider these principles, you can start by exploring your able-bodied privilege. Read the [prompts on able-bodied privilege](https://autistichoya.files.wordpress.com/2016/03/brief-abled-privilege-checklist-mar-2016.pdf) from the Autistic Hoya blog, written by Autistic disability justice activist and lawyer Lydia X. Z. Brown (they/them).

<https://autistichoya.files.wordpress.com/2016/03/brief-abled-privilege-checklist-mar-2016.pdf>

Which items are most salient to you? You may consider the list items from a personal and/or a professional perspective, focusing on how you may or may not experience these issues yourself or how you may have encountered these issues as a social worker. Also, consider how your race and ethnicity factor into able-bodied privilege. This is about thinking intersectionally. Continue by building your personal disability awareness. What values and/or ideas do you hold that may unconsciously perpetuate ableism in your child protection practice? Where did you pick up these values? Think intersectional: How does this play out with your disabled clients of color?

Just as it is important to acknowledge our potential for racism as people raised in a racist society, so too is it important to recognize the ways we may have engaged in the use of ableist language or expression of ableist attitudes. How have you or your agency/organization/company unconsciously or consciously used ableist language or expressed ableist attitudes? How do race and ethnicity factor in here? How can you change things moving forward?

And now, let’s summarize what we’ve learned so far about how to engage in intersectional, anti-racist practice with the disability community in this service arena:

1. Check your ableism and able-bodied privilege

2. Use the guiding principles to guide child protection practice
3. Respect disabled people as the experts on disability
4. Keep developing your disability competence lens
5. Work to promote all aspects of accessibility
6. Watch for the ways in which all social identities intersect with disability to impact processes and outcomes, for example, race, ethnicity, and gender
7. Embrace the concept of supported parenting

## Application of Theoretical Perspectives and Practice Model from Chapter 2

Chapter 2 of this textbook presents a practice model for working with disabled clients. This model addresses the combined use of critical cultural competence, anti-oppressive practice, and intersectionality in case practice while keeping in mind the guiding principles of disability social work, such as nothing about us without us, community inclusion, and the dignity of risk, among others.

In this practice arena, applying the theoretical model can especially be accomplished in working with children or parents at the assessment and intervention phases by providing information about where parents have decision points in the case process as part of the power-sharing anti-oppressive practice is known for. This also connects to the “nothing about us without us” guiding principle.

Infusing the dignity of risk concept in the intervention phase will be especially important to consider but challenging for structural and cultural issues related to the family policing system. The dignity of risk concept is an incredibly challenging one for social workers to embrace as a guiding principle of empowering disability social work practice because of their primary duty towards child safety. However, child protection workers should be aware of the benefits of learning through the dignity of risk in combination with the fact that disabled parents can parent with accommodations that are not known to many workers at the first meeting.

Keep the theoretical practice model in mind as you read the following case study about a disabled mother, her daughter, and their family. How might this practice model have been used to good effect in this case scenario?

## Case Study

Sara Gordon is a 21-year-old woman who has a developmental disability. In 2012, she gave birth to Dana. Two days later, DCF removed the baby from Sara’s custody while she was recovering from childbirth in the hospital and placed her in foster care. Sara lives with her parents, who do not have developmental disabilities.

Her parents have continually intended to provide her support in parenting her child. Ms. Gordon's mother quit her job to provide full-time support for Sara and Dana.

Information about Sara Gordon's developmental disability: Due to Sara's developmental disability, she requires repetition, hands-on instruction, and frequency to learn new things. She has difficulty reading and following oral instructions and explains that she learns best visually and through practice. Nonetheless, an expert had evaluated her and said that with support from her family, she could safely care for her child.

Information about Sara Gordon's life: Sara lives with her parents in rural Massachusetts. Sara volunteers for an organization in her community, matching families with donated clothing and household items. Sara is finishing a few courses in a special education program at her high school to obtain her diploma. Mostly, Sara aspires to parent Dana – to teach her to hike and fish. However, Sara has realistic expectations and acknowledges that it would be difficult to care for Dana on her own, and fully recognizes that she needs the assistance of her parents.

Removal of Dana Gordon by DCF: While Sara Gordon was in the hospital, recovering from giving birth to Dana two days earlier, DCF received a report containing allegations of neglect.” In DCF's intake report about the matter, concerns included the fact that Ms. Gordon “was not able to comprehend how to handle or care for the child due to the mother's mental retardation.” Investigators said she had difficulties holding and feeding Dana and that she had to be reminded by an investigator to burp the baby and clean spit out of the baby's mouth. Sara was uncomfortable with changing the baby's diaper. Sara forgot to feed Dana during one night shift. Sara explained to the investigators that she could not read an analog clock, which is why she had trouble remembering when she last fed her daughter. Sara also reported that she started keeping a journal to track feedings.

The grandparents' plans to support Dana and Sara Gordon: Sara Gordon's mother and father intended to assist Sara with parenting Dana. DCF was concerned because the Gordons had been involved with the agency in the 1990s, although all services to the family were closed based on the Gordons' cooperation and successful completion of a service plan. No current or recent safety concerns were noted, and ample baby supplies were in the home. The Gordon family-supported parenting plan involves the Gordons obtaining guardianship and responsibility for making educational, medical, and other significant decisions, while Sara would live in the home and learn how to care for her daughter with her mother's assistance. However, DCF decided to place the baby in a non-kinship foster placement.

Reasons for non-kinship foster care placement: Sara was “unable to recognize, comprehend and react to the demands of an infant. . . . The concerns are there are no services in place. . . . [Dana] needs to come into foster care at this time. There are concerns with [Sara's] ability to meet the basic needs of a newborn child.” DCF also noted that Sara and her parents had a previous history with DCF and that she has “serious developmental delays.”

Sara's early visits with Dana: Sara had some difficulty with feeding, diaper changes, and transitioning Dana between people. DCF also noted that Sara walked away from the changing table on a couple of occasions

during supervised visits. Since that time, Sara has participated in numerous parenting classes, and her parenting skills have improved significantly.

**Interventions from DCF:** Over the next two years, DCF provided Sara with basic support and opportunities while she sought to reunify with Dana. Visitation was set at once per week for one hour, despite Sara's request for more frequent visits. DCF supervised visits outside of the family home. DCF would not permit the Gordons or vocational support caseworkers specializing in working with parents with disabilities to assist/teach Sara for most of the visits. The frequency of visits was reduced to once every other week after seven months when DCF changed Dana's permanency planning goal from reunification to adoption. Sara participated in and successfully completed DCF-sponsored parenting classes.

**Late assignment of a parent aide:** Sara agreed with DCF's requirement to work with a parent aide during her visitation with Dana to learn and utilize effective parenting skills. A parent aide is a trained individual who supports and strengthens parenting skills. However, DCF failed to provide Sara with parent-aide services for more than eight months and only provided these services after it had already been decided that Sara would not be fit to parent and changed the goal to adoption. Moreover, even after the parent aide was secured, DCF limited the parent aide's participation to the last thirty minutes of Sara's visits with Dana. The agency otherwise tasked the parent aide with teaching Sara parenting skills using a "life-like" doll.

**Dana's treatment by her foster parents:** Numerous safety concerns were noted in Dana's pre-adoptive foster care placement. In two years, Dana received a black eye, bumps, bruises, scrapes, and burnt hands on two occasions, and was left unattended on a kitchen table when she was only a few weeks old.

**Note:** Dana and Sara's case uses a pseudonym, but it is a real case from Massachusetts. This case led to a Federal investigation against Massachusetts' child protection authority. Massachusetts is in the process of working to become more disability-culturally competent as a child protection agency as a result. It is likely that, slowly, other states will have to follow suit. Sara and Dana were reunited in 2016.

## Discussion Questions

Ableism is defined as "the belief that because persons with disabilities are not typical of the non-disabled majority, they are inferior. Ableism precipitates devaluation, while the results of devaluation, including exclusion, ostracism, and a lack of privilege, can reinforce the attitudes, behaviors, and government actions of those who oppress. Four manifestations of oppression characterize ableism, "containment, expendability, compartmentalization and blaming the victim" (Mackelprang & Salsgiver, 2015, p. 105).

1. How do you see the four manifestations of ableism manifested in this case? If so, in what ways?
2. How would you have approached working with the family in this case if you were the child welfare worker? How might this practice model have been used to good effect in this case scenario?
3. How could you have implemented the guiding principles for disability social work practice in this case? See Chapter 1 for a review of those principles (e.g., self-determination, dignity of risk, "nothing about us

without us,” community inclusion, and circles of support).

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## 7.

# GENDER, GENDER IDENTITY, GENDER EXPRESSION, AND DISABILITY

Lisa Johnson and Katie Sweet

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### Learning Objectives:

- To learn about key issues at the intersection of disability and gender identities, including theoretical perspectives on disability and gender.
- To understand gendered experiences of disability and how issues such as employment discrimination have varied influences on the lives of disabled people of different gender identities.
- To learn from disabled people about their experiences at the intersection of gender and disability identities.

## Introduction

This chapter addresses the intersection of disability, gender, and other social identities. We will discuss gender-conscious theories and examine how they are and are not inclusive of disability. Also discussed are normative social gender roles and expectations, including those surrounding reproduction, and how they intersect with disability identity. We will address gender-based employment discrimination experienced by disabled people<sup>[1]</sup>. This chapter also attends to gender identity and expression via discussion of the experiences of those with transgender, nonbinary, agender, and queer gender identities within the disability community. We will review key gender-related laws, policies, and programs relevant to disabled people in the U.S. We will also

discuss historical and current women's rights movements and the representation of disabled people in these movements.

## Disability and Gender

Mohamed and Shefer (2015), drawing on the work of other authors, describe disability as “deeply gendered” (p. 2), an idea which encourages deeper examination of how people negotiate life at the intersection of these identities. However, before we delve into further consideration of disability and gender, it is important to define gender just as disability was defined earlier in this textbook[2]. Like disability, gender is a socially constructed phenomenon, and the construction of gender varies among cultures and has changed over time. According to a definition from the Gay, Lesbian and Straight Education Network (GLSEN, 2014), gender refers to

a set of cultural identities, expressions, and roles—codified as feminine or masculine—that are assigned to people, based upon the interpretation of their bodies, and more specifically, their sexual and reproductive anatomy. Since gender is a social construction, it is possible to reject or modify the assignment made, and develop something that feels truer and just to oneself. (n.p.)

Gender identity is an individual's internal sense of gender, which may be male, female, neither, or both, and which may be the same or different from their sex assigned at birth (New York City Commission on Human Rights (NYCCHR), 2019). Gender expression is representation of gender through characteristics such as pronouns, clothing, hairstyle, behavior, or voice (NYCCHR, 2019). Cisgender people are those whose gender identity matches the sex they were assigned at birth (NYCCHR, 2019). Transgender people are those “whose gender identity is different from the gender they were thought to be at birth” ([National Center for Transgender Equality](#), 2016, p. 1). “People whose gender is not male or female use many different terms to describe themselves, with non-binary being one of the most common. Other terms include genderqueer, agender, bigender, and more” ([National Center for Transgender Equality](#), 2018, n.p.).

Studies of disability tend to treat disabled people as a “monolithic and ahistorical group” (Mohamed & Shefer, 2015, p. 5), which can also be described as “intersectional invisibility” (Travis, 2017, p. 840). Given the diversity within disability communities, we should consider how gender identity and gendered experiences interact with disability identity and experience. Doing so contests the “degendering of disability” (p. 840), which is important given that “a genderless conception of disability...leads to neither gender neutral nor gender-inclusive social, political, or legal responses. When gender is ignored, [androcentrism](#) fills the void” (Travis, 2017, p. 841). Androcentrism refers to the centering of men's needs and positioning of maleness as the gender-neutral standard in society (Bailey, LaFrance, & Dovidio, 2018). Therefore, using an intersectional lens to highlight the diversity of gender identities and experiences among disabled people counteracts a default to a male-centric or cisgender-centric framing of disability.



## Prevalence

Though statistical groupings cannot fully capture the nuances at the intersection of gender and disability, they can provide a scope for consideration of this topic. According to the Centers for Disease Control and Prevention ([2019](#)), among adults, 25.4% of men and 28.1% women in the U.S. identified as disabled or were diagnosed with a disability in 2019. Globally, the most recent available data from the World Health Organization (2011) via the [World Report on Disability](#) indicate a higher prevalence of disability among women than men. According to the report of the 2015 U.S. Transgender Survey (USTS; James et al., [2016](#)), which is the largest survey examining the experiences of transgender people in the United States, 39% of respondents indicated that they had one or more disability[\[3\]](#), compared to 15% of the general population[\[4\]](#).

## Theoretical Perspectives on Disability and Gender

Feminist theories have been among the theories most engaged in understanding the construction and implications of gender in society. In advancing feminist theorizing beyond a singular focus on gender, scholars increased attention to how gender intersected with other social characteristics such as race and class, and eventually disability (Gerschick, 2000). In the 1980s and 1990s, there was a growing emphasis, via feminist perspectives, on the gendered experiences of disabled women and men (Shuttleworth, Wedgwood, and Wilson, 2012), “making feminist theories of gender more inclusive, complex, and nuanced” (Gerschick (2000, p. 1263). Authors Fine and Asch (1981) introduced the concept of ‘rolelessness’ experienced by disabled women in a society where there are “fewer socially sanctioned roles...viewed as appropriate for [them], and relevant disabled role models are virtually invisible” (p. 233). In another example of early writing about gender and disability, Begum (1992) explored how the “concerns of disabled women strike at the core of both the disability rights and feminist movements” through consideration of gender roles, self-image, and sexuality at the intersections of gender and disability experiences (p. 70). Though most early feminist disability scholarship focused on women, in 1989, Harlan Hahn began to “provide a more comprehensive interpretation of disabled masculinity...derived from his own personal experience but augmented through his long-term involvement in disability rights and the feminist-inspired gender and disability literature of the time” (Shuttleworth et al., 2012, p. 176).

Gerschick (2000) notes that “disability has a profound effect on the material and nonmaterial experience of gender” (p. 1267) and argues that contextualizing the experiences of individuals with physical disabilities requires attending to “three sets of social dynamics: the stigma assigned to disability, gender as an interactional process, and the importance of the body to enacting gender” (p. 1264). These social dynamics are also noted in Garland-Thomson’s (2002) discussion of a feminist disability approach, which addresses concerns such as the “unity of the category woman, the status of the lived body, the politics of appearance, the medicalization of the body, the privilege of normalcy, multiculturalism, sexuality, the social construction of identity, and

the commitment to integration” (p. 4). A powerful example of the points raised by Gerschick and Garland-Thomson can be seen in the work of vlogger, writer, and advocate, Annie Elaine (2018), who, in a YouTube [video](#), shares experiences of navigating disability, fashion, and gender presentation. At one point in the video, Elaine says:

Currently, pants hurt a lot, and I feel a lot more physically at ease/less in pain when I’m wearing things that don’t put pressure on my knees, like skirts, dresses, and shorts. I feel like I’ve been a little bit forced into them lately by my disability, meaning there are days that I would truly, truly, truly very strongly not want to wear a skirt or a dress or present myself as feminine at all, but I still have to wear those items for the sake of my pain levels. Describing this feeling to people who may not relate, I think, is so hard. I’ve tried to explain it like it feels like you’re forced into a uniform that you feel ridiculous in or an itchy sweater. It’s just uncomfortable. It feels like someone else has control over what you’re wearing, and it feels like you’re being inauthentic. It feels like you can’t be yourself.

In this same video, Elaine (2018) goes on to say that:

There are some [fashion] choices that I would have never come up with or ever gone through with if it weren’t for my disability, and it turns out that they’re very fun, excellent, fashionable choices. So, I’m really kind of grateful for that, that my disability kind of expands my mind and makes me think of creative ways of expressing myself. So, it’s not all bad.

Elaine’s discussion highlights both challenges and opportunities for self-expression at the intersections of disability, gender, and other social identities and experiences.

The importance of nuanced and multi-faceted representations of lived experiences of disability in concert with gender and other identities is a key feature of a feminist disability framework (Mohamed & Shefer, 2015). As highlighted by Garland-Thompson (2002) and in Annie Elaine’s (2018) story, the politics of appearance are often complicated further by disability. Furthermore, as Mohamed and Shefer point out, we see similar complexities at the intersections of disability and gendered sexuality, given that women with physical disabilities are often stereotyped as asexual, and women with intellectual or emotional disabilities are stereotyped as hypersexual. “These paradoxical and contradictory responses to disabled femininity draw on notions of embodiment and gendered ideologies of beauty, motherhood and reproduction, representation, discourses on rationality, autonomy, and choice, amongst others” (Mohamed & Shefer, p. 8).

Regarding masculinity and disability, Shuttleworth, Wedgwood, and Wilson (2012) note that cultural ideas regarding masculinity and disability conflict given that disability is associated with weakness and masculinity is associated with strength. Furthermore, they contend that the study of the intersection of gender (masculinity in particular) with disability assumes a static, ‘generic category’ rather than how “masculinity (or masculinities) intersect(s) differently with various types of impairment” (p. 188). Gahman (2017) adds to this theoretical consideration of disability and masculinity by conceptualizing masculinities as constructed through place, time, and culture, noting that this “proves to be effective in understanding how gendered power relations shift across social, political, and economic sites and situations” (p. 702).

Another theoretical perspective that can be seen as germane to considerations of gender and disability is crip theory. This theory, first promulgated in the early 2000s, grew out of the interdisciplinary fields of disability studies and queer theory. Works employing crip theory tend to focus both on the “margins of disability identification as well as on the intersections where gender, race, and sexuality come together” (McRuer & Cassabaum, 2021, n.p.). Like the feminist frameworks discussed above, crip theory can be used to examine the implications of gendered disability as experienced through physical, psychological, social, political, and other human contexts. For example, Gahman (2017) uses crip theory to uncover the ways in which notions of “manhood” are influenced by normative ideas about able-bodiedness and able-mindedness that are linked to culture and place.

Although gains have been made in applying empowerment and critical perspectives to the intersections of disability and gender, along with other identities, several authors argue that there is more to accomplish. Bailey and Mobley (2019) contend that “when disability is more seriously regarded within Black Studies, race within Disability Studies, and gender in both, there are an infinite number of revolutions that a Black feminist disability framework can help bring about” (p. 35). Miles (2019) furthers the discussion of the intersections of disability, gender, and race, noting the particular burdens placed on Black, disabled women who are simultaneously met with the social construction of women with disabilities as “weak, dependent, and unfit as providers,” and expectations for the fulfillment of a Strong Black Woman schema, which itself is rooted in ableist ideology (p. 44). According to Miles (2019),

The feminist intersectional disability framework is grounded in the following assumptions: First, race, class, gender, and other markers of difference, and the associated systems of oppression, collectively contribute to how disability is acquired, experienced, and socially constructed. Second, the intersection of race, class, gender, and ability oppression contributes to disabled women of color’s differential access to resources, opportunities, and treatment in society. Third, disabled women of color experience marginalization within dominant majority communities (i.e., white, able-bodied, middle-class communities) as well as within their minority communities (i.e., black, disabled, poor communities). Finally, ableism is commonly an unaccounted predictor of structural inequality. Because many social problems examined by researchers exclude disability inquiry and its intersections, the conclusions developed to rectify these problems are often incomplete and inadequate. (p. 46)

## Gendered Experiences of Disability

### Gender-Based Employment Discrimination

Discrimination is faced by all people with disabilities regardless of their gender identity. However, the way it manifests and how it impacts an individual with a disability can be greatly influenced by their gender identity and expression. Compared to men with disabilities, women with disabilities are half as likely to be employed

(Pough & Eld, 2021), and once employed, in comparison to able-bodied women in the workforce, women with disabilities face multiple forms of discrimination, including both sexism and ableism (Kim, 2019). The myriad types of discrimination that women with disabilities experience include unequal hiring and promotion standards, unequal access to training, unequal pay, occupational segregation, as well as not receiving the chance to participate in economic decision-making (Pough & Eld, 2021). These discriminatory practices extend even further for minority women with disabilities who receive the brunt of discrimination in the workforce due to intersecting experiences of oppression. Minority populations with disabilities are at risk of being unemployed due to inadequate preparation, such as lack of education or vocational rehabilitation services (Smith, 2008) as a result of shortages of such resources in their communities. Further, even when these resources do exist, women with disabilities, especially women of color, are less likely to have received vocational services that prepare disabled people for the workforce due to lack of accessibility and lack of education about the resources (Smith, 2008). This is a phenomenon often referred to as double or triple jeopardy. This phenomenon occurs when people with multiple marginalized identities experience compounded discrimination and/or disadvantage (Goodman, Morris, Boston, & Walton, 2017).

The varied discrimination that is experienced in the workplace by women and individuals of color is further compounded by a variety of socio-economic factors that are faced disproportionately compared to their able-bodied peers. Women and racial minority groups with disabilities experience the highest poverty levels, and the lowest income and have a greater reliance on income sources outside of the labor market, such as social security disability insurance (Maroto, Pettinicchio, & Patterson, 2019). This directly impacts how women with disabilities are viewed by their able-bodied peers; they are often seen as less competent, less productive, helpless, and weak in comparison to able-bodied workers (Maroto et al., 2019). This has been captured in studies done by Mereish (as cited in Maroto et al., 2019), who found that Asian American and Pacific Islander women with disabilities were more likely to report being discriminated against in the workplace than their able-bodied counterparts. Additionally, Shaw, Chan, and McMahon (as cited in Maroto et al., 2019) found that Mexican and American Indian women with behavioral disorders were more likely to make harassment complaints in the workplace.

Men with disabilities also experience discrimination in the workplace. However, these challenges often differ in how they manifest and their impact on one's identity compared to women with disabilities. According to Ostrander (2008), disability has a direct impact on masculinity in the workplace because it is continually contested and in need of proving through making a substantial salary. Men with disabilities may find this more challenging as they are less likely than men without disabilities to make a substantial salary based on the jobs that are available to them (Sang, Richards, & Marks, 2016). Woodham and colleagues (2015) argue that men with disabilities face a greater pay penalty than other marginalized groups. Similar to women with disabilities, men with disabilities may be perceived as weak and dependent. In a patriarchal society, able-bodied men and men with disabilities feel as if they are supposed to be portrayed as masculine and independent. Men with disabilities who gain employment express greater pride in their identity, which leads to a change in their approach to masculinity. Different disabilities pose different outcomes for men, as seen in a study in the U.K.

where Butler reports that men with a stuttering disability reported avoidance of typical ‘masculine’ jobs such as architecture or construction professions due to not wanting to be seen as less than or incompetent (Sang et al., 2016).

In addition to men and women with disabilities, transgender individuals with disabilities are also subjected to discriminatory experiences in and out of the workplace. According to Chope and Strom (2008), transgender people with disabilities such as mental health issues are more likely to be unemployed and underemployed, given experiences with workplace stigma and discrimination despite wanting to work. These authors state that transgender people who encounter discrimination based on their transgender identity in the workplace may have lower confidence and invoke psychiatric distress (2008). The 2015 U.S. Transgender Survey (USTS; James et al., 2016) reported that 24% of transgender people from the U.S. were unemployed and 45% were living in poverty. The USTS reported that 29% of trans people with disabilities respondents were more likely to receive assistance such as Supplemental Nutrition Assistance Program (SNAP) and/or Women, Infants, and Children Nutrition Program (WIC) due to economic distress and financial instability (James et al., 2016).

## Experiences of Being a Transgender or Non-Binary Disabled Person

According to the 2015 U.S. Transgender Survey (USTS), three to five million transgender people have disabilities (James et al., 2016). Although the 2015 USTS does not capture the experiences of all transgender people in the United States, with 27,715 respondents from all fifty states, the District of Columbia, American Samoa, Guam, Puerto Rico, and U.S. military bases overseas, there is valuable information regarding transgender people with disabilities. In particular, transgender people with disabilities report limited access to inclusive and fully accessible services, including affordable and inclusive health care and community services and supports. Spaces focused on disability may not foster transgender people’s unique experiences, and in transgender spaces, services and facilities may not be inclusive or accessible, for example, having accessible buildings or restrooms, ASL interpreters, or options used specifically for people who have a visual impairment (James et al., 2016).

In an article on BuzzFeed from 2017, a 28-year-old non-binary trans person with hemophilia expressed not feeling accepted by the trans or non-binary circles due to their disability. They expressed feeling more comfortable in disabled spaces because they felt as if their gender identity and orientation were more easily understood and accepted by people with disabilities (Lynn, 2017). In the same article, a 36-year-old trans woman with a disability described withholding disability information from her primary care doctor out of fear that it would impact her transition treatment or ongoing hormone replacement therapy maintenance. Like many other people transgender people with disabilities, she feels as if her doctor has power over her ongoing care, and she may be more susceptible to losing certain medications or treatments that are needed for her emotional well-being and transition (Lynn, 2017).

Furthermore, according to the USTS, transgender people with disabilities are twice as likely to experience

mental health conditions that impact their daily lives compared to those without a disability (James, 2016). They were six times more likely to report having serious difficulty concentrating, remembering, or making decisions and four times more likely to report difficulty doing errands alone, such as visiting doctor's offices or shopping, because of a physical, mental, or emotional condition. Experiencing mental health disorders and access to appropriate health care may be some of the reasons that 12% of respondents with disabilities from the USTS attempted suicide within the past year (James et al., 2016).

LGBTQIA+ people with an intellectual or developmental disability (IDD) may experience specific forms of exclusion and discrimination related to their non-heterosexuality or gender diversity, which could be interpreted as a behavioral issue rather than self-identity (Smith et al., 2022). There is a lack of literature specific to transgender and gender-diverse people with intellectual disabilities. Smith and colleagues (2022) suggest that this is due to the difficulties recruiting transgender and gender-diverse people with IDD into studies or the lack of support for the IDD population in encouraging exploring their gender identity.

## Reproduction and Gender Roles/Expectations

Women with disabilities disproportionately face challenges to their reproductive health and rights compared to able-bodied women. Women with disabilities receive less access to needed health care (Silvers, Francis, & Badesch, 2016) as well as receive cesarean sections and induction of labor occur more frequently even if there is no indication that this was needed for a medical reason. Societal views may hinder women with disabilities' views on whether they can or should have children (Silvers et al., 2016). Those views can often extend to being infantilized or being considered as asexual. In an excerpt from the Disability & Philanthropy Forum's webinar on gender, sexuality, and disability, Robin Wilson-Beattie, a Black woman with visible and invisible disabilities, addresses how ableism and racism manifest within the field of reproductive health. Wilson-Beattie discusses how ableism promotes the narrative that people with disabilities do not have the right to be sexual beings (Silvers et al., 2016).

Additionally, women with disabilities are vulnerable to adverse maternal and child health outcomes (Powell, Andrews, & Eysers, 2022). Parents with disabilities experience many barriers when accessing health care before, during, and after pregnancy (Powell et al., 2022). Some of these barriers include physical, communication, and programmatic barriers (2021). Physical barriers for people with disabilities may include architectural barriers or inaccessible equipment. Communication barriers may include no translation services for people who are deaf. Programmatic barriers may include a scarcity of policies and procedures about caring for parents with disabilities, negative attitudes, and lack of knowledge among healthcare providers (2021). People with disabilities may be discouraged from having children out of fear that the child will also have disabilities (Silvers, 2016). Those who have experienced pregnancies report complaints and criticisms from people calling them selfish under the assumption that others will have to raise their children for them (2016). Systemic stigmatizations of women with disabilities have not only led to reduced or complete loss of reproductive



autonomy but also to the limited inclusion or complete exclusion from political movements that would otherwise advance and improve their standing (2016).

People with disabilities continue to have reproductive rights taken away from them by sterilization (forced or coerced). According to the National Women's Law Center Forced Sterilization Report (2021), women with intellectual and developmental disabilities get sterilized more than nondisabled women, women with disabilities are sterilized more often than men with disabilities, and Black women with disabilities are more likely to be sterilized than White women with disabilities. Eugenics, racism, and ableism have been the fuel for forced sterilization of women of color. One study using information from the 2011 – 2015 National Survey of Family Growth found that 41 percent of Black women with disabilities used sterilization as a contraceptive method, compared with 28 percent of White women with disabilities (Mosher et al, 2018). These statistics could be due to a lack of financial resources, trouble getting other types of birth control, and feeling pressured to make the decision to become sterilized (National Women's Law Center, 2021).

## Disability Representation in Women's Rights Movement

The Women's Rights movement has been slow to make space for women with disabilities (Goyal, 2016). Women with disabilities have been excluded by most women's rights movements through either omission or commission (Price, 2011). Price concludes that as of late, more women without disabilities are prepared to stand alongside women with disabilities to elicit the change that they both want to see in the world. In the 1970's and 1980's feminists rarely addressed the issues of women with disabilities seeing it as a more individualized problem for women with impairments (2011). Even within the disability movement, the voices of women with disabilities are overlooked because the movement has historically been male dominated. As a result, women with disabilities who engage in political activity, draw upon feminism to aide in the discussion of disability oppression (2011), but do so often without the support of the larger feminist movement and communities.

The absence of support and inclusion of women with disabilities in the larger movement for women's rights is considerable. Some women with physical, sensory, or cognitive impairments believe they are marginalized in the feminist theory just as much as they are in the patriarchal society (Price, 2011). This is due to women with disabilities having to live with the stigma of being dependent, helpless, vulnerable individuals, and non-disabled feminists are worried that this image will make all women look this way as they try to project a picture of a strong, capable woman (Price, 2011). Fine and Asch (1985) argue that the popular view of women with disabilities has been one mixed with repugnance. Perceiving disabled women as childlike, helpless, and victimized, non-disabled feminists have functionally severed them from the sisterhood in an effort to advance more powerful, competent, and appealing female icons (Price, 2011). Women with disabilities were used for



political appearances, such as sitting in on group photos or acting as a token instead of being part of the sisterhood of the feminist movement (Price, 2011).

## Policies

Title IX, a U.S. federal civil rights law that was enacted as part (Title IX) of the Education Amendments of 1972, prohibits discrimination on the basis of sex in any education program or activity receiving federal financial assistance (Becker, 2019). All public high schools, middle schools, and elementary schools must comply with Title IX. Under Title IX, public schools are required to protect students from sexual harassment and sexual assault (Becker, 2019). Public schools must also comply with federal laws which protect the rights of students with disabilities such as Section 504 of the Rehabilitation Act, a U.S. federal law which prevents discrimination against individuals with disabilities and ensures equal access to education (Becker, 2019). Unfortunately, Title IX protection and disability protection can clash and provide significant challenges for students, their parents, and the schools which are required to protect all students (Becker, 2019).

Becker discusses a recent case in Palo Alto, California, which shows the inadvertent clash between Title IX and disability protection laws. In this case, the school district In Palo Alto asked a judge to uphold a lower court's decision to permit a male high school student who had sexually harassed (via text messages and verbal comments) a female high school student, to remain on the school's robotics team where the girl participates. The boy had an individualized education plan (IEP) for his "significant pragmatic speech disability," (Becker, 2019). The school system had initially barred the boy from the robotics team until legal action was taken by the boy's mother. The school system then allowed the boy to participate in robotics, provided that an additional staff member was present. The girl's parents then filed a motion which resulted in the school system again barring him from robotics. The boy's mother then argued that, by barring him from robotics, the school district violated the Individuals with Disabilities Education Act, IDEA, and discriminated against him on the basis of his disability. She argued that the text messages and comments her son made to the girl were manifestations of his disability (2019). She also advocated that her son's "emotional health and well-being would be seriously impacted by his continued exclusion" from robotics in an article provided by Elena Kadvany with Palo Alto Weekly News (2019). The resolution of this case was that both children were allowed to continue on the team but ending in a legal battle, the girl was awarded \$150,000 for the violation of Title IX by the Palo Alto School District (Veit, 2019).

Allen (2019) suggests there are other statistical trends that may conflict with Title IX and section 504 of the Rehabilitation Act: (1) more students are being diagnosed with mental health disorders, (2) people with disabilities are more likely to be sexually assaulted than their nondisabled peers, and (3) social movements which aim to protect people from being harassed or assaulted, such as the #metoo movement, have resulted in more efficient enforcement of the Title IX conduct codes in schools. Without the proper education relating

to people with disabilities, especially neuro-developmental disabilities, Title IX policies can have irreversible consequences for people who may not have the ability to understand the ramifications.

## Voices of Disabled People on the Intersection of Gender and Disability

Keri Gray , founder and CEO of the Keri Gray Group, advises young professionals, businesses, and organizations on issues around disability, race, gender, and intersectionality. She illustrates how the framework of intersectionality, including gender, is essential to true inclusion:

The reality is, is that you have people like myself, who are black, disabled, and women, and so many other things. And when you live at the intersections of all three of those, then you can't split your political and social dynamics between these different groups. It doesn't produce real results of freedom and it doesn't produce real results of access to employment and other opportunities that you're looking for. ([Ford Foundation, 2020](#))

Niles Clipson, a member of the Gay, Lesbian, and Straight Education Network's ([GLSEN](#)) National Student Council, in an essay titled, "[I'm a Trans, Disabled Young Person, Not One or the Other](#)," asserts an intersectional framework for social justice:

Accommodations for trans people OR disabled people OR people of color isn't enough. This type of thinking separates identities that are inextricably linked. Disability justice is LGBTQ justice is racial justice is healthcare justice, and so on. In working towards social justice, we must recognize these as intertwined, and understand that addressing these individually, instead of collectively, further marginalizes those with multifaceted identities rather than work towards collective liberation. I don't want to have to choose between using the stairs and risking passing out from the pain or taking the elevator and having to interact with the kid who always harasses me for my gender and disability.

In a powerful [article focusing on disability, race, and parenting](#), social worker Vilissa Thompson (2021) amplifies the voices of Black disabled mothers who share their stories of "the complex joys, frustrations, and lessons learned that come from parenting with a disability" (n.p.). Thompson notes that:

Black disabled mothers are subjected to hyper-focused scrutiny, whether they are taking inventory of their family planning options, seeking prenatal care, in the delivery room, or are gearing up to take their bundle of joy home for the first time. And as Black disabled women, they are especially aware of how dangerous the intersections of misogynoir and ableism can be for them and their babies during both pre- and post-natal care. (n.p.).

Thompson's article also highlights the strengths and contributions of Black disabled mothers. As Reyma McCoy McDeid, a mother and activist profiled in the article notes, being a Black disabled mother is "a revolutionary act" (n.p.).

Other insights from disabled people related to the intersections of disability, gender, and other social identities can be found at the links below.

- The Disability and Philanthropy Forum [webinar on Gender, Sexuality, and Disability](#) (2021) featuring New York Women's Foundation President and CEO Ana Oliveira in conversation with disability activists Victoria M. Rodríguez-Roldán, Robin Wilson-Beattie, and Leslie Templeton
- An essay on [disability and gender roles](#) by Erica Mones (2015)
- [Becoming Comfortable with the Uncomfortable: Researching Women's Health Issues for Women with Physical Disabilities](#), an essay by Rebecca Parten, LMSW for the [Women Enabled International Rewriting the Narrative](#) blog

## Case Example

You are a social worker who is working with young adults in a community-based independent living program funded by the state child welfare department. Among the young adults in the program you work with are Shannon, a 19-year-old who identifies as female, Latina (Puerto Rican), and disabled (she has been diagnosed as having bipolar disorder with psychosis), and Shannon's partner, Jamie, a 20-year-old transgender man who also identifies as Latino (Dominican) and disabled (diagnosed with PTSD and substance use disorder).

Shannon and Jamie live in separate apartments, funded by the agency that runs the independent living program. However, when they are not working or at school, they spend most of their time together. Shannon and Jamie have been dating for one year. They met at an event sponsored by the independent living program focused on budgeting and finances. Jamie, who is currently receiving gender affirming hormone therapy, began transitioning several months after he and Shannon met. Jamie often speaks about how Shannon has supported him '100%' in his gender identity and expression.

Jamie frequently talks about his experience in foster care prior to entering the independent living program. Especially salient for him was how he felt his gender identity was ignored by his social workers and caregivers<sup>[5]</sup>. Jamie has openly identified as male since he was 13 years old. After being in several family foster placements, he was placed in a group home. Because the group homes in his area are separated along a gender binary, Jamie was placed in a home for girls with psychiatric disabilities. He faced a lot of bullying from the other residents and was often misgendered by staff. When he tried to speak with the staff about hormone blockers, they refused to give him any information or even have a conversation about it, saying it was 'too risky, especially since you're dealing with mental illness already.'

Shannon and Jamie are part-time college students. Shannon is a member of [Active Minds](#), a nonprofit organization supporting mental health awareness and education for young adults. She has been working with other members of the group to develop programming on how gender and other identities intersect with disability. Shannon decided on this project after conversations with Jamie about their different experiences as disabled people based on their gender identities and expression. Shannon said that she often feels that she is stereotyped as unstable, irrational, and overly emotional as a woman with mental illness, while Jamie, as a man, is less vulnerable to these stereotypes but can feel hindered in expressing his true emotions.

Shannon is majoring in social work and minoring in gender studies. She believes that her experiences in the foster care and mental health systems give her insight and motivate her to make changes so that other youths do not have the same negative experiences she had. Jamie feels very differently about this—to him, the system is beyond repair, and he does not want to have anything further to do with human services once he completes the independent living program. He is majoring in computer science and wants to start a tech company one day.

Though Shannon and Jamie are not considering having children anytime soon, they think about how gender and disability may influence their experience in this area. They talk about adopting one day, but Shannon is especially worried that she will not be considered fit to be a mother because of her disability.

For both Shannon and Jamie, spirituality is an important part of their lives. Shannon is Wiccan, and considers her spiritual practice to be a coping mechanism, especially when dealing with injustices she faces as a disabled person. Jamie identified as Christian growing up. He now identifies as a [Humanist](#) and sees many of the tenets of Humanism as supporting his desire for justice as a disabled transgender person.

## Discussion Questions

Putting yourself in the position of the social worker working with Shannon and Jamie, consider the following:

- What knowledge do you need to gain related to the intersections of gender, disability, and other identities/experiences to work effectively with Shannon and Jamie? What additional questions would you have for Shannon and Jamie about their personal lived experiences, given their disability, gender, and other identities/experiences?
- Can you identify examples of ableism, gender discrimination, and transgender discrimination experienced by Shannon and Jamie?
- Can you identify examples of strengths demonstrated by Shannon and Jamie?
- How might you utilize theoretical perspectives discussed in this chapter or in other chapters in the textbook in your work with Shannon and Jamie?
- What resources in your area might you recommend (groups, services, providers, etc.) that could be useful supports for Shannon and/or Jamie? Are these resources (e.g., healthcare, mental health), disability and gender(trans) inclusive?
- With an understanding that degendering disability and focusing only on disability experience/identity can lead to neglecting to address relationship experiences and needs, how might you support Shannon and Jamie in developing and maintaining healthy relationship skills?
- Can you identify any advocacy organizations in your area that Shannon and/or Jamie may be interested in connecting with?

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[1] Both identity-first and person-first language are used in this chapter.

[2] See Chapter 1 of this textbook. Wendell (2013) offers a perspective on the social construction of disability: “I see disability as socially constructed in ways ranging from social conditions that straightforwardly create illnesses, injuries, and poor physical functioning, to subtle cultural factors that determine standards of normality and exclude those who do not meet them from full participation in their societies” (p. 481).

[3] As described in the 2015 American Community Survey of the U.S. Census Bureau

[4] In 2015

[5] See this [report](#) by the Massachusetts Commission on Lesbian, Gay, Bisexual, Transgender, Queer, and Questioning Youth (2021) for an example of a review of LGBTQ youth experiences in a foster care system.

8.

# SEXUAL ORIENTATION, SEXUALITY, AND THE DISABILITY COMMUNITY

Ami Goulden and Shanna Katz Kattari

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## Learning Objectives:

- To apply Crip Theory in understanding experiences of sexuality among members of the disability communities
- To identify key themes in the experiences of the disability community around sexuality
- To explore the intersectional experiences of disability communities with different sexual orientations

## Introduction

This chapter addresses the intersectionality of being disabled and lesbian, gay, bisexual, pansexual, queer (generally referred to as queer in this chapter) or heterosexual. Topics include the prevalence of queer and disabled people and experiences of coming out as queer and/or disabled when living with multiple cultural identities. Theories related to sexual orientation (e.g., queer theory) are critiqued relative to their inclusion of disability identity. We also consider the contributions of queer disabled people to queer civil rights movement despite the marginalization of disabled people within these movements. Also included in this chapter is a discussion of human sexuality and disability as it relates to social norms, stigmas and body image. Common views and portrayals of disabled people as de-sexualized and labeled as non-sexual will be addressed. We will also address how the dignity of risk concept relates to sexuality among disabled people, focusing on intellectually or developmentally disabled people. This point will be related to the challenge of not getting inclusive sex

education for disabled youth and adults. We will review key sexual orientation and sexuality-related laws, policies, programs and exemplar agency regulations relevant to disabled people in the United States. For example, we discuss federal laws that allow for same-gender marriage. We also discuss national and local policies regarding sex education curricula.

## Introduction

Sexuality is central to the human experience. It encompasses sex, gender identities and roles, sexual orientation, eroticism, and social well-being related to an individual's sexuality (WHO, 2002). How individuals experience and express sexuality varies and can be influenced by biological, psychological, social, cultural, and religious factors (Southard & Keller, 2009). Disabled people have similar sexual and social needs as their non-disabled counterparts, but they experience unique barriers related to their sexuality (Goulden, 2021; Kaufman et al., 2007; Lee et al., 2020; Liddiard, 2013; Owens, 2015; Shakespeare, 2000). For instance, disabled people experience harmful societal stereotypes that de-sexualize and label them as non-sexual, incapable, or uninterested in sex/relationships (Addlakha, 2007; McCabe & Holmes, 2014; Toft et al., 2019), heightened vulnerability (Mueller-Johnson et al., 2014) and infantilization (Shildrick, 2007). These stereotypes and other ableist misconstructions conspire to restrict disabled people's access to cultural representations, suitable education and resources, and professional services and support in the community.

In the early 1900s, the primary focus of the disability rights movement was to increase disabled people's access to physical spaces and employment opportunities. Organizations that contributed to the disability rights movement have been in place since the 1800s but became more widespread in the 1900s (Grim, 2015). The *Americans with Disability Act (ADA)* (1990) and the subsequent *ADA Amendments Act* (2008) are major civil rights laws that prohibit discrimination against disabled people in many aspects of public life (e.g., employment, schools, transportation) and places that are open to the general public. Regardless of the progress, the disability rights movement continues to advocate for equal rights, especially those related to sexual and reproductive rights. Sexual and reproductive rights have not been central to human rights initiatives and the disability rights movement, being largely ignored. In the early 1990s, Anne Finger (1992), an American disabled author and activist, wrote,

Sexuality is often the source of our deepest oppression; it is also often the source of our deepest pain. It's easier for us to talk about—and formulate strategies for changing—discrimination in employment, education, and housing than to talk about our exclusion from sexuality and reproduction (p. 3).

Shakespeare (2000) concurs that sexuality has been easier to ignore within disability rights advocacy than to engage with something from which so many people have been excluded. Just confronting topics of sex and love can be very intimidating since disabled people have a long history of experiencing abuse and living in isolation (Shakespeare, 2000; Shakespeare & Richardson, 2018). However, as initiatives for increased access to physical

and social spaces have increased, many disabled people have begun rejecting sexual oppression and advocating for sexual and reproductive rights (Liddiard, 2018; Santinelle Martino & Campbell, 2019).

## Sexual and Reproductive Rights

Sexual and reproductive rights are fundamental to the philosophical foundation of social work practice because of the profession's overall goals to improve the health status of populations, advocate effectively for social justice, and respond to global realities (Alzate, 2009). Achieving sexual and reproductive rights involves accessing health services and education, particularly sexual and reproductive health services and education (Alzate, 2009). Social workers can play fundamental roles in sexual and reproductive health services and education and are well-placed to advocate for positive and necessary changes.

Disabled people face adversity in achieving their sexual and reproductive rights and accessing health services and education due to various social and structural factors. Petchesky (2000) identifies several broadly defined factors that limit access to sexual and reproductive health services and education, such as government policy and laws, insufficient investment in health care services, inadequate health insurance coverage, and lack of enabling conditions to make individual choices among others.

Research suggests there are several barriers for disabled people accessing sexual and reproductive health services and education. First, many social service workers within healthcare institutions acknowledge their discomfort and unpreparedness in supporting disabled people with issues related to their sexual health and refrain from including this domain within their professional practice (Bolin et al., 2018; Kattari & Turner, 2017). Second, pre-existing sexual and reproductive health education tends to be designed for non-disabled people and is often inapplicable to or inaccessible to people with disabilities (Ballan, 2008; Campbell et al., 2020; Kijak, 2011; Löfgren-Mårtenson, 2011). Third, within social work research and practice, issues related to sexuality are predominantly focused on risk behavior and negative sexual experiences (Myers & Milner, 2007; Shildrick, 2007).

## Sexual Health Risk Perspective

Sexual health is typically defined by the absence of disease, dysfunction, and illness (WHO, 2006). Sexual and reproductive health research primarily focuses on risk and negative sexual experiences, such as youth pregnancy, sexual abuse, and sexually transmitted infections (Lee et al., 2020; Myers & Milner, 2007; Shildrick, 2007). A review of scientific literature from January 2006 to May 2017 found that most online sexual education resources for young people primarily focused on risk-related behaviours and prevention (e.g., STIs, pregnancy, sexual abuse) (Todaro et al., 2018).

The focus on sexuality as solely risk-based is dominant in social work literature, education, and practice (Dodd & Tolman, 2017). A traditional risk perspective of sexual health reinforces imbalanced perspectives

between positive sexuality and sexual health risk factors in the profession, emphasizing the latter (Dodd & Tolman, 2017). One explanation for a dominant sexual health risk perspective in social work may be the profession's focus on negative sexual experiences (e.g., abuse) in the field (Myers & Milner, 2007). One perilous outcome of prioritizing sexual health risk factors over other aspects of sexuality in the profession is the impulse to label some service users in particular as sexually vulnerable or 'dangerous,' which can reinforce restrictions on opportunities for sexual development (Fish, 2016; Lee, 2020) and the marginalization of certain groups (Turner & Crane, 2016).

## Sex-Positive Social Work

Sex-positive social work embraces sexuality as a human right (Dodd, 2020). It promotes positive discourse about healthy sexuality and aligns more with a strengths-based perspective (Dodd, 2020; Dodd & Tolman, 2017). A sex-positive social work perspective encourages human agency in sexual decision-making and embraces consensual sexual activity as healthy and something to be enjoyed without stigma or shame. Human agency is "an individual's capacity to determine and make meaning from their environment through purposive consciousness and reflective and creative action" (Houston, 2010, as cited in Parsell et al., 2017, p. 239). Although sexuality is prominent within social work practice, as social workers are engaged with aspects of sexuality across virtually all practice domains, many social workers have internalized sociocultural taboos about discussing sexuality, so the topic gets avoided. While social workers have embraced the notion of working from a strengths-based perspective, sexuality is still predominantly approached from the opposite direction, focused on risks and possible harms.

## Gender and Sexual Diversity

There are over 20 million lesbian, gay, bisexual, and transgender (LGBT) adults in the United States (nearly 8% of the adult population), which is much higher than previous estimates (HRC, 2021).<sup>[1]</sup> LGBT people are more likely to experience disability than the general population (Movement Advancement Project, 2019). Findings from a study conducted with data from the Washington State Behavioral Risk Factor Surveillance System suggest that the prevalence of disability is higher among LGB adults than among individuals who self-identify as heterosexual (Fredriksen-Goldsen et al., 2012). While there is a need for more research on this, some of this may be due to the mental health challenges that accrue in response to living in a world rife with homophobia and transphobia. In addition, the *2015 United States (U.S.) Transgender Survey* reported that nearly 40% of transgender people in the United States are disabled (James et al., 2016).

It is important to note that there are potential inaccuracies related to the size and prevalence of the LGBT population due to a limited understanding of gender and sexually diverse populations in research and the use of non-comprehensive measures (Bragg, 2020). For example, the conflation of constructs used to comprise and



define human sexuality (e.g., gender and sex) within research studies perpetuate an underrepresentation and erasure of groups of people who are non-identifiable within the preconceived labels.

## Experiences of Coming Out as Queer

The challenges and processes related to coming out primarily depend on a person's intersecting identities, social and family environment, and personal goals and values, among others (Author's Own, under review). For many people, coming out means losing friends and family and nurturing new community belonging (Author's Own, under review). For disabled people, coming out can be particularly difficult (Stoffelen et al., 2018). For instance, when lesbian and bisexual women with intellectual disabilities were asked about coming out, they reported dealing with the process alone, feeling insecure about themselves, having challenges standing up for themselves, and experiencing challenges being understood (Stoffelen et al., 2018). The marginalization of queer and disabled people is not new (Brownworth & Raffo, 1999). They experience discrimination, violence, and mistreatment in the systems they are engaged with, including policing, employment, housing, and intimate partner violence (Ridriguez-Roldan, 2020). In a recent study with 13 disabled LGBTQ+ youth, participants reported that their decisions to come out were complex and complicated by both ableism and heteronormativity (Toft, 2020). Participants also expressed the importance of being involved in communities of like-minded people, which positively impacted their identity management (Toft, 2020). Many queer and disabled people do not share these identities with immediate family members or in certain care relationships, emphasizing the importance of community (Samuels, 2003).

The phrase “coming out” typically refers to experiences of lesbian, gay, bisexual, queer, asexual, and other non-heterosexual identities (Author's Own, under review). Yet, this phrase is associated with other identities like disability (Author's Own, under review). Individuals with hidden disabilities also contemplate coming out (Kattari & Beltran, 2019; Spangenberg, 2018). Therefore, many LGBTQ people with invisible disabilities may perform their coming out process multiple times with the same person or partner (Kattari, 2015). Because of their experiences living with marginalized identities, it is crucial to have a partner(s) that understands and supports both identities (Kattari, 2015).

Many LGBTQ young people with disabilities feel isolated, making coming out particularly difficult. Eric Ascher, a neurodiverse gay man, shares that “I was afraid to be seen as gay because I already was being bullied ... and I knew being “the gay kid” could only worsen my situation” (Ascher, 2018). Women with intellectual disabilities often deal with the coming out process in isolation due to the lack of connections with other queer women and representation (Stoffelen et al., 2018). When disabled queer people come out, they sometimes experience invisibility and erasure from the communities they identify with, leading to increased feelings of isolation and seclusion (Kattari & Beltran, 2019).

## Theoretical Perspectives

We highlight three prevalent theoretical perspectives informed by disabled scholars and promote an intersectional anti-oppressive approach: crip theory, queer theory, and sexual citizenship. Although these theoretical perspectives have only recently appeared within social work literature and education, they are valuable for disability social work practice and promoting an anti-ableist agenda.

### Crip Theory

Crip theory is situated within critical disability studies (Goodley, 2014). Crip is the non-compliant and anti-assimilationist position that disability is a desirable part of the world (McRuer, 2006). It is a lens that directly challenges the medical model of disability. It does not consider disability as inferior or needing fixing but as an aspect of human diversity that brings value to the world (Linton et al., 2017).

Crip theory radically challenges the separation between what is defined as normal and abnormal (McRuer, 2006). McRuer (2006) reasons that abnormality is contextualized by “normal” and vice versa. McRuer does not visualize abnormality and normality as a dichotomy but suggests that “normal” is dominated within institutionalized systems and then dominates what is considered abnormal. The perception of normality creates the person’s desire to be in the dominant “normal” group (i.e., non-disabled) and avoid being classified within the non-dominant group. This phenomenon is named compulsory able-bodiedness/able-mindedness in crip theory (McRuer, 2006). More precisely, compulsory able-bodiedness is the expectation that normalcy is something everyone wants to achieve (McRuer, 2006).

Compulsory able-bodiedness assumes that everyone has the desire to be non-disabled (McRuer, 2006). Therefore, the absence of disability is not just a standard for what is considered normal, but everyone is endeavoring to achieve normalcy to reach their full value of what it means to be human. However, the normalcy standard is not achievable nor desired for or by everyone. Crip theory emphasizes a distinct disabled identity and culture made up of individuals who must challenge discriminatory texts and actions which appropriate them (Rohleder et al., 2018). In McRuer’s (2006) text, he visualizes crip as that which “questions – or takes a sledgehammer to – that which has been concretized” (p. 35). Crip is used more frequently by individuals self-identifying as disabled and their allies to deconstruct those meanings (Chandler, 2012; Clare, 1999; Sandahl, 2003). Like queer theory, the community has reclaimed these words that are typically used against both groups.

Crip is considered an inclusive term, representing all disabilities experienced by people with vastly different physical and psychological differences. However, as some authors note (Santinele Martino & Fudge Schormans, 2018), attention to intellectual disability is largely absent in crip theorizing. To help prevent fragmentation within the disability community and exclude people from fully participating in the disability community, crip theory rejects disability hierarchies that place value on different disability groups over others.

In addition to “crip” being used to describe a person in the disability community, the term crip is often used as a verb. Sandahl (2003) describes crippling as “spinning mainstream representations or practices to reveal able-bodied assumptions and exclusionary effects” (p. 37).

Crip theory interrogates constructions of normality by focusing on the differentiation between disabled and non-disabled bodies/minds (Löfgren-Mårtenson, 2013) and considering impairment as more than an “unwelcome presence” (Shildrick, 2009, p. 32). This provides a foundation for intersecting disability and sexuality. Crip theory modifies the pathological discourse from undesired bodies to make room for thinking about the crip body as desirable and fulfilling (Liddiard, 2018). Within sexuality, this shift exceeds normative expectations and boundaries for the body (Liddiard, 2018). As discussed at the beginning of this section, assimilation is not the goal of crip theory, nor is it to normalize disability in this context; crip theory pursues the possibility of disability itself as desirable (McRuer, 2006). As Liddiard (2018) states in her text, “Crip bodies are dynamic in their non-normativity: casting away medically imposed notions of deficit to reimagine bodies that may be ill, sick, and impaired as transgressive and vital” (p. 38).

In Liddiard’s (2018) study, disabled men were interviewed about their intimate and sexual lives. One participant described their disgust when touching others, feeling the warm breath and bodily warmth, which developed in his earlier experiences with illness and disability. For the participant, looking and observing were safe and how he engaged with his sexuality and desire. Liddiard applies crip theory to this participant’s story by considering how their engagement with pleasure offers a “transformative potential of crip” by the crippling of pleasure through decentering touch and affirming eroticism through visual models (p. 107). In the participant’s example, crip theory deconstructs notions of normalcy and emphasizes that an everyday existence exists and that disabled people are often excluded from it. McRuer (2006) claims that the objective of crip theory is not to eliminate constructions of normalcy because this feat is impossible; instead, the goal is to re-evaluate and reassess able-bodiedness to create transformative spaces where participation does not rest with the functional body. It can be emancipatory in this way (Sykes, 2009). As Goodley (2014) affirms, “being disabled is not a tragedy but a possibility, an affirmation, a crip space for rethinking what it means to be human, to live a quality life and a life with quality” (p. 160).

Crip theory poses that disability is a valued, diverse, and desirable part of the world. It is non-compliant and anti-assimilationist in relation to normalized ideas about being human and living in the world. Crip theory enhances the widely accepted social model of disability by expanding discussions around accessibility issues to include ideas about disability identity and embodiment. Additionally, it provokes new ways of thinking about sexuality by applying the concept of compulsory able-bodiedness to deconstruct, re-evaluate, and reassess preconceived notions of sexual and reproductive health.

## Application to Disability Social Work Practice

Crip theory is minimally acknowledged in social work practice, research, and literature. This lack of representation is unsurprising given the lack of disability content and disability studies crossover with social

work education, and the structural and organizational barriers that prevent professional representation in the field. Thompson (2019) offers a critical commentary on how she, a self-identified Black disabled woman, has worked to fill a representation gap within social work. Thompson explains how she created her online platform to offer her perspective on integrating crip theory and social work. She suggests technology as one approach to connecting social work with the disability community because it increases accessibility for people who are typically excluded from the discussion.

Implementing crip theory in social work practice aids the practitioner in broadening their preconceived notions and conceptualizations of sex and sexuality. To “crip” social work practice and our understandings of sexuality is to expose discourses of compulsory able-bodiedness, even in contexts not explicitly focused on disability (McRuer, 2006). Social workers can reflect on how the meanings of sexuality and sex are defined within their practice contexts and subsequently expose meanings that are produced within conventions that privilege able bodies and normalcy. For example, meanings of sex are often inexplicably linked to the physical body; however, some disabled people consider physical aspects of sexual well-being inferior to emotional, social, and psychological ones (Lee, 2020). It is vital within social work practice to refrain from assuming what sexuality and sex mean for disabled clients as these vary widely.

## Queer Theory

Queer is a political identity and positionality adopted by individuals who experience marginalization due to their sexuality (Sullivan, 2003). The term queer has evolved, being repositioned as a term of pride and socio-political identity (Sandahl, 2003, as cited in Chappell, 2015). Queer challenges “normal” behavior ideals and resists the status quo (Warner, 1993). It is undefinable (Greteman, 2017) and embraces uncertainty and ambiguity in its foundation (Halperin, 1995; Sullivan, 2003). Moreover, queerness does not adopt a fundamental logic or a consistent set of characteristics (Jagose, 1996, p. 96). Still, it is adopted by individuals and groups who experience marginalization based on their sexual practices (Halperin, 1995).

Queer theory evolved throughout the 1980s and early 1990s, inspired by a combination of queer politics, philosophical theorizing of gender, sex, and bodies (Butler, 1990; Halperin, 1990; Sedgwick, 1990), and the rise of homophobia and the AIDS epidemic (as cited in Greteman, 2017). Queer theory is a “vague and undefinable set of practices and (political) positions” that is capable of challenging normative behavior, ways of knowing, and identities (Greteman, 2017, p. 43-44). Individuals often ask for a concrete definition of Queer, whether it means sexual orientation, gender, or something else. In response, we believe this quote sums it up nicely; “queer is by definition whatever is at odds with the normal, the legitimate, the dominant. There is nothing particular to which it necessarily refers” (Halperin, 1997, p. 62).

Queer theory challenges heteronormativity and the othering of homosexual identities (Steyn & Van Zyl, 2009). Heteronormativity is an ideology that promotes gender conventionality, heterosexuality, and family traditionalism as the preferred and standard way for individuals to experience their lives (Ingraham, 1996; Oswald et al., 2005). Heteronormativity presently and historically privileges cisgender men and women,

heterosexuality, and nuclear families (i.e., two parents and children), which marginalizes and oppresses individuals who do not identify as members of these groups (Allen & Mensez, 2018). Both queer theory and critical disability studies overlap and challenge hegemonic constructs of normalcy and universal norms (Chappell, 2015; Sherry, 2004).

## Application to Disability Social Work Practice

Social work has lingered in its contribution to gender and sexuality studies (Mulé, 2016). This lag risks the profession adopting and perpetuating antiquated discourses, theories, and perspectives, with potential implications for practice and further marginalization of communities (Mulé, 2016). The social work profession has often paralleled society's moralizing, pathologizing, and criminalizing approaches to gender and sexually diverse communities (Mulé, 2016). For example, this is evident in the profession's continued support of the Diagnostic and Statistical Manual of Mental Disorders (DSM), which has been detrimental to gender and sexually diverse people (Daley & Mulé, 2014; Westbrook & Schilt, 2014). For instance, the diagnosis for transgender people of all ages (i.e., Gender Dysphoria (G.D.) considers "inverted" gendered expressions as pathological, stigmatizing transgender people (Davy, 2015). Like social work, many professional programs neglect to educate students about queer theory and gender and sexually diverse populations (Bragg, 2020).

## Sexual Citizenship Theory

According to Weeks (1998), sexuality is contingent, culturally specific, and often a relationship of related but separate elements of bodily potentials, desires, practices, concepts and beliefs, identities, and institutional forms. Sexual norms have hegemonic patterns, defined by excluding certain people and shaped by culturally and materially defined differences between class, age, ethnicity, nationality, and geography (Weeks, 1998).

The sexual citizen is a concept first defined by Weeks (1998) in his work on sexuality and queer theory. Sexual citizenship was an attempt to expand upon earlier notions of citizenship to make it more comprehensive and inclusive of sexuality. Discussion of citizenship is traditionally focused on civil, legal, political, and social concepts. Yet, in the context of sexual citizenship, citizenship is more broadly defined as empowerment, inclusion, belonging, equity, and justice (Weeks, 1998).

The term sexual citizen seems contradictory. Being sexual often signifies a private part of people's lives and focuses on intimacy, including pleasure, pain, love, violence, power, and resistance (Weeks, 1998). Yet, citizenship is ordinarily a concept focused on an individual's involvement in broader society. Operating in a wider society acknowledges and recognizes rights, entitlements, and responsibilities to fellow citizens and the community (Weeks, 1998). Hence, Weeks intertwines private and public in his understanding of sexual citizenship, making the private elements public and political (Weeks, 1998).

Sexual citizenship has gained prominence in disability and social work studies (Lee et al., 2018; Liddiard, 2018; Siebers, 2008; Wilkerson, 2002). Disability studies, in particular, recognize that silencing and denying

disabled people sexual and reproductive rights have been greatly ignored within frameworks of legal rights and social integration (Shildrick, 2013). Disabled people remain largely excluded worldwide from enjoying equal control, access, and choice regarding their sexuality and sexual and reproductive rights (Rohleder et al., 2018). Nonetheless, a growing movement of disabled and non-disabled activists and theorists advocate for their sexual citizenship (Shildrick, 2013).

Shakespeare (2000) defines three dimensions that are necessary for achieving sexual citizenship for disabled people:

First, is a demand for control: we demand control over our bodies, over our feelings, and over our relationships.

Second, is a demand for access: we demand access to representations, relationships, and public spaces. Third, is a demand for choice: we demand choices about identities, our lifestyles, our gender experiences (p. 165).

These three dimensions include more than sexual health and intimacy; they include important aspects of a person's sexual well-being. Control, access, and choice (autonomy) are described within the context of sexuality but are broadened and inclusive of whole parts of the self. For example, having control is not only about being physical with another person but also incorporates feelings and relationships. Shakespeare (2000) states that the vision of sexuality for disabled people should not be focused entirely on sexual desire and physical intimacy but rather on identity, solidarity, rights, and respect. Sexual citizenship theory challenges the dominant discourse that sexual and reproductive health are applicable and important to only specific groups of people. Promoting sexual citizenship across the lifespan is one approach to alleviating some of the problematic conditions disabled people face to achieve positive sexual development and well-being in their lives (Bolin et al., 2018).

## Application to Disability Social Work Practice

Sexual citizenship is applied in social work scholarship and literature to conceptualize practice approaches for disabled people (Bolin et al., 2018; Drummond & Brotman, 2014; Lee & Fenge, 2016). For instance, Lee and Fenge (2016) define sexual citizenship as a social work rights-based approach because sexual citizenship shifts the perception of sexual well-being to a positive one that prioritizes empowerment and the entitlement to full participation for disabled people. One of the practical approaches stressed in their article is for social workers to promote the right of disabled people to have access to information, services, and sex pertaining to their sexual and reproductive rights.

## Consent and Consent Laws

Historically, consent has been defined as “no means no,” with much of the discussion centering on (presumably heterosexual and cisgender) girls and women using the term “no” to gatekeep their bodies from



(presumably heterosexual and cisgender) boys and men (Gilbert, 2018). It was not until the 1990s that activists and scholars began a deeper conversation about the idea of affirmative consent, or “yes means yes” (Mitchell et al., 1996). This shift happened across the U.S. and Canada, with courts in the latter moving away from questions of “Did she say no?” and asking “Did she say yes?” However, this model still made major assumptions about the gender and sexuality of both the perpetrator and survivor (Plaxton, 2015).

General laws on the age of consent for sexual activity range from 16 in Canada (though with flexibility for those ages 12-15 who are close in age to one another) to 16 to 18 in most states and provinces in the U.S., Australia, the United Kingdom, and New Zealand (Gilbert, 2018). However, for disabled people, even being of a certain age may not be enough for them to be deemed as able to consent, particularly those with intellectual or developmental disabilities. Scholars have long named the tension between ensuring disabled people can engage in their sexuality and sexual experiences and protecting them from harm caused by others (Stavis, 1991). This tension is often seen in the creation of consent-related laws, which target disabled people as naturally asexual, infantilized, and incapable of consenting to sexual activity in any capacity (Medina-Rico et al., 2018). These laws often align with health providers, who may also not understand that sexuality and disability are mutually exclusive (Gougeon, 2009; Saxe & Flanagan, 2014; Suris et al., 1996).

## How Consent is Taught (or not) to Disabled People

From a young age, most parents are navigating how to talk to their kids about owning their bodies, good touch versus bad touch, and introducing the topic of consent. In fact, the internet has hosted many lively discussions about whether children should be forced to hug relatives or if young children should be allowed to tell a parent(s) that they cannot touch their body. This emerging conversation continues to evolve because, as Alderson (1999) points out, “Until recently, obedience rather than autonomy has been expected of children” (pg. 38).

As difficult as these conversations around consent may be with children in general, it can be infinitely more complicated with young disabled children, particularly those with impairments or medical conditions that require ongoing medical intervention. For example, if a five-year-old tells their parent that they don’t want their doctor to touch them, how is the parent who may have had to schedule this appointment months ago, take off work, and figure out transit for their child to respond? Children are often told to let medical professionals touch their bodies and poke and prod them. Depending on the individual’s condition, they may sometimes be asked to do things in various stages of undressing away from their parents (Rooted in Rights, 2021). This experience of “having” to allow certain people to touch their bodies can create tension around consent in the future, especially regarding who is allowed to touch their bodies and whether or not they have the right to reject such touch.

For those disabled people who are institutionalized, they may be denied the ability to consent to certain activities based on the rules of the facilities in which they are housed and/or the bias of those working in these spaces (Young et al., 2012). There also are often contested issues around who can consent, not only when



it comes to age but also mental capacity, with different jurisdictions, communities, and institutions defining mental capacity to consent in a multitude of different ways (Alderson, 1999), many of which are outdated and ableist (Harris, 2018). Ergo, it is a challenge to understand different consent laws in different areas, talk about consent in various contexts, and think about and disrupt how consent may have been violated by trusted adults in any given disabled individual's life.

## Sexuality Education in Schools

Sexuality education in the U.S. and Canada has historically been fraught and at the center of culture wars dialogue, as with many issues regarding sexuality and sexual identities. In the U.S., much of the sexuality education dialogue has centered around what should be taught to youth in schools, whether abstinence should be centered, and if the offering of medically accurate sexuality education is connected to an increase in the age of first sexual experience, the number of partners, transmission of sexually transmitted infections, unintended pregnancies, etc. According to SIECUS (2021), a US-based non-profit that focuses on “Sex Ed for Social Change,” 33 states (and Washington D.C.) mandate sexuality education. However, 34 states mandate an emphasis on abstinence whenever sexuality education or HIV education is provided, and only 16 states require information on condoms or contraception to be included. In Canada, while many urban areas may be seen as more progressive than in the U.S., a report by Action Canada for Sexual Health & Rights (ACSHR) (2019) found that most of the sexuality education information given to young people was outdated, not meeting international standards, not comprehensive, and taught by people who had a low level of comfort. This chapter will similarly address these two countries, despite having somewhat different politics and policies.

## Sexuality Education and In/Exclusion of Queer Identities

For decades, the lack of queer-inclusive content in sexuality education programs has been an issue (McCarty-Caplan, 2013). The moving of sexuality education into the responsibility of the middle school and high school education in the 1980s included the goal of promoting heterosexuality and marriage while at the same time reducing pregnancies outside of wedlock (Moran, 2000). Although some areas attempt to ensure their modern sexuality education includes individuals of all sexual orientations, that sadly is not the case across the board.

In the U.S., only ten states have policies requiring affirming instruction regarding LGBTQ youth or discussing sexual health for LGBTQ youth (SIECUS, 2021). Conversely, eight states specifically call for discriminatory information about LGBTQ identities to be shared with students in sexuality education instruction (SIECUS, 2021). In Canada, many schools “outsource” their sexuality education courses to local organizations, many of whom are anti-choice groups offering “free sexual health courses” that not only center on abstinence as the only option but also include homophobic materials in their instruction (ACSHR, 2019). Ergo, while individuals living in more progressive or resourced areas (i.e., San Francisco, New York, Toronto)

may have access to more LGBTQ-inclusive and affirming sexuality education, those living in more rural communities or areas with fewer resources are likely to not experience LGBTQ identities in sexuality education at best or be exposed to discriminatory (and inaccurate) information at worst.

## Sexuality Education and Disabled Young People

Unfortunately, disabled youth are often not given access to the same sexuality education as their peers, despite being significantly more likely to be sexually active than their non-disabled counterparts (Horner-Johnson et al., 2021). Historically, less than 5% of disabled people could access sexuality education or counseling services that gave them the information and support they needed around sexuality (Szasz, 1991). While these numbers have improved over the past few decades, a more recent study found that access to sexuality education varied by type of disability or impairment, with only 25.0% of those who are disabled individuals with intellectual or developmental disabilities (IDD) being able to access such education, compared to 47.5% of their disabled peers without IDD (Barnard-Brak et al., 2014). For those disabled young people who are in pull-out learning spaces<sup>[2]</sup>, many will never have access to sexuality education. In contrast, others in more mainstream settings may be told not to come to class on the day(s) when sexuality education will be offered or may not offer appropriate accommodations to engage with the material. Even when they can engage in sexuality education, disabled youth (and adults) are less likely to have access to information about sexual pleasure and may find their education is even more focused on pregnancy and STI prevention than the general population (Tepper, 2000; Turner & Crane, 2016).

It is important to note that the vast majority of the extant research looks at the sexuality education experiences of disabled young people and queer young people separately without pausing to explore the experiences of those who are both queer AND disabled. Tarasoff (2021) calls for a need for sexuality education that is inclusive and affirming of both marginalized groups while commending Horner-Johnson and colleagues (2021), whose recent study was one of the first to look at disability and among queer, trans, and nonbinary identities.

Moreover, despite a lack of sexuality education information given to disabled LGBTQ individuals, this indicates that they are no less sexually active than their heterosexual and non-disabled peers. Often, they may be more creative in defining sex and sexual activities. One study found that sexual and gender minorities are likely to use the skills they have gained in navigating ‘coming out’ with their identities to navigate ‘coming out’ as disabled and asking for their needs to be met by sexual partners (Kattari, 2015). Another study of disabled adults noted that disabled adults of all sexual orientations defined “sex” in a wide variety of ways, including activities from watching porn together to sexting, spanking to massage (Kattari & Turner, 2017), indicating the need for more robust types of sex education that go beyond the heterosexist and ableist norm of sexuality education being focused solely on pregnancy and STI prevention about penis in vagina intercourse.

## Curricula and Those Providing It

Frequently, sexuality education courses are taught by health teachers, biology teachers, gym teachers, and others who are un- or under-prepared to educate on this content (ACSHR, 2019). Human service professionals working in school settings are also often lacking in knowledge about both issues related to sexuality and those related to disability. In both the U.S. and Canada, few social work programs have courses specifically on sexuality, with less on sexual orientation and even fewer having courses dedicated to disability (Ballan, 2008; Ogden et al., 2017). In psychology, a similarly low number of programs offer content on sexuality (Mollen et al., 2020) and disabilities, especially outside of psychiatric disabilities (Rosa et al., 2016). Content often focuses on abstinence, puberty, anatomy, STI information (mainly on prevention), condoms/birth control/contraception, relationship information (including marriage promotion in some states and provenance and healthy relationships in others), and sometimes consent (SIECUS, 2021). It is rare for most of this information to be inclusive across LGBTQ identities, except in the states that require it, despite affirming and inclusive information being tied to better mental health and sexual health outcomes for LGBTQ youth (GLSEN, 2015). Good news is on the horizon, however, with research delving into the type of sexuality education that is desired by/useful for disabled people (East & Orchard, 2014; Grieve et al., 2007; Schaafsma et al., 2015; Schaafsma et al., 2017), as well as LGBTQ individuals (Gowen & Winges-Yanez, 2014; Meadows, 2018), and even some on the ideal sexuality education for those who are both queer and disabled (Toft & Franklin, 2020).

## Best Practices Both Personally and Professionally

Hopefully, as you read this chapter, you have recognized the importance of thinking about how you can adjust both your practice and personal life to be more inclusive and affirming of disabled individuals, especially those who are also LGBTQ or those exploring their sexuality. Below is some low-hanging fruit you can start with to make these important shifts. We also encourage you to connect with other social workers, with disabled friends, family, colleagues, and community members, and queer folks as well, so that you make these changes not only in response to this chapter but also in a way that is in an ongoing, culturally responsive way that notes the consistently shifting needs of both disabled and queer individuals.

- Create accessible spaces from intake forms to parking lots to physical spaces to events (and ensure these are all communicated on your website and event pages). This may include having sensory-friendly spaces, low-scent spaces, encouraging partners or caregivers to accompany attendees or clients, etc., and having wheelchair-accessible buildings, chairs that are friendly for all bodies, etc.
- Pay queer and disabled folks to consult with you about your practice, strategic plans, etc. We often wait until a problem has arisen before we try to reverse engineer making something more inclusive. Instead,

consult with community individuals from the get-go, and acknowledge their expertise and labor by paying them for their support.

- Remember that sexual orientation and disability status are not mutually exclusive, nor are all disabled people either hypersexual or asexual. Instead, ask open-ended questions, express curiosity rather than surprise (“You’ve said your queerness is directly related to your cripness – I’m curious to hear more!”), and be ready to do extra research on the back end so as not to make your clients (or friends, family, colleagues, or community members) do the work of educating you on these issues.
- Consume media created by queer disabled people. Some examples include *Sins Invalid*, *Crutches & Spice*, Leah Lakshmi Piepzna-Samarasinha, the *Queer Sex Ed* podcast, *Disability After Dark* podcast, and many more! Share these posts, books, clips, videos, podcasts, and more with your colleagues and community.
- Work on dismantling ableism in yourself, even if it is internalized ableism. You do not have to do this on your own – find a community to support you in this!
- Get connected to Queer affirming, anti-ableist practitioners in your community so you can refer to other social workers, health care providers, organizations, and more that will also support your queer disabled clients.

## Conclusion

Throughout this chapter, we have explored many of the experiences, challenges, and unique resilience opportunities that happen for disabled and chronically ill individuals, both for those who are also LGBTQ and those wanting to experience and explore their sexualities for the first time. Undergirded in queer and crip theories and enacted on our bodies and minds by local, state, federal, and even organizational policies, this information is critical for social workers to understand, acknowledge, and disrupt ongoing systems of ableism and queerphobia. Social workers and other human service professionals should be prepared to connect clients and their partners, families, and other health team members to Queer and disability-affirming resources, consider offering disability-inclusive sex education and sex therapy, and re-create spaces (physical, virtual, and conceptual) that are inclusive of disabled individuals across all sexualities, and work on dismantling ableism and homophobia in all aspects of both their personal and professional lives.

## Case Study

Dacia, a 32-year-old Black cisgender queer femme, comes for an intake to your private practice. On your intake form, she notes her pronouns are she/her. She is disabled and neurodivergent, is in a new relationship, and presents concerns, including navigating sexual activity with her new partner. She is a high school history teacher, lives in a rented condo with her dog and two cats, and enjoys cooking, cross-stitching, and reality T.V.

shows. She notes that she has been in therapy previously to get her diagnosis but never really felt comfortable with her previous therapy encounters. She certainly didn't discuss sexual orientation or sexuality issues with previous therapists.

## Pre-Engagement Questions:

- What do you need to consider before Dacia arrives at her first appointment?
- How might your identities come into play? How can you navigate them?
- What potential research or outreach do you need to engage in before your first session?
- How else might you best prepare for meeting Dacia for the first time?
- What other access should you consider?

## Engagement

Dacia comes into your office for her first appointment. While sitting in the waiting room, she looks around at the images on your wall and the books on the shelves. You notice that she spends extra time looking at the queer people of color artwork you have from the Repeal Hyde Amendment Art Project and the Next World Tarot collection. You come out to meet her, and she points to them, remarking that she has never had a therapist with art that looked like her. As she wheels her rollator into your office, she notes appreciation for having information about parking, elevators, and the scent-free space in your confirmation email. She chooses the most comfortable furniture for her body and looks around a bit, clearly looking for something. When she does not see it, she reaches for her purse and asks if it is okay to use stimming items. You let her know that is fine and start your conversation. Throughout it, you spend a lot of time asking questions, including about the language she uses (identity first), how she identifies her disabilities (she has EDS and chronic pain, anxiety, and depression, and is autistic), her other identities (queer dyke, Black femme, a daughter and sister, an educator, cisgender, and middle class), and her concerns.

While Dacia seems relatively comfortable with her disabled and neurodivergent identity, she shares that her family has not always accepted her queer identity or being autistic. However, they are more supportive of her EDS and chronic pain. Dacia shares a bit about the challenges of holding multiple oppressed identities and often choosing just one at any given moment. It also seems that her relationship with her new partner, Andi, a white Jewish masculine-of-center nonbinary queer person, is going well. Still, she is unsure how to start a conversation about sex. As you talk, Dacia shares that she has sensory issues with sounds, smells, and textures that worry her about sex with Andi. In addition, she has concerns about navigating EDS dislocation and chronic pain. Dacia has had sex before but spent most of those instances in what sounds like a dissociative state and uses phrases like “just to get through it” or “once it was over.” She has not had a queer partner before, and Andi is the first person who has been willing to take their time with her to make sure her needs are met,

but she does not know how to start. As you move into your second session, you share your thoughts and even some resources that you have found with her and engage your positionality and how your own identities may impact your intersections.

- What questions might you ask Dacia about how she wants to show up, her communication style, etc.?
- How would you ground your work with Dacia using an intersectional, anti-oppressive, and culturally responsive approach?
- What would you consider sharing with Dacia about yourself, your identities, and your therapy style?
- What resources might you use, either for yourself or share with Dacia?

## Assessment

As you move forward in working with Dacia and helping her feel more comfortable and confident in figuring out what some of her sexuality needs and supports are and how she might communicate them with Andi, consider some of the following questions:

- In addition to the specific issue Dacia shared about communication with Andi, what other issues such as race, gender, disability, and previous experiences may intersect with the issue?
- What approach(es) do you think is/are best to use moving forward with Dacia? Why?
- What circles of support could you encourage Dacia to connect with or reach out to? What might be some barriers here?
- How will you ensure Dacia's narrative and point of view are centered?

## Intervention

Once you have both agreed on the “intervention” approach, consider reflecting on the following questions:

- How will you be assessing whether this process is working for Dacia? How can the two of you communicate that? If it is not working, how can it be tweaked?
- Are there structural or organizational change issues that need to be addressed? If so, what are they, and how will you, Dacia, or both of you engage them?
- How will you embody and operationalize “nothing about us without us” as an undergirding of this work?
- What tools might you bring to your sessions, and how will they support the process? Examples include (but are not limited to!) worksheets, role plays, educational adult movies, journaling, etc.

## Termination

As you move toward the end of your time together with Dacia, please consider the following:

- Who will initiate termination? What if the other party disagrees?
- How will you ensure Dacia has the ongoing support to continue being empowered around her sexuality and sexual experiences?
- Do you have a plan to follow up? If so, what does it look like? Will Dacia be able to reach out to you again if she needs to? What if she and Andi desire a relationship therapist – do you have BIPOC and queer-affirming accessible recommendations?

## Evaluation

Finally, you have been doing self-reflection and evaluation throughout this process with Dacia. When you think about evaluation:

- Was it explicit, implicit, or both?
- How did you ensure Dacia was a part of the ongoing evaluative process and that her thoughts were included?
- What measures did you use to evaluate the process? How did you know that your time together was “successful?”
- What did you do to ensure that your measures and definitions of success were anti-oppressive and intersectional?
- How would you improve the evaluative process with future clients?

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[1] This statistic only includes adults who self-identified as lesbian, gay, bisexual, and transgender.

[2] A pull-out learning space refers to situations in which some students learn in settings apart from their peers (Nes et al., 2018).



9.

# MENTAL HEALTH AND ADDICTIONS IN DISABILITY COMMUNITIES

Rose Singh; Andrea Murray-Lichtman; and Elspeth Slayter

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## Learning Objectives:

- To explore unique areas of concern for members of the disability community with mental health conditions and substance use challenges
- To articulate the experiences of the disability community receiving mental health and substance use disorder interventions
- To explore anti-oppressive practice approaches designed to support members of the disability community with mental health conditions or substance use disorders

## Introduction

This chapter provides an overview of disability, mental health, and addictions from a social work perspective. Language, terminology, and models of disability, mental health, and addictions are introduced. The history and context of mental health and addictions in the disability communities within the United States are explored. Prevalence and risk factors for mental health and substance use in the disability community within the United States are presented, followed by treatment options and barriers to treatment. The dearth of evidence-based practice models for behavioral health assessment and treatment for specific disability communities, including Deaf/hard of hearing people and intellectually or developmentally disabled people, are addressed. Key laws, policies, and programs in the United States which are relevant to disabled people and behavioral health are reviewed. Practice implications for social work, as well as voices and perspectives of

disabled people with mental health conditions and addictions, are presented, followed by critical theoretical perspectives and application of a model for social work practice with disabled people with lived experience of mental health and substance use. Lastly, a case study with questions for discussion is included.

## Introduction

Mental health and substance use disorders exist across the population in the United States (U.S.). Regarding substance use disorders, those who have been or are addicted to substances, but are no longer using or are in active recovery from substance use disorders are protected under the Americans with Disabilities Act (ADA) of 1990 (Civil Rights Commission Amendments Act of 1994; [Pub. L. 103–419, §1](#)). However, not all people who live with these conditions may be perceived as disabled, consider themselves as disabled, or view themselves as members of the disability community. Additionally, people using substances who overdose may acquire a disability (Ore et al., 2019) and live with co-occurring mental health disorders. Further, disabled people may also live with mental health conditions and addictions, and these conditions are prevalent across the disability community. For disabled people diagnosed with mental health and substance use disorders, disability may or may not be their primary concern, and their mental health or substance use may or may not be impacting them most. However, disabled people with mental health conditions and who use substances may find that social work or health professionals make determinations for them without full consideration of their experiences. Further, disabled people with mental health conditions and addictions often encounter obstacles in accessing services and support (Cree et al., 2020), as disability, mental health, and addictions resources have existed separately and have not captured the realities and lived experiences of disabled people who have mental health concerns and substance use issues. Moreover, the stigma, prejudice, discrimination, and oppression that exists and is experienced by disabled people with mental health concerns and addictions create devastating impacts on their quality-of-life trajectories. In the next section, we introduce language, terminology, and models of disability, mental health, and addictions, to help build an understanding of each before moving into discussions that encompass experiences of disability, mental health, and addictions together.

## Language and Terminology

Critically thinking and reflecting on the language and terminology that we, as social workers, use is central to working with the disability community and from an intersectional, critical cultural competency, and anti-oppressive perspective, as outlined by Johnson et al., 2022 in chapter two of this text, in which a practice model for empowerment-oriented disability practice is presented. Further, we acknowledge that the people and communities we are part of and/or work with may use various terms, and that language and terminology shift

over time. Thus, it is crucial to listen and be responsive to the language and terms suggested and used by the people and communities you are working with (Johnson et al., 2022).

## Disability

A more extensive definition and discussion of disability, impairment, disability identity, culture, and community are offered by Slayter and Johnson (2022) in chapter one of this text, in which key concepts about disability social work are presented. Here, we briefly highlight impairment and disability as well as disability identity and community before providing an overview of mental health and addictions. Drawing on the social model of disability, impairment is a “condition or attribute,” whereas disability is “how society has responded to or failed to respond to, the needs of people with impairments” (Cameron, 2014, p. 137). This perspective acknowledges the impacts of living with an impairment while emphasizing the attitudinal, structural, and systemic barriers related to disability.

## Disability, Identity, and Community

How someone describes their identity and lived experiences is personal, political, and contextual. In this chapter, speaking of a disability, we primarily use identity-first language—for instance, disabled people. Identity first language puts disability at the forefront, centering the lived experience of disability and disability identity, culture, and pride (Slayter & Johnson, 2022). In comparison, person-first language, often used in social work practice, emphasizes the person before noting disability—for example, person with disabilities (Slayter & Johnson, 2022). A critique of person-first language is that individualizes disability, rather than recognizing how people are disabled by attitudinal, structural, and systemic barriers. Disability community broadly refers to people who self-identify as disabled, have shared and unique experiences of disability, but also have various personal and social identities, and positionalities (Johnson et al., 2022; Slayter & Johnson, 2022).

## Mental Health

Mental health is described across a spectrum, from wellness to severe and persistent impacts to functioning (Jones et al., 2021; World Health Organization, 2019). People may experience mental wellness to significant mental distress and impairment (Cree et al., 2020). Similar to those represented in disability studies, models pertaining to mental health offer medical and social perspectives. The medical model positions mental health conditions as individualized illnesses, diseases, or disorders of the brain (Beresford, 2012; Burstow, 2015; Cohen, 2008; Joseph, 2013), classified and diagnosed by health professionals according to the Diagnostic and Statistical Manual of Mental Disorders (or DSM) (Doherty, 2005; Fawcett, 2012). Mental health diagnoses in the DSM include (but are not limited to) anxiety disorders (e.g., generalized anxiety disorder, panic disorder),

depressive disorders (e.g., major depressive disorder), and schizophrenia spectrum and other psychotic disorders (e.g., schizophrenia, schizoaffective disorder) (American Psychiatric Association, 2022; Nussbaum, 2013). Comparatively, what Beresford (2012) refers to as the “social model of madness and distress” (p. 65) centers on the lived experience and voices of people with mental health concerns. This social model also locates societal constructs, discourses, and contexts as the issue and not the individual living with mental health conditions (Beresford, 2012).

## Mental Health, Identity, and Community

Persons with mental health conditions use various language and terms to self-identify or to share what they are living with. Some people may use the diagnostic labels ascribed to them by health professionals, while other people may use identity-first language and reclaimed terms – or all, depending on their preferences, experiences, and contexts. Examples of language and terms include psychiatric disabilities, psychiatric survivors, ex-patients, mental health service users, consumers, or mad (Boxall & Beresford, 2013; Jones et al., 2021; Price, 2013; Reid & Poole, 2013). In this chapter, we use the term person or people with a mental health condition. However, when describing the literature or research cited, we follow the language utilized since specific diagnoses may be part of the criteria for participants in the studies referenced. The community of people with lived experience of mental health concerns is diverse, and they may or may not align with having a disabling condition.

## Addiction

Considering addiction as occurring across a continuum provides a broader understanding of the experiences of people using substances (Csiernik, 2016). For instance, people may use substances but not be addicted. Comparatively, someone may use a substance or substances and be both physically and psychologically dependent on the drug(s) they use (Csiernik & Rowe, 2017). Some people may use substances and wish to seek support, others may not want to seek treatment, or be mandated to attend treatment (Smith, 2022). As with disability and mental health, there are models of addiction that give different perspectives on substance use. For instance, the medical model views addiction as a brain disease (Pickard et al., 2015). Within the Diagnostic and Statistical Manual of Mental Disorders manual, the DSM-5, specific diagnostic criteria are devoted to substance use disorders and the subsequent symptoms, behaviors, and problems that someone experiences when using such substances (Nussbaum, 2013). In contrast, the moral model of addiction situates substance use as the personal responsibility and failure of the person using drugs (Pickard et al., 2015), which has drastic and considerable negative implications for addictions policies, programs, treatment, and support for people who use substances (Csiernik, 2016). While there are models of addiction from a recovery and a biopsychosocial lens (Begun, 2017; Csiernik, 2016; Csiernik & Rowe, 2017), a comparable social model to that which exists for disability and mental health is absent for addiction. We propose a social model of substance

use and addiction that considers how people who use substances navigate their experiences of using drugs in addition to living with the stigma, discrimination, limited support, and resources from the society around them.

## Substance Use, Identity, and Community

The language and terminology used when referring to addictions have long been stigmatizing, with “addict” being such an example (Csiernik & Rowe, 2017, p. 22). People who use substances have various ways they describe their experiences of addiction and communities. Options may include person with an addiction (Csiernik & Rowe, 2017), people who use drugs (Mitra et al., 2021; Salazar et al., 2021; Smith, 2016), or people with lived or living experience of drug use (People with Lived Expertise of Drug Use National Working Group et al., 2021). In this chapter, we also use the term person with a substance use condition or person with substance use disorder, especially where the literature and research cited refer to people who have diagnosed addictions.

## Concurrent or Co-Occurring Conditions, Dual Diagnosis

Not only is there language and terminology that reflects a singular experience of disability, mental health, or addictions, there is medicalized terminology utilized to describe when a person is diagnosed with a mental health condition and addiction. For instance, the term concurrent disorder is often used when a person has both mental health and substance use diagnoses (Kimberley & Ormond, 2017). These may also be labeled as co-occurring disorders in disability contexts (NIMH, 2021). Concurrent or co-occurring disorders may also be referred to as dual diagnoses as well (NAMI, 2020). However, dual diagnosis in disability settings more commonly denotes a developmental disability as well as a mental health diagnosis (Lunsky & Weiss, 2012). Behavioral health is a commonly used term in the United States, which, in this context, often indicates treatment and services addressing mental health and substance use (SAMHSA, 2021). Moving away from this medicalized terminology, which may focus on labels and individualized issues or perceived deficits, we strive to use language that centers the person and their lived experience, while also acknowledging the limitations of the literature and influences of the medical model in our field. As such, we shift between terms that honor identity and lived experience to terms that are more medicalized when citing behavioral health literature and research.

## History of Mental Health and Substance Use Disorders in Disability Communities

There is a long history of stigma surrounding the presence of mental health and substance use disorders in

general in western society. Throughout history, this phenomenon has confounded treatment and approaches to working with people living with mental health and substance use disorders. The paradox of responding to mental health and substance use disorders for western society has often rested on the intertwining of social forces like religion, politics, economics, and the philosophical values that undergird the determination of who and what condition of human suffering is deemed worthy of support (Daugherty et al., 2020; Grob, 1973; Shorter, 2008). Therefore, despite the advancement of medicine and scientific approaches, many assessing the advances of mental health and substance use disorder treatment who claim improvements in the field still vacillate between outright harm such as criminalization to underfunded benevolence that applies a band-aid solution (Daugherty et al., 2020; Scull, 2015). Indeed, depending on where a body lands on the spectrum of worthiness shaped and continues to inform the approach to treatment or the mistreatment of those bodies in need of mental health and substance use disorder treatment (Medlock et al., 2019; Metzl, 2009). Consequently, the stigma associated with mental health and substance use disorders intersects with the judgments made of those living with disabilities, confounding the identification and treatment of mental health and substance use disorders in the disability communities. The oppression and racism that exist against people of color and other marginalized identities in society often magnify the mistreatment in this regard. This is specifically troubling for the health and well-being of those living within the disability communities. This section provides a timeline of the history of mental health and substance use disorders and the intersections with the disability community within the United States.

A review of the history of mental health and substance use disorders in the United States demonstrates the evolution of society's view of mental health disorders and substance use disorders. Given the influence/predominance of religion in the social and political philosophy underlying societal norms in the history of civilization, Scull (2015) found that various religious influences equated madness with ties to punishments from supernatural beings. Historically, this often meant that people were removed or set away from their families and society to face this punishment from their deity (Scull, 2015). The linking of mental illness to supernatural evil by religious influences eventually began to wane in modern history.

During the 1700s, madness was seen as an organic or physical occurrence with no connection to the soul or moral accountability (Augstein, 1996). While people were no longer set aside from the community to be dealt with by their deity, people who were diagnosed with mental illness were institutionalized in asylums and often treated inhumanely (Chapman et al., 2014). People living with disabilities and who were poor during the colonial period were often confined and criminalized, while people with more financial means were taken care of within their families (Chapman et al., 2014). Enslaved Africans often saw much harsher treatment and were not included in the "rehabilitative" aspects of the changes that began to occur on behalf of those living with mental illness. By the end of the century, a movement focusing on the moral treatment of people living with mental illness began to develop (Chapman et al., 2014). Despite this movement, throughout the 1800s, there was an increase in the number of asylums around the country and specialized institutional settings for people living with certain disabilities, e.g., blindness and deafness. Some leaders in the moral movement desired

more humane treatment for people living with mental illness and yet saw institutionalized ‘rehabilitation and training’ as options for people with some disabilities (Augstein, 1996; Chapman et al., 2014).

In 1844, the Association of Medical Superintendents of American Institutions (AMSAI) for the Insane accepted psychiatry as a medical specialty (Suris et al., 2016). This closed the chapter on the overt influence of religion on the treatment of mental illness and disability, shepherding the United States into the 1900s and a more medicalized approach to mental health and substance use disorders and disability. However, as the next sections demonstrate, societal views and influence are an enduring theme in the treatment of mental health and substance use disorders and disability. The social influence continued to impact care positively and negatively for those living with disabilities and mental health and substance use disorders (Scull, 2015; Shorter, 2008).

The era of the 1900s saw many changes in the medical treatment of people living with mental health and substance use disorders and disability. As the century turned, there was a transition from the pejorative categorization of people living with mental illness in the asylum as ‘asylum inmates’ to ‘patients’. The ‘mental hygiene’ movement emerged because of the atrocities that were happening to people institutionalized within asylums. The mental hygiene movement sought to promote and preserve mental health and focused on prevention and efforts to re-socialize the patients (Bridges, 1928). By 1921, the American Psychiatric Association emerged from the AMSAI, although it would be several decades before standardized diagnosis and treatment would occur. Prior to this time, diagnostic systems existed in siloed institutions across the United States with little agreement on the criteria for mental health diagnoses (Kendler et al., 2010; Suris et al., 2016). During the 1930s, originating in Europe, the use of electric shock and lobotomy for treatment became standard treatment for several mental health diagnoses, including obsessive-compulsive disorders, affective disorders, and schizophrenia in the United States (Kurcharski, 1984; Lebensohn, 1999). Despite the negative patient outcomes and the social and media attention, the use of lobotomy continued until psychotropic medications were developed in the mid-1950s (Caruso & Sheehan, 2017). Electric shock, also known as electroconvulsive therapy (ECT), was first used in the United States in 1940 (Lebensohn, 1999) and is still used to some degree to this day (Shorter, 2008; Weiner & Coffey, 1991). From the 1930s to the 1950s, the population of hospitalized people living with mental illness grew, as did the devastating impact of eugenics and involuntary sterilization of those deemed mentally ill and living with intellectual disabilities (Reilly, 1987).

The 1940s saw the increasing popularity of Freudian theory, which offered a psychoanalytic approach to treatment that broke with the conceptualization of mental health and substance use disorders as connected to neuropathology. Initially, Freud explained human behavior and psychological distress as evolving from sexual trauma; however, after World War I, sexual trauma shifted to any trauma (Kenny, n.d.; Scull, 2015) and unconscious impulses hidden in the individual psyche. Those supporting Freud’s theory believed psychoanalysis provided the means through talk therapy to ‘cure’ these problems (Scull, 2015). Freudian theories dominated psychiatry for almost two decades, and tension existed between psychoanalysis and psychiatric diagnosis (Kendler et al., 2010). The domination of Freudian theory and the lack of focus on the social context and organic disease of people living with mental health and substance use disorders and disability



may have furthered marginalization. However, the mechanism of a mental health or substance use disorder is not always considered the same as a cause.

Psychoanalysis and psychodynamic diagnosis reigned as the dominant method in mental health and substance use disorder treatment. It finally lost its foothold in psychiatry in the 1950s with the advent of psychiatric medications and research discoveries of the neurotransmitters in the brain, which indicated a neurological basis for mental health disorders (Suris et al., 2016). Another change was the Children's Bureau's focus on children's welfare and the start of the child's guidance clinics (Lindenmeyer, n.d.). Mental health among children became a focal point, especially after WWII, as the childhood backgrounds of soldiers became a resource to retrospectively track behavioral issues and their connections to outcomes. In 1946, President Truman signed the National Mental Health Act to combat mental illness (Schowalter, 2003).

The 1950s heralded the use of psychotropic medications to treat anxiety and psychiatric symptoms. There was also success in the use of certain drugs, like Thorazine, to treat people living with chronic mental illness (Shorter, 2008). Another factor at play was the media coverage of the ills and mistreatment of patients living in mental hospitals. This exposure moved mental illness from the shadows into the public spotlight. Movies made popular during this time and into the 1970s often dramatized the mistreatment of people living with mental illness and showcased the inhumanity that was hidden from view of relatives and the general public (e.g., *The Snake Pit* and *One Flew Over the Cuckoo's Nest*). The widespread coverage and outrage by the public heralded a push for public policy for deinstitutionalization and more humane treatment of people living with mental illness. As such, over the next several decades, a policy was developed to move people with serious brain disorders out of large state institutions and then permanently close part or all of those institutions. Following the closing of mental institutions, efforts began to re-socialize patients and begin treatment in the community (Scull, 2015; Yohanna, 2013).

The development of the Diagnostic and Statistical Manual (DSM) and the International Classification of Diseases (ICD) aided the standardization and classification of mental health and substance use disorders (Fischer, 2012). However, the DSM began in controversy and still holds a controversial place as the diagnoses have been heavily influenced by social norms, positivist claims, and the pathologizing of non-normative behavior (Galatzer-Levy & Galatzer-Levy, 2007; Scull, 2015; Welch et al., 2013). In fact, along with cultural identities, social identities were impacted by the DSM. Homosexuality, a term used to describe same-gender emotional or physical relationships, was included as pathological behavior and not removed as a disorder from the DSM until 1973 (Drescher, 2015). The DSM's ties to the pharmaceutical industry have also come under scrutiny (Scull, 2015; Welch et al., 2013). Daughtery et al.'s (2020) assessment of society's vacillation between treatment and mistreatment of people living with mental health and substance use disorders still rings true and impacts the standardization of mental health and substance use disorders.

The 21st-century response to mental health and substance use disorders is still weighted under the societal values of our distant and recent history. While our approach has moved from those living with mental health conditions, substance use, and disabilities being housed in large hospitals, we have institutionalized disabled people with mental health conditions and addictions using our criminal legal systems (Fazel et al., 2016;

Hartwell, 2003). The United States falls far short of its goals to integrate effective treatment of disabled people living with mental health and substance use disorders. The mistreatment of mental health and substance use disorders contributes to the growing number of those experiencing homelessness and incarceration (Hartwell, 2003). Currently, jails and prisons often serve as the first place that many people in the United States receive mental health services (Subramanian et al., 2015). The criminalization of mental health and substance use disorders has been a boon for the prison industrial complex but has fallen far short of the help needed by disabled people living with mental health and substance use disorders (view Chapter 12, “Disability and the Criminal Legal System” for more information on criminalization). Unfortunately, the traumatization and re-traumatization within the criminal legal system creates a cyclical pattern and revolving door in the criminal legal system for disabled people living with mental health and substance use disorders. The disparate treatment and mistreatment of mental health and substance use disorders is still a problem, and the impact is devastating for disabled people.

## Prevalence of Mental Health and Substance Use Disorders in Disability Communities

### Mental Health Disorders

Mental health and substance use disorders are both prevalent in disability communities and also constitute conditions that qualify people as members of disability communities. While there is limited literature on the prevalence of mental health conditions in disability communities broadly, we do have one source. Starting with mental health, based on data from the Centers for Disease Control and Prevention, we know that one-third of disabled adults experience frequent mental distress as compared with just over seven percent of the non-disabled population. This translates into almost 17 and a half million adults in the United States. The term ‘frequent mental distress’ is defined as “14 or more self-reported mentally unhealthy days in the past 30 days” and “is associated with adverse health behaviors, increased use of health services, mental health conditions (e.g., diagnosis of major depressive disorder), chronic diseases, and functional limitations (Cree et al., 2020, p. 1238). This study also looked at the prevalence of frequent mental distress within segments of the disability community and found that people with comorbid cognitive and physical/mobility impairments were most likely to report these conditions. 55.6% of the population with cognitive and physical or mobility impairments had frequent mental distress (Cree et al., 2020, p. 1238). Other examinations of demographics among the disability community with respect to frequent mental distress revealed that people identifying as female, unmarried, unemployed, LGBTQIA, or living in lower-income households were more likely to experience this condition as compared to people in opposing categories (Cree et al., 2020, p. 1239). Other members of the disability community who identified as Latinx/Hispanic, Asian/Pacific Islander, or middle-aged reported less

mental distress (Cree et al., 2020, p. 1240). Interestingly, among veterans and employed people, there were no differences in the prevalence of frequent mental distress (Cree et al., 2020, p. 1240).

National data looking at the prevalence of mental health conditions in the general population (not specific to the disability community) reveals that 1 in 5 U.S. adults experience mental health conditions each year, whereas 1 in 20 U.S. adults experience what is referred to as serious mental illness, at the higher end of the spectrum, each year (National Alliance on Mental Illness, 2022). Among young people aged 6 to 17 years old, 1 in 6 experience a mental health condition annually (National Alliance on Mental Illness, 2022). We also know that half of all lifetime mental health conditions commence by age 14, and roughly three-quarters commence by age 24 (National Alliance on Mental Illness, 2022). Another alarming fact about the mental health status of young people is that suicide is the second leading cause of death among people aged 10-34 (National Alliance on Mental Illness, 2022).

## Substance Use Disorders

Moving to what is known about the prevalence of substance use disorders in the disability community, relatively few resources exist about the national prevalence of this condition in this community. The United States Department of Health and Human Services estimates that 4.7 million adults have substance use disorders comorbid to their disabilities (Office of Disability, 2006a; 2006b). This suggests that 12% of the disabled adult U.S. population has a substance use disorder and that this is 3% less than the non-disabled population. Other estimates from 2007 suggest that substance use disorder prevalence rates are twice as high among disabled adults versus non-disabled adults (Krahn et al., 2007). Furthermore, over 20% of people eligible for the services of vocational rehabilitation services in state systems report substance use disorders (CSAT, 2009; Moore et al., 1994; Moore & Li, 1998). Another older national study (one of very few, which is why we report on it) determined that at least half of disabled adults with co-occurring substance use disorders were not being identified accurately by the service systems they were involved in (Rehabilitation Research and Training Center on Drugs and Disability (RRTC), 1996).

One other population-based study used state data to look at the question of the prevalence of disability among those receiving substance use disorder treatment, and while not an ideal study, it does give us some insights for social work practice. New York State is one of the few states that gathers data on this topic in all addiction treatment facilities. Although the data from this study are also older, sometimes older data are the best we have to understand a phenomenon. In 1997, these data showed that of a quarter of a million people receiving services at licensed addiction programs in New York, 22.4% were listed as being physically or mentally disabled. Looking at this specific group, almost 60% had a disability that was not related to mental illness. In other words, it was related to mobility, vision impairment, or hearing impairment, for example (OASAS, 1998). Because these data were gathered by addiction treatment staff who were not trained to clinically diagnose disability, these may be undercounts. Therefore, the state estimates that given the presence of ‘hidden’ disabling conditions, the prevalence rate could be 40 percent of all clients served in their system.

Finally, looking just at alcohol use in more recent data, estimates from the Centers for Disease Control and Prevention suggest that slightly over a third of the adult members of the disability community report engaging in binge drinking (Cree et al., 2020, p. 1). Binge drinking was defined here as having 5 or more drinks for men or 4 or more drinks for women on an occasion in the past 30 days.

A number of studies have also examined the prevalence of specific mental health conditions and substance use disorders within segments of the disability community although the literature is not comprehensive about reporting on all conditions in all parts of the disability community. Significant research has focused on the prevalence of mental health conditions among people with intellectual and developmental disabilities and autism, so much so that there is an organization devoted to this topic, the National Association for the Dually Diagnosed (NADD). This organization has a wealth of clinical practice information for social workers and other clinicians engaged in practice with members of this community. Below, we share a bit about what is known about the prevalence of specific conditions in this community as an example of how the treatment literature focuses on one population.

## People with Intellectual and Developmental Disabilities and Co-Occurring Conditions

Looking at mental health, as with the overall disability community, people with intellectual and developmental disabilities are widely documented as having higher rates of these conditions (Dagnan et al., 2018). Estimates from an English population-based study suggest that between 25-40% of the community with intellectual and developmental disabilities have these conditions (Giraud-Saunders, 2011). Specifically, these conditions include affective and anxiety disorders – including generalized anxiety disorder, agoraphobia, social phobia, post-traumatic stress disorder, and other specific phobias (Dagnan et al., 2018).

With respect to substance use disorders, a literature review by Didden et al. (2020) establishes that many individuals with mild intellectual disabilities use tobacco, alcohol, and drugs but that rates of substance use disorder are either the same as or higher than non-disabled peers. More specific estimates suggest that between 7-8 million people with intellectual and developmental disability experience this condition (Chapman & Wu, 2012). This translates to between 1-20% of the population, depending on the study sample (Salavert et al., 2018). Looking just at alcohol use, the 2014 National Health Interview Survey (NHIS) revealed that of adults with intellectual and developmental disabilities, 22.3% of the population reported any drinking at all, and only 1% reported feeling that they had a problem with alcohol (Slayter, 2020).

Co-occurring mental health and substance use disorders are also noted among people with intellectual and developmental disabilities. Within mental health services agencies, this population is noted to range from between 1% and 34% of clinical populations (Doody et al., 2000; Edelstein & Glenwick, 1997; Fotheringham et al., 1993; Holden & Neff, 2000; Strain et al., 1993). In a national study of Medicaid insurance beneficiaries in the U.S., it was noted that 54% of people with co-occurring intellectual disabilities and substance use disorders who were receiving addiction treatment also had a mental health condition (Slayter, 2010).

Challenging behaviors are also noted among people with intellectual and developmental disabilities at a rate of 10-15% of the population (Emerson et al., 2001). Challenging behaviors include aggression, self-injury, and property destruction that are often lifelong and can result in negative outcomes such as physical injury to oneself or others (Matson et al., 2011). Another segment of the community to consider is children with intellectual disabilities who have co-occurring autism spectrum disorder. This population is noted to present with higher rates of challenging or ‘problem behaviors’ as compared to their typically developing peers (Gurney et al., 2006). Problem behavior refers to actions that pose risks to a person or others around them and that are disruptive to a person’s functioning. For example, these behaviors can include self-injurious behaviors such as head banging, skin picking, self-biting, and head hitting. Other behaviors might include aggression towards other people, the ingestion of non-food substances (known as pica), destroying property and throwing items, and running away from a caregiver (Newcomb & Hagopian, 2018)

Finally, another topic for a social work practitioner interested in this population to learn about relates to sex offenses. Although some of these studies are old, they are seminal studies on the topic. Estimates suggest that rates of criminal offenders with intellectual and developmental disabilities convicted of a sexual offense are circa 3.7%, compared to 4% of offenders convicted without intellectual and developmental disabilities (Hayes, 1991; Jones & Chaplin, 2017; Swanson & Garwick, 1990). This is important context due to the fact that the common narrative is that people with intellectual and developmental disabilities are overrepresented among sex offenders. However, this connection is due to the fact that many studies on the topic take place in locked hospital settings or prisons, which skews the sample (Lindsay, 2002) and, therefore, is not representative of the larger population of people with intellectual and developmental disabilities.

This section has given an idea of how mental health and substance use disorder diagnoses play out prevalence-wise in the disability community, which will give you an indication of what to consider for client populations you work with. In the next section of the chapter, we highlight how the disability community receives services for these conditions in the United States.

## Mental Health and Substance Use Disorder Treatment Service Trends

While disability communities need the same care in mental health and substance use disorder services as the rest of the population, there are aspects of treatment in which they may need accessibility accommodations or modifications. However, there is only a very small empirical literature base on interventions for selected members of disability communities, so it is difficult to address this topic for all of the communities. To inform your social work practice, ensure best practice by paying attention to empirical research and critically reviewing what the literature states about the specific population and potential interventions for working with them.

In considering service trends related to mental health and substance use disorder treatment experienced by disability communities in the United States, we are going to focus on challenges with access to care, what

we know about treatment outcomes, and the nascent clinical guidance for supporting treatment. Although a discussion of how these topics play out for various groups within disability communities (i.e., d/Deaf and Hard-of-Hearing, people who are b/Blind, or people with physical disabilities) is impossible given the scope and space limitations of this chapter, one example is provided for the population with intellectual developmental disorders.

## Access to Mental Health and Substance Use Disorder Care for Disability Communities

A range of different types of access barriers to treatment are documented for many populations with disabilities across both mental health and substance use disorder service settings (West, 2007). Such barriers may be physical, visual, cognitive, and more (e.g. wheelchair access, Braille paperwork, relay services). Notable access barriers in the provision of mental health services have been noted for disabled people broadly (Kattari, 2020) and specific groups, such as the d/Deaf community (Austin & McGrath, 2006), people with mental health disorders (Rowan et al., 2013), and people with intellectual and developmental disabilities (Whittle et al., 2019). While we do not have national data on access for disability communities in both of these sectors, we do have some strong population-based studies that can help illustrate substance use disorder treatment access (e.g., Krahn et al., 2007). One seminal study in the state of Oregon documented that disabled adults in the Medicaid program are only half as likely as other Medicaid enrollees to enter substance use disorder treatment during any year (Krahn et al., 2007). Therefore, although substance use disorder treatment needs are higher, entry into such care is lower. Specific concerns such as physical access barriers, inappropriate or inaccessible educational materials, and the lack of sign language interpreters can get in the way of disability communities' members seeking out and receiving treatment (Office of Disability, 2006b).

### Example of Access Barriers: Substance Use Disorder Treatment for People with Intellectual and Developmental Disabilities

Despite being at high risk of addictions, people with intellectual and developmental disabilities have less access to appropriate treatment services. We know that among people with Medicaid coverage across 49 states, this population that had co-occurring substance use disorders were less likely to initiate and attend treatment, had shorter lengths of stay, and were more likely to drop out of treatment than those without intellectual and developmental disabilities (Slayter et al., 2010). One reason for lower substance use disorder treatment among these individuals is the lack of connection between the addiction and disability services systems, which are characterized by different treatment cultures, philosophies, values, and definitions of success (Slayter & Steenrod, 2009). For example, whereas laboratory-verified abstinence from alcohol and drugs may be the 'gold standard' measure of treatment effectiveness in addictions treatment, the benefits of maintaining abstinence



in the disability system (not uncommonly achieved by placing individuals in more restrictive settings) must be balanced against individual rights, freedoms, and the dignity of risk. Therefore, addiction treatment organizations are generally unfamiliar with this population and their needs, and disability programs generally lack expertise in the principles of effective addiction treatment (Slayter, 2008).

Perhaps the most substantial access barrier faced by people with intellectual and developmental disabilities is a lack of access to developmentally appropriate treatment (Hammink et al., 2007). Most programs use cognitive behavioral therapy (CBT) for addiction (McHugh et al., 2010), which helps people identify triggers that increase the risk of alcohol or drug use, develop plans to avoid those triggers and learn new strategies to cope with unavoidable triggers (Copersino et al., 2022). CBT requires abstract thinking, planning, and reasoning that often goes beyond the abilities of people with intellectual and developmental disabilities. Therefore, in standard addiction treatment, this population is more likely to be tasked with unrealistic treatment goals (Phillips, 2004), more likely to have their limited comprehension of this treatment modality be misunderstood for lack of treatment motivation (CSAT, 1998), and more likely to be identified as a ‘treatment failure’ (McGillivray & Newton, 2016; Slayter & Copersino, 2018).

The above-described barriers are apparent in the data in a range of studies that have examined different populations within the community of people with intellectual and developmental disabilities. In a series of national studies looking at people receiving Medicaid health insurance coverage, access to treatment in this population was examined (Slayter, 2016; 2010a; 2010b; 2010c). Adults with intellectual and developmental disabilities were approximately 30% less likely to initiate or begin treatment and approximately 32% less likely to engage or remain in treatment as compared with people without disabilities, controlling for benefit coverage, comorbidities, geographic location, gender, race, and age.

This same analysis was done for several populations within the community of people with intellectual and developmental disabilities. First, people with co-occurring intellectual or developmental disability, substance use disorders, and serious mental health conditions were less likely than their counterparts without these conditions to access treatment. Factors associated with initiating substance use disorder treatment in this group included being non-White, living in a rural area, and not being dually eligible for Medicare. Factors associated with engagement, or remaining in care for up to a month, included all of the same as those for initiation and having a fee-for-service plan or a chronic substance use disorder-related condition (such as cirrhosis of the liver). Second, women with intellectual and developmental disabilities were less likely than men with the same disability (or women without disabilities) to access treatment, suggesting both gender and disability-related barriers (Slayter, 2016). Women with intellectual and developmental disabilities who were White, urban, or who had a serious mental health diagnosis were slightly more likely to initiate or engage in treatment. Third, youth with intellectual and developmental disabilities and substance use disorders were less likely to initiate treatment or remain in treatment for a month, the latter of which was associated with being male and/or non-White (Slayter, 2010c).

## Substance Use Disorder Treatment Outcomes in the



## Disability Community

Treatment outcomes for mental health and substance use disorder services differ greatly for the various segments of the disability community. Looking at the above-mentioned Oregon study of adults with disabilities, substance use disorder treatment appears to be just as successful for adults admitted into treatment as those without disabilities (Krahn et al., 2007). This study notes that disabled adults were just about as likely to remain in treatment, to meet treatment goals, and to abstain from using their primary drug of choice during the study period (Krahn et al., 2007). This study tracked individuals for six years and learned that disabled adults remained in treatment for generally as long as those without disabilities, although rates of treatment completion were slightly lower for those meeting treatment goals (Krahn et al., 2007). Among people with outpatient readmission, disabled adults were equally or slightly less likely to be readmitted than those without disabilities (Krahn et al., 2007). Disabled adults self-reported slightly less success in abstaining from their primary drug of choice during the last 30 days prior to discharge (Krahn et al., 2007).

## Guidance for Mental Health and Substance Use Disorder Treatment with the Disability Community

While there is no one set of guiding principles for how to provide mental health services or substance use disorder treatment for all disability communities, a central tenet of practice in either type of setting is operational and relates to the need to create the foundation for treatment by eliminating access barriers, whether physical, communication-related or attitudinal (NARIC, 2011; SAMHSA, 2012). There is a range of literature on approaches to practice with specific communities under this larger umbrella. Treatment programs have an ethical and legal responsibility to make treatment as effective as possible (SAMHSA, 2012). One central overarching principle, however, likely relates to the fact that reasons for entering mental health or substance use disorder treatment may not always derive from a person identifying as having a disability or being disabled, a common misconception among social workers who often list disability as a ‘presenting problem’ without asking their clients about this first. Another important factor to consider is that disability communities broadly experience exclusion, stigma, and oppression in the forms of ableism and sanism – with many also experiencing high rates of victimization. All of these factors may be correlated with higher rates of seeking mental health and substance use treatment services.

Disabilities may not always be something that social workers are aware of when beginning work with clients, so screening for disability is a best practice (SAMHSA, 2012). Different screening techniques exist for different populations, such as the d/Deaf community, whose languages may differ from the English or Spanish (or other languages) used in standard written screening tools. More population-specific treatment guidance is available in the Treatment Improvement Protocol (TIP) series developed by the Substance Abuse and Mental Health Administration, such as the TIP 29: Substance Use Disorder Treatment for People with Physical and Cognitive

Disabilities. It is important to note that while these TIP documents draw on the evidence base where it is available, much of these documents also draw on anecdotal evidence from clinicians that are not technically data-driven in the classic sense of the term.

## Example of Evidence-Based Treatment for Substance Use Disorder Among People with Intellectual and Developmental Disabilities

The following is a discussion of treatment guidance for one particular condition in one particular population, substance use disorders in the population with intellectual and developmental disabilities, a field where we have only a nascent evidence base. To date, only one study has conducted a clinical trial of an intervention focused on this population (Kouimtsidis et al., 2017). Several other non-controlled studies are pointing us in possible directions for treatment, however (Copersino et al., 2022; Kerr et al., 2013). Without evidence-based or evidence-informed treatments to draw on, addiction treatment providers are often at a loss for how to work with this population in their settings, which are often based on cognitive behavioral talk therapy techniques that are not as appropriate for people with intellectual and developmental disabilities (Slayter & Copersino, 2020). One English study focused on young people with intellectual and developmental disabilities who had binge drinking problems (i.e., Kouimtsidis et al., 2017). An extended brief intervention that drew on both motivational interviewing and an unspecified form of modified cognitive behavioral therapy (CBT) was tested against a treatment-as-usual model and found to reduce harmful drinking (Kouimtsidis et al., 2017). Of cognitive behavioral therapy, Copersino et al. (2022) write:

Despite a scarcity of research in this area, CBT elements focusing on knowledge and skill attainment “in the here and now” appear to provide developmentally appropriate instructional techniques for people with ID. For example, experiential training methods including role-play are commonly used to empower ID individuals with assertiveness skills, and to build social competency and self-efficacy...Furthermore, these instructional techniques can reinforce valuable target behaviors in people with ID for whom social adaptive functioning deficits are associated with increased risk of AOD problems. (p. 3)

Building on these ideas, these authors conducted a study in the United States which examined the clinical utility of an alcohol and other drug refusal skills intervention designed to be cognitively accessible to adults with IDD (Copersino et al., 2022). Thirty individuals at high risk or in recovery for an addiction disorder in developmental disability services (DDS) community residential and day habilitation settings participated in the 2-week refusal skills group. Curriculum content was drawn from source material on general education about alcohol and other drugs, motivational strategies for recovery, assertiveness training for people with IDD, and their coping strategies for stressful social interactions. The core alcohol and other drug refusal strategies were adapted from The James Stanfield Company Life Facts Series, Substance Abuse and Smart Trust volumes, and NIDA Therapy Manual 1: A Cognitive-Behavioral Approach to Treating Addiction. There was a strong effect for refusal skill acquisition in the group (Copersino et al., 2022).

Three small studies conducted in England and Scotland studied interventions for alcohol use disorders

(Forbat 1999; Mendel & Hipkins 2002; Steel & Ritchie 2004). Specifically, two of these studies were focused on increasing clients' motivation to change their behavior around alcohol use (Mendel & Hipkins 2002; Steel & Ritchie 2004), while the Steel and Ritchie (2004) study sought to help clients increase their knowledge levels about this topic on a one-on-one basis for 12 weeks. Motivational interviewing techniques merged with psychoeducation were used in the Mendel and Hipkins (2002) study using a group approach over three sessions spanning two weeks. While numbers were small in these studies and the studies have been critiqued for their methods, Steel and Ritchie (2004) and Forbat (1999) reported that participants' knowledge levels rose (with a combined total of six participants). Mendel and Hipkins (2002) reported an increase in readiness to change alcohol-related behavior (although participants were in an alcohol-free secure setting).

Two other studies in Scotland and the United States looked at interventions designed to address both tobacco and alcohol at the same time (i.e., Lindsay et al., 1998; Demers et al., 2000). Lindsay et al.'s (1998) intervention focused on increasing AOD knowledge through small group discussions that ran over a two-month period. People in the study showed a significant increase in knowledge levels (compared with a control group) that remained for three months. Demers et al. (2000) worked in a school with children to develop both attitudes and refusal skills to assist with peer pressure over a school year. While there were no statistically significant findings, students in the intervention group achieved higher and more positive outcomes than those in the control group. We hope that this one 'deep dive' into the evidence base for substance use disorder treatment for one population gives you a sense of the need to look specifically at the needs of each segment of the disability communities instead of thinking of the communities en masse.

## Disability-Specific Topics in Mental Health and Substance Use Disorder Treatment Service Settings

In this section, we touch on three of the most controversial topics for members of disability communities who are receiving mental health and substance use disorder treatment services: the need for specialty addiction treatment for the d/Deaf and hard of hearing community, the lack of evidence-based practices for people with intellectual and developmental disabilities, and the use of conservatorships for people with mental health disorders.

### Substance Use Disorder Services in the d/Deaf and Hard of Hearing Community

Given the higher prevalence of substance use disorders in the disability community overall, there is a need for specialized screening and assessment tools for d/Deaf and hard-of-hearing community members. Many social workers are under the impression that all d/Deaf and hard of hearing people use American Sign Language,

while some do not. Some people, for example, use Black Sign Language or Puerto Rican Sign Language – or regional variations of all three (Lucas et al., 2020). Not all of these languages share the same signs, and not all interpreters speak all of these languages. Translating addiction screening and assessment tools into any of these languages may be challenging as some of the dominant English language terms used do not exist in American Sign Language or the other Sign Languages (e.g., “eye-opener” in the CAGE screener). This causes problems for addiction treatment intake workers trying to work with d/Deaf and hard of hearing clients because they may not be gathering accurate data about their alcohol or drug use, among other topics. While researchers and clinicians have partnered to create specialized instruments and programs for the d/Deaf and hard of hearing community, access to these is few and far between (Guthmann et al., 2017). This likely causes disparities in treatment access for d/Deaf and hard of hearing people, as well as issues in both the quality of care received and in the outcomes of that treatment.

## Substance Use Disorder Treatment for People with Intellectual and Developmental Disabilities

Much scholarship has focused on concerns about substance use disorders in the population with intellectual and developmental disabilities, given their higher rate of victimization and use of psychotropic medicines that do not interact well with alcohol and drugs, for example (Degenhardt, 2000). Researchers and activists have documented that stigma and insurance-related factors both contribute to barriers in accessing substance use disorder treatment for this population (Slayter, 2016). Another barrier getting in the way of good quality treatment and positive treatment outcomes for this population is the lack of evidence-based or evidence-informed treatment interventions for people with intellectual and developmental disabilities (McLaughlin et al., 2007). To date, only one study has conducted a clinical trial of interventions focused on the treatment of substance use disorders in this population (i.e., Kouimtsidis et al., 2017). Several other non-controlled studies are pointing us in possible directions (i.e., Copersino et al., 2022; Kerr et al., 2013). Without evidence-based or evidence-informed treatments to draw on, addiction treatment providers are often at a loss for how to work with this population in their settings, which are often based on cognitive behavioral talk therapy techniques that are not as appropriate for people with intellectual and developmental disabilities (Slayter & Copersino, 2020).

The nascent research in this area tells us that hazardous drinking may best be treated through the use of extended brief interventions that draw on both motivational interviewing and a modified form of cognitive behavioral therapy in a group format (Kouimtsidis et al., 2017). This approach was tested against a treatment-as-usual model and found to reduce harmful drinking in a trial of English adults with intellectual and developmental disabilities (Kouimtsidis et al., 2017). This research is supported by a handful of other non-controlled studies that have examined motivational interviewing, psychoeducational, and other forms of modified cognitive behavioral therapy (including ‘refusal skills’), all in group formats (Kerr et al., 2013).

## Conservatorships for People receiving Mental Health Treatment Services

Conservatorships or guardianships are put in place when a person is deemed to be unable to manage their own financial or personal affairs. They are put into place by a court that appoints either a family member or a professional to act on behalf of what is considered the ‘incapacitated’ person. Pop singer Britney Spears famously made the news when she testified in court about how her legal conservator (now ended) kept her from having children. She had been under a legal conservatorship for many years due to mental health challenges. Specifically, Ms. Spears said:

I want to be able to get married and have a baby . . . I wanted to take the (IUD) out so I could start trying to have another baby. But this so-called team won’t let me go to the doctor to take it out because they don’t want me to have children—any more children. (Powell, 2021)

Even with her fame, resources, and privilege, Ms. Spears suffered under a conservatorship in which her relationship with her conservator was strained – leading to unjust situations. A less famous and high-profile case in Massachusetts highlights the impact that conservatorships or guardianships can have on people with mental health challenges. A 32-year-old woman named “Mary Moe” (a pseudonym) became pregnant. Due to her mental health condition, her parents petitioned a state court for guardianship over her so that they could obtain the right to force her to have an abortion. Mary Moe, however, was clear that she very much did not want to have an abortion. Disability legal scholar Robyn Powell documents that “the trial court appointed her parents as co-guardians and authorized that Mary Moe be “coaxed, bribed, or even enticed . . . by ruse” into a hospital for an abortion...Further, the trial judge ordered *sua sponte*, and without notice, that Mary Moe be sterilized “to avoid this painful situation from recurring in the future” (Powell, 2021, p. 1). While this legal decision was reversed on appeal, Ms. Moe’s situation is an example of the ways in which the disability community faces threats to their reproductive autonomy even within the context of a court system that should be protecting their rights (Powell, 2021). Powell (2021) notes that Britney Spears’s and Mary Moe’s experiences are quite common. Further, she points out that the idea that “people with actual or perceived disabilities—including physical, intellectual, sensory, and psychiatric disabilities—should not have reproductive autonomy, is woven into our nation’s fabric” (p. 1). Reflecting on this further, Powell (2021) points out that these reproductive injustices are even more egregious for disabled people of color and LGBTQ people in disability communities.

So how should social workers involved in a conservatorship case approach their work with disabled clients? Centering the principles of empowerment-oriented disability practice and the disability justice principles would be a good start. Recognizing that the oppression of people with mental health conditions (among other disabilities) vis-a-vis conservatorships in general and regarding reproductive autonomy in particular is deeply woven into our social consciousness, needing to be unwoven.

## Policies and Programs Related to Mental Health and Substance Use Disorder Treatment for Disability Communities

Next, we review state and Federal policies and programs relevant to mental health and substance use disorder treatment for disability communities. Care for people with mental health conditions and substance use disorders in the United States is delivered through a complicated network consisting of a mix of public and private organizations as well as public and private funders. Funders can be private companies, such as Google or Apple, or public health insurance programs, such as Medicaid or Medicare, for example. These funders exist at both the federal and state levels in the public sector. Depending on how someone receives their health care coverage, their benefits for mental health or substance use disorder care will look different as different insurance plans make different decisions about treating and intervening with people with the same diagnoses across those plans.

Many disabled people receive their health insurance coverage through the public sector, specifically via the Medicaid and/or the Medicare programs (Kennedy, 2017). At present, more than 10 million people in the United States are Medicaid beneficiaries as a result of their disability (Medicaid and CHIP Payment and Access Commission, 2022). Some of these community members are known as ‘dual eligibles,’ meaning that they are dually eligible for Medicare and Medicaid, although most of this group (about 6 million) do not have Medicare insurance (Medicaid and CHIP Payment and Access Commission, 2022). Most people think of Medicare as a benefit for people who are elders over the age of 65. Those who are under the age of 65 who receive Medicaid coverage because they are disabled do so as a result of being disabled from birth or due to acquiring a disability. About a third of this population receives Medicaid as a result of their participation in the Supplemental Security Income (SSI) program, which is the federal cash assistance program for people who are elderly or disabled who have low income and/or assets (Medicaid and CHIP Payment and Access Commission, 2022). Medicaid is the single largest funder of treatment for mental health conditions and substance use disorder treatments in the United States, which makes this program especially valuable to the disability community (Mental Health America, 2022).

Overall, the primary funds for services for the treatment of mental health conditions and substance use disorder treatment come from the federal government through both Medicare and the Department of Veterans Affairs (also known as the ‘VA’) (Kennedy-Hendricks et al., 2018; Walker et al., 2015). The Medicaid program partners with states and matches Medicaid and CHIP (Children’s Health Insurance Program) dollars at rates of 50-70%, varying from state to state (Mental Health America, 2022). Additionally, Mental Health Block Grants (MHBG) are provided to states by the federal government (Walker et al., 2015). These allow states to provide community-based mental health services (Mental Health America, 2022). Looking at the state side of the equation, how states structure their services varies significantly across the country because each has freedom



in designing and funding its service system and deciding what is and is not covered (Mental Health America, 2022).

Since the passage of the Affordable Care Act (ACA) in 2010, known colloquially as ‘Obamacare,’ disabled adults who are working age may be more likely to be covered by an insurance plan, and, therefore, may be less likely to face barriers to accessing care Kennedy (2017). Nonetheless, this community still faces significantly high costs for health care, which impedes their overall access to services. Additionally, people with mental health conditions appear to have higher chances of not having insurance despite this policy shift (Kaye, 2019). The passage of the ACA was important for the provision of treatment for mental health and substance use disorder treatment because it protected people around coverage for pre-existing conditions and impacted access to services for those specific conditions (Burns & Wolfe, 2016). Under the ACA, coverage of treatment for mental health conditions and substance use disorder services is one of ten ‘essential health benefit’ categories in non-grandfathered individual and small group plans (Burns & Wolfe, 2016).

Of particular note for social workers to be aware of is the Mental Health Parity and Addiction Equity Act (MHPAEA) (Centers for Medicare and Medicaid Services (CMS), 2022). This is a federal law that generally prohibits group health plans and other health insurance plans that provide benefits for mental health treatment or substance use disorder benefits from offering less favorable benefits for that care than for medical and surgical benefits (CMS, 2022). More specifically, social workers need to know that this policy doesn’t require insurers to cover these benefits, a common misconception, only those that choose to include these options (Thalmayer et al., 2017).

Two other policies of special interest to social workers interested in treatment for mental health and substance use disorders relate to the care of children and how the United Nations has weighed in on the rights of people with these conditions worldwide. In 1991, the United Nations passed a resolution known as the “Protection of persons with mental illness and Improvement of mental health care treaty.” This is targeted to improve the rights and opportunities of the disability community in the countries that sign on to the rules and regulations within this treaty. Soon after, in the United States, in 1992, the Children’s and Community Mental Health Services Improvement Act was passed. This created funding for states to create ‘systems of care’ for the support of children with serious emotional disturbances. Systems of care are designed to provide wraparound services to children and their families using a holistic approach and look different from state to state.

## Policy and Practice Implications for Working with Disabled People in this Service System

Across all mental health and substance use disorder treatment service settings, a number of principles are central to the care and support of the disability community vis-a-vis policy and practice implications. These core principles include community inclusion, self-determination, dignity of risk, circles of support, and “nothing about us without us” (HIV/AIDS Legal Network, 2008). In this part of the chapter, we discuss how



these principles influence mental health and substance use disorder treatment practice where social workers are working with members of the disability community. We also note the implications for social workers to ensure ethical and socially just policies and practices with disability communities.

At its core, community inclusion is about the location in which a person is receiving services and living. The idea is that wherever and whenever possible, the disability community should be based in the least restrictive environment, ideally in the community. This is due to the extensive history of over-institutionalization that the disability community has experienced – especially disabled people of color.

When we think about community inclusion in the context of mental health and substance use disorder treatment with disabled people, our first thought might be to focus on placement decisions as well as integration with non-disabled people in program activities. Disability communities lift up self-determination as another core principle key to empowerment-oriented disability social work. We may think of this as the process of making something happen in one's own life – allowing people to make their own choices, set their own goals, solve their own problems, and generally make decisions on their own. In the context of mental health treatment, clients should have the right to create their own treatment goals, choose their own treatment modality, and guide their own treatment process in consultation with their clinician. In the context of substance use disorder treatment, and especially in the context of the recovery process, this may relate to how people engage with those in their life who use substances while trying to remain sober. This example connects to the next concept, the dignity of risk.

Many have noted the learning that comes along with engaging in everyday risk – or risk that comes along with greater than everyday risk. This means that social workers need to sit with clients in facing the consequences of their choices in order for the learning to happen despite the risk of endangerment. In the context of substance use disorder treatment, this might include the risks that accompany a person in recovery socializing with old friends who are still using substances, something that might trigger a relapse. This example leads us to think about circles of support. These are the groups of supportive people composed of formal staff, family members, friends, or neighbors that encircle the disabled person. As people enter the recovery phase for their mental health or substance use disorder conditions, circles of support are central resources for tracking symptoms and providing feedback and comfort.

Social workers in practice in mental health and addiction settings must embrace the “nothing about us without us” (HIV/AIDS Legal Network, 2008) principle, especially at the goal-setting stage of treatment or intervention work. This phrase came about as part of the disability civil rights movement and is used to this day. The idea is that no decision should be made without the input of the disabled person themselves weighing in (which links back to self-determination). All too often, clinical goals are set by social workers, without client input. This phrase can be used to help keep social workers centered in their practice to empower their disabled clients.

These core principles align with social workers' ethical principles and core values. The social workers' code of ethics obligates them to respect the inherent dignity and worth of individuals and to challenge social injustice (NASW, 2021a). Disability communities are a part of the larger community, and members

of disability communities face challenges from accessing treatment to engagement in treatment for their mental health and substance use. In fact, social workers have often been perpetrators of oppression and racism against people of color in treatment with overdiagnosis of certain disorders like schizophrenia and underdiagnosis of mood disorders (Elkassem & Murray-Lichtman, 2022; NASW, 2021b). This negatively impacts all disability communities. Social workers must critically examine policies and practices that negatively impact historically oppressed groups within disability communities to make sure that they are not furthering social injustice (Murray-Lichtman et al., 2022). It is easy to recognize historical atrocities in hindsight; it is much harder to recognize them as you take part in their enactment. The first step in ending western society's long history of mistreatment of those living with mental health and substance use disorders within disability communities begins with collective action and the refusal to continue repeating the patterns of criminalization and underfunded benevolence. Collective action begins at the individual level; therefore, social workers must also critically examine their own biases while promoting social change in disability communities and the broader community (Murray-Lichtman & Elkassem, 2022).

Finally, the historical marginalization of disability communities and those living with mental health and substance use disorders, particularly among group members facing oppression in the larger society, call for social workers to be at the forefront of leading social change which ensures the dignity and worth of the individual. Social workers have an ethical obligation and are uniquely suited to lead in social change with disabilities communities by empowering them and enhancing their abilities to make sure that their voices are heard and their needs are met.

## Voices and perspectives of People Involved in this System

As apparent through our discussions in this chapter, historically and to the present day, the voices and perspectives of disabled people with mental health conditions and addictions have not been at the forefront. Instead, persons in positions of power across various roles, organizations, and systems have been making decisions for this community and not with this community.

Returning to the principle of “nothing about us without us” (HIV/AIDS Legal Network, 2008), there are existing and potential ways to have the voices and perspectives of disabled people with mental health conditions and addictions amplified.

Centering the lived experience of disabled people with mental health conditions and those who use substances happens through community organizing and events. The Vancouver Area Network of Drug Users (VANDU) is an organization created by and for people who use drugs (VANDU, n.d.). Mad Pride is an event example specific to the mad or mental health community (Dart, n.d.). Art installations, photovoice, digital storytelling, personal narratives, and lived experience expertise have been increasingly shared on websites, social media, zines, and podcasts. Activists with lived expertise of drug use created a photovoice journal titled

“(Re)Visualizing the overdose crisis” (People with Lived Expertise National Working Group, n.d.). An example of a webzine is “Mad in America”, which is intended for people involved in the mental health system (Mad in America, 2022). Crackdown is a podcast created by activists with lived experience of substance use who discuss a range of topics, such as drug policy and the war on drugs (Crackdown, n.d.).

There have been ways that disabled people with mental health conditions who also use drugs have become involved in the behavioral health system. However, these roles have been secondary to the health professionals dominating and dictating these services and programs. An example is increasing the opportunities for disabled people with significant mental health conditions who use drugs to work in peer support roles, which are well-paid and include health benefits, pension contributions, and ongoing training and development (HIV/AIDS Legal Network, 2008; People with Lived Expertise of Drug Use National Working Group et al., 2021). More involvement of disabled people with significant mental health conditions who use substances as paid and recognized research team members gives way to inquiry that reflects the needs of these communities (Boucher et al., 2017; Elkhailifa et al., 2020; Jones et al., 2021; Salazar et al., 2021).

Within social work, there are opportunities to increase the admission and retention of disabled people with lived experiences of mental health conditions and addictions as students in social work programs. Disabled people with lived experiences of mental health conditions and addictions should be represented in social work programs, as compensated guest speakers, course facilitators, instructors, faculty, and staff.

Additionally, there is a need to have disabled people with lived experiences of mental health conditions and addictions in leadership positions, as policy makers, administrators, organization executives, and politicians. While disabled people with lived experiences of mental health conditions and addictions have, through some initiatives, been included in policy creation (People with Lived and Living Experience of Drug Use National Working Group, 2021), there are limited members of these communities in leadership roles (People with Lived Expertise of Drug Use National Working Group et al., 2021). We invite anyone involved in the disability and behavioral health systems to consider what change and transformation could result if members of these communities had their voices and perspectives centered and were represented in meaningful and well-compensated roles and leadership positions.

## Application of Critical Theoretical Perspectives and Practice Model from Chapter Two

Three critical theoretical perspectives – critical cultural competence, intersectionality, and anti-oppressive practice – in conjunction with the planned change process, were integrated by Johnson et al. (2022) to create the model for social work practice with the disability community highlighted in chapter two of this text. We offer considerations for practice with disabled people with mental health conditions and addictions and members of these communities, using this model for social work practice with disability communities by Johnson et al. (2022).

## Pre-Engagement

Before even meeting with the person with mental health conditions and addictions that may be referred to or seeking services, a social worker may begin with critical self-reflection and analysis of their own personal and social identities, positionalities, and consider which aspects of themselves contribute to their privilege and oppression, and the marginalization of the people and communities around them. In this pre-engagement stage, a social worker continuously examines how they are implicated in structures and systems of power and the ramifications of this when working with people and communities that have had their voices and agency taken away or suppressed.

## Engagement

A social worker beginning to work with a disabled person with living experience of mental health conditions and drug use recognizes the scope of their personal and professional knowledge and approaches their practice with humility and openness. The social worker honors and acknowledges the lived experience and expertise of the people they work with and creates time and space for the people they support to share knowledge, inform, and educate them (the social worker) only if or when the person wishes to do so. While the social worker promotes this sharing, they do not rely on the people they work with to educate them and, rather, engage in personal and professional development and supervision to address any knowledge gaps they (the social worker) may have.

## Assessment

When seeking to understand and assess the presenting concerns and circumstances of the disabled person with mental health conditions and addictions, the social worker ensures the person's voice and perspectives are centered. The person is encouraged to define and elaborate on their identities, culture, and communities. The social worker honors the ways the person self-identifies and the language and terminology they use. The social worker also encourages the person to note the informal and formal supports they may have in their life and recognizes the multiple ways that people connect and cope. If any screening tools or assessments are used or required by the organization where the social worker is employed, they are offered in multiple languages and formats, ensuring accessibility and broad usability by members of various disability communities.

## Intervention

The person accessing services is recognized as knowing what their needs are and what treatment or support may be helpful to them. Remaining true to the principle of “nothing about us without us” (HIV/AIDS Legal

Network, 2008), the disabled person with living experience of mental health conditions and substance use guides what or which treatment options or resources would be potentially beneficial. They determine whether disability, mental health, or addictions, or other areas of their life are their main concern(s) and reason(s) for accessing services and support. The social worker addresses their own bias, beliefs, and assumptions about what may be their presenting problem(s) and allows the disabled person with mental health concerns and addictions to lead or co-create treatment plans and goals. The social worker identifies a range of informal and formal community-based programs and supports and informs the person of what is available and accessible where they are. From there, the social worker and disabled person with mental health concerns and addictions work together, continually revisiting the treatment plans and goals, any programs, services, or supports accessed, and their effectiveness for the person.

## Termination

The social worker recognizes the power dynamics between themselves and the person they are working with, the organization that they are employed with, and the broader community. The social worker also appreciates how ending their work with the person may take many forms. For instance, the person may wish to no longer access treatment services or support, the person may have needs better addressed with another organization, or there may be time-limited or specific service parameters. The social worker addresses these power dynamics and termination considerations with open and collaborative conversations with the disabled person with living experience of mental health conditions and substance use.

## Evaluation

During and after their work together, the social worker seeks feedback from the disabled person with mental health conditions and addictions, and the social worker adjusts their approach based on the information received. The social worker considers both informal and formal mechanisms of evaluation. The social worker prioritizes what the disabled person with mental health conditions and addictions identifies as progress and success, and how the person describes their experiences in working with the social worker and accessing treatment services or supports. The social worker continuously evaluates their own practice and examines how the treatment services or programs could better serve the person and members of the disability communities.

## Case Study

Jessica Sanchez is a 39-year-old Latina who grew up in the Hunt's Point neighborhood of the South Bronx. Raised in a loving family of first-generation immigrants from the Dominican Republic, Jessica grew up

attending church and volunteering in her local hospital. Diagnosed with learning disabilities related to reading and receptive language at age ten, Jessica always struggled in school but managed to obtain her high school degree. Soon after obtaining work in a school cafeteria, Jessica became pregnant, starting her life as a mother with her long-term partner.

In her late 20s, Jessica and her boyfriend went out for dinner one night. As they drove to the movie theater, they were caught in the crossfire of a gang fight, causing their car to crash. Jessica's partner died of his gunshot wound, and as a result of her injuries, she became visually and physically disabled. As she struggled to support her family on one income – and to parent her children alone – she also began to adjust to her reduced vision and physical disability. Jessica's application was rejected for an accessible apartment as available facilities were not designed to accommodate families. She also struggled to manage the chronic pain from her injuries at a time before doctors were aware of the risks of opioid addiction. After meeting her years later, you learn that soon, Jessica was no longer able to access her pain medication from her doctors and she was not offered alternative pain management treatments by her healthcare team.

With time, Jessica became dependent on heroin, leading her to earn money as a sex worker, the combination of which led to the removal of her children and a series of arrests. Over the next few years, Jessica was able to enter methadone treatment and regain custody of some of her children. However, she then experienced a relapse – common in substance use recovery. The effects of stress and trauma on Jessica were also apparent. During her last relapse into heroin use, Jessica became infected with both the Human Immunodeficiency Virus (HIV) and Hepatitis C.

When Jessica was most recently arrested for the sale and possession of heroin, you began working together. Although you felt empathy and compassion for her situation, you found yourself wondering how a person with such significant disabilities and difficult life circumstances could parent her children. At times, you resented the amount of effort that the child protection authority put into getting her children to Rikers Island jail for family visits, thinking that jail was not a great place for children to see their mothers. You kept these feelings to yourself, but you also fought for Jessica to have access to counseling while in jail.

Jessica now faces a ten-year prison sentence. You note that a White woman with a similar criminal history record and set of challenges who was on your colleague's caseload was recently offered a much shorter sentence. Your job as Jessica's defense team's forensic social worker is to present the court with mitigating information about Jessica's life in order to argue for an equitable sentence that would address the underlying challenges leading to her court involvement. This means that you must find an alternative to incarceration that both provides substance use disorder treatment and can accommodate Jessica's disabilities, health conditions, and two youngest children. Her other children will be placed with relatives – and you think, "Thank goodness I don't have to manage that process" and "She's lucky she has someone to take care of her older children" as finding a program that would accept her and all of her children would be next to impossible.

Turning your attention to your task, you note that an alternative-to-incarceration program is one that provides treatment instead of incarceration (where little treatment is available anymore due to funding shortages) for the time a person would have been incarcerated. Your goal is to obtain an alternative to

incarceration program in lieu of a sentence for a two-year long-term residential drug treatment program and 8 years of probation in place of a ten-year sentence. After the standard two weeks that social workers are given to locate alternative placements during the pre-trial phase, you have found that no program would accept Jessica due to her special set of needs. The judge on the case has offered an extension but says if no program is found soon, he will have to give her the full ten-year sentence even though others without disabilities, medical conditions, and children receive alternatives to incarceration very easily – a clear violation of the Americans with Disabilities Act.

Jessica is despondent, and she is losing hope fast. Jessica's family members are very worried about her and also feel overwhelmed with the care of her children, who are acting out due to missing their mother. You work hard on this case, despite your private feelings about Jessica, and after facing many obstacles and many more closed doors due to Jessica's unique set of characteristics, you obtain a placement for her in lieu of incarceration. This involves many phone calls and meetings with Hawthorne House, a recovery program that agrees to accept Jessica even with all of her health conditions and requirements for childcare. You share all of Jessica's paperwork with their intake office (after obtaining a consent form from Jessica), and you are told everything is good to go.

On the day before Jessica is set to be released, you call the program to re-confirm that they have all they need for her admission the next day. On the day of Jessica's release, you and her attorney wait for hours at the door where people are released from the jailhouse in order to take her to her alternative to incarceration program. It is almost 4 p.m. by the time Jessica is released, and she has not had her daily methadone dose, so she is starting to feel "dope sick," but you have to get to the program to check in during office hours, and you hope they will be able to accommodate her with her methadone dose there. As you sit through the intake interview with her at the program, the social worker looks at Jessica's Medicaid card and says, "This is the wrong kind of Medicaid, we can't accept her, and you'll have to take her back to jail." You are not able to convince the program to accept Jessica for the night. By this time, it is after 5 p.m. You drop by the methadone clinic near your office to see if you can get Jessica her methadone as she is experiencing vomiting and diarrhea due to heroin withdrawal, but the clinic is closed. You also know that the courthouse is also closed, leaving you no way to return Jessica to jail. You try taking Jessica to the nearest police station to try to get them to return her to jail, but they say they do not have the jurisdiction to do so. You then focus on her health needs again and take her to the emergency room, hoping for assistance with the methadone, but after four hours, you are also turned away from there with instructions to visit a methadone clinic in the morning.

You return to your office, where you meet with your supervisor, Jessica, the lawyer you partner with, and the executive director, all of whom are stymied about what to do. Finally, without warning, the executive director looks at Jessica and says, "I'm giving you \$20. Do what you need to do and be back here by 7 a.m. tomorrow morning to return to the courthouse with us in order to explain all of this to the judge." You think to yourself, "She's essentially giving her permission to go out and buy some heroin so that she isn't dope sick anymore with the hope that she'll show up tomorrow morning. It's a gamble, but what else are we going to do? We've run out of all other options?" You feel sick inside about what is going to happen.



## Discussion Questions

- What are your thoughts about where the situation has been left off?
- Drawing on the NASW Code of Ethics (Links to an external site), how would you manage your personal feelings and professional obligations in addressing this situation?
- How are self-determination and the dignity of risk apparent in this situation? And at what cost?
- Consider the critical theoretical frameworks and practice model discussed in chapter two. How would you apply an intersectional, critical cultural competency, and anti-oppressive perspective when working with Jessica?
- How would you use reflection and reflexion, discussed in chapter two, to work through your ableist feelings about Jessica so that they do not interfere with your practice?
- How might you have worked with Jessica differently, if at all?
- How might this case differ in a rural setting versus an urban one?
- What would your next actions be when working with Jessica?

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10.

# EMPLOYMENT, HOUSING, POVERTY AND THE DISABILITY COMMUNITY

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## Learning Objectives:

- To explore connection between unemployment, housing and poverty in the disability communities;
- To analyze causes of poverty in the disability communities
- To characterize challenges faced by the disability community in obtaining accessible housing

## Introduction

Much of the literature on the economic issues of disabled people [\[1\]](#) has focused solely on their disability status and lacked attention to mechanisms within the cultural structure of the United States that marginalized their multifaceted lived experiences. This chapter focuses on an intersectionally-informed and anti-oppressive social work perspective on the economic issues of disabled people. We begin by providing an overview of disabled people with various social identities in the arena of employment, housing, and poverty. Then, we discuss the voices of disabled people in disability-related debates in this arena. We provide policy and practice implications for working with disabled people in this arena, and we conclude the chapter with a case study.

# Disability and Social Identity in the Arena of Employment, Housing, and Poverty

A social identity is the lens through which other people view an individual based on their embodied, hidden, or inherited characteristics (Morgaine & Capuos-Desyllas, 2015). Characteristics can include, for example, gender, race, disability status, and sexual orientation. These identities are constructed through interactions with the social environment where social meanings are created and assigned to them. These meanings are tied to culturally-bounded values and create assumptions of inferiority and superiority between people, which are related to privilege and disadvantage. Individuals have multiple identities that intersect granting privilege in some areas and disadvantage in others.

This section focuses on the prevalence, history, service trends, cultural elements, and relevant policies to disabled people, including the intersection of disability and other various social identities in the arena of employment, housing, and poverty. Whether visible or hidden, disability status is a social identity that has been tied to assumptions of inferiority and consequently disadvantage for disabled people for people in this arena.

## Prevalence

Disabled people experience disparities in poverty, employment, and housing. In the year 2018, an estimated 26% (about 5,023,300 out of 19,302,500) of non-institutionalized, disabled people aged 21 to 64 in the United States were living in poverty while, in contrast, an estimated 10% (about 16,587,7000 out of 165,681,000) of non-institutionalized, non-disabled people within the same age group were living in poverty (Erickson et al., 2021). Similarly, in 2018, an estimated 37.8% (about 7,316,900 out of 19,338,800) of non-institutionalized, disabled people ages 21-64 in the United States were employed while 80% (about 133,159,200 out of 166,425,00) of non-institutionalized, non-disabled people in the United States were employed (Erickson et al., 2021). In the same year, Black/African American people with disabilities were employed at a lower percentage (30.5%) compared to Whites (39.2%), Asians (44%), and Hispanic (40%) disabled people (Erickson et al., 2021).

As for housing, it is estimated that only 4% of the nation's housing is considered accessible to disabled people (National Academies of Sciences, Engineering, and Medicine, 2017). For those living in United States Department of Housing and Urban Development (HUD)-assisted units (i.e. affordable housing), only 30 percent of households with disabled members who requested accessibility features in their housing actually received them (Dawkins & Miller, 2015). Kiesel (2018), a disabled writer, has argued that the disparity between the costs of housing, low disability payments, and the experience of labor market discrimination has made housing unaffordable for many disabled people. The disparity in the capacity for home ownership experienced by disabled people prevents the accumulation of a significant asset that has been used to transmit wealth intergenerationally.

## History

### The Connection Between Poverty and Disability

Poverty and disability have been closely linked in the United States. Hughes and Avoke (2010) identified that federal poverty policy has historically exacerbated the experience of disability for United States citizens by failing to address this connection. Disability has been a cause and effect of poverty. Disabled people frequently experience barriers to employment or are underemployed. People with disabilities have been disproportionately relegated to low-skill, low-pay, stagnant jobs that suppress their quality of life, particularly disabled people who are Black, Indigenous peoples, or people of color (Hughes & Avoke, 2010; Toldráa & Santosb, 2013).

For disabled people, poverty has been about more than money. Poverty has represented a cumulative series of barriers to economic independence, and the denial of adequate resources for income, health care, education, and housing has resulted in unnecessary chronic stressors for this population (Hughes & Avoke, 2010). Incomes for disabled people have lagged significantly far behind the nondisabled population. In particular, Social Security's Supplemental Security Income (SSI)[\[2\]](#) and Social Security Disability Insurance (SSDI)[\[3\]](#) programs provide a poverty-level income that has created barriers to work for people with disabilities by reducing health and social benefits for work (Mackelprang, 2013). SSI and many state-level programs require people with disabilities to be in poverty, and have limited assets to qualify, which disincentivizes work. In turn, if disabled people work too much or earn too much, they can lose the benefits that enabled them to work. This then exacerbates the socially stigmatizing narrative that people with disabilities do not want to work, when in fact it is the system that creates this cycle of poverty.

## Employment, Poverty, and Disability

### Stigma, Disability Hierarchy, and Microaggressions in the Hiring Phase

Disabled people have historically experienced stigma during the hiring phase in employment situations (Gewurtz et al., 2016). A stigma has been defined as “a mark of disgrace (either literal or figurative) attached to characteristics or behaviors that are defined as undesirable in a given society” (Robbins et al., 2012, p. 306). Stigma due to appearance in the case of visible disabilities or conduct for individuals with non-visible disabilities has obstructed disabled people from being selected for employment when interviewing for jobs. A scoping literature review on the topic of hiring people with disabilities found that the level of stigma influencing hiring preferences was related to the type of disability (e.g., physical disability, mental health disability, intellectual disability, sensory disability; Gewurtz et al., 2016). Although this finding was somewhat supported in consultations with key informants with disabilities, these informants also had differing opinions



about the nature of stigma in the hiring process. Some informants with physical disabilities indicated they felt the stigma had more to do with the visibility of the disability rather than the type of disability. It should also be noted the review did not analyze disability status within the context of other social identities (e.g. race, gender, sexual orientation).

We contend that the disability hierarchy also influences discrimination during the hiring phase. The disability hierarchy is a complex, context-dependent differential valuation of disabled people that defines who can and should be accommodated and integrated into society based on the intersection of a variety of factors (Schalk, 2020). Based on this definition, applicants who most approximate the ideal of the white, English-speaking, male, cisgender, heterosexual, non-veteran, and non-visibly disabled adult would be the most likely disabled people that receive interviews. People who were also married, thin, symmetrically-featured, and with anglicized names would be prioritized. In contrast, those who less likely approximate these social identities would be more vulnerable to hiring discrimination.

Microaggressions have been a challenge faced by disabled people during the hiring phase. Microaggressions have been defined as “everyday verbal, nonverbal, and environmental slights, snubs, or insults, whether intentional or unintentional, that communicate hostile derogatory, or negative messages to target persons based solely upon their marginalized group membership” (Sue, 2010, p. 3). Similar to stigma, visibility of disability status has been correlated with experiencing ableist microaggressions (Kattari, 2020), and increased microaggressions have been negatively associated with positive mental health outcomes (Kattari, 2020; Lui & Quezada, 2019), although much of this knowledge has not been situated within the context of multiple social identities. During the hiring phase, disabled people may experience microaggressions such as non-relevant “physical requirements” (e.g., must be able to lift 25 lbs.) in job postings, being asked to disclose their disability status in inappropriate situations, observing a lack of people with their disability status in positions of power within the agency, or extensive requests for proof of disability status, which may compound stress experienced as part of the hiring process.

## Barriers to Access in Employment Situations

Access to employment for disabled people has been identified as a complex issue intertwined with the experience of labor discrimination (Mondéjar-Jiménez et al., 2009; Nind & Seale, 2009). The residual social welfare (i.e., piecemeal) policy approach to addressing barriers to mass unemployment or underemployment for disabled people in the United States has failed to recognize the challenges of poverty-level wages (e.g., getting access to health care, adequate housing) and the increased expenses of living with a disability (e.g., home health aides, accessible transportation, mobility devices or equipment, housing with proper accommodations) on the well-being and quality of life of disabled people (Hughes & Avoke, 2010). Employers have been increasingly relying on online job postings and applications. However, people with disabilities have not routinely been included in usability testing for these systems and accessibility problems have been continuing to occur (Lazar et al., 2012; O’Halloran, 2014).

Disabled people who are employed also face barriers to accessing accommodations. Disabled people have reported needing to spend their personal rather than work time to keep up with changes in assistive technology (Okungu et al., 2019). Negative reactions from employers when requesting accommodations have been described by some people with cerebral palsy and spinal cord injuries, especially those accommodations that cost money (Graham et al., 2018). People with multiple sclerosis have disclosed they feared disclosing their disability in the workplace and were overlooked for job promotions or were terminated after disclosing their disability (Reed et al., 2017). In the field of intellectual and development disabilities, staff are also vulnerable to a lack of belief in the employability of people with these disabilities, particularly people with the most significant intellectual and developmental disabilities (Wehman et al., 2018).

Brought about by the COVID-19 pandemic, universal attention to remote work set-ups and improvement to websites and software to facilitate remote work have impacted the experiences of disabled people in hiring and employment. Some individuals with disabilities have reported experiencing less stigma in virtual rather than in-person interviews since the individual has more control over the disclosure of their disability (Schuster, 2021; Smith, 2021). Although remote work arrangements are being increasingly recognized as a reasonable work accommodation (Crosgrove et al., 2015; Strickland, 2021), the COVID-19 pandemic rapidly accelerated the proliferation of technology to support this accommodation. The proliferation of an accommodation that had been inconsistently applied previously has been identified by disabled people as a bittersweet victory (Bohra & Willingham, 2021) and exposes the continuing influence of ableism (Ocean, 2021).

## Housing, Poverty, and Disability

Disability status has been intertwined with housing disparities, which have been compounded by economic deprivation. Access to affordable, accessible housing in proximity to employment is central to equality of opportunity, resources, and well-being, especially for adults of color, who have experienced the life-long effects of segregation (Hughes & Avoke, 2010; Humber, 2014; Sullivan, 2017). Problematic state and federal housing policies have spatially concentrated economically deprived disabled people, especially disabled people from minority groups, particularly people who are unemployed or underemployed and female head of households (Emerson & Brigham, 2014; Martone, 2014; McCarty, 2008). Many public housing programs (e.g., Section 8) have very limited access to accessible housing, which results in longer wait times and fewer options for housing in these programs for many disabled people, most notably people with mobility disabilities. Frischmuth (2014), a disabled person and housing advocate, reported experiencing a housing system that located difficulties with maintaining housing as personal problems without equal attention to social and economic systems as well.

## Service Trends

Before providing information on service trends in the arena of poverty, employment, and housing, it is vital for the reader to understand that service trends that are relevant to people with different disabilities vary greatly. For example, service trends regarding individuals with developmental disabilities will be different from service trends for people with sensory disabilities. It is beyond the scope of this chapter to capture these nuances, and readers are encouraged to supplement what is discussed in this section with individual exploration on the service trends for specific disability groups and populations.

The reader is also encouraged to bear in mind that service trends are intimately linked with national, state, and local policies and programs. A trend in one region may not be a trend in a geographically different location. This knowledge is presented to again encourage readers to supplement the information that is presented within this section with exploration of their local, state, and national program and policy context.

## Poverty

A targeted approach is needed to move disabled people out of poverty. Poverty has been increasingly recognized as not solely a lack of income, but rather as a multidimensional construct composed of barriers and deprivations (Hughes & Avoke, 2010; Lang et al., 2019; Trani et al., 2016). Worldwide, poverty alleviation services are recognizing their services need to be particularized for disabled people in contrast to other people living in poverty (Opoku et al., 2019). These services would provide differential levels of cash assistance to supplement needs related to disability status that also recognize the local economic context. Access to targeted educational and vocational services that acknowledge the geoeconomic educational and employment landscape would also be assistive. Programs that address residential and community physical-environmental access needs for disabled and non-disabled people would also be beneficial. Barriers concerning healthcare and access to quality education and public services need to be addressed to move disabled people out of poverty (Lang et al., 2019; Mactaggart et al., 2018).

## Employment

Models for disability inclusion in employment have been focused on employment mainstreaming and social firms. Social firms take many forms including “social enterprises, affirmative businesses, adapted enterprises, cooperatives, collectives, consumer/survivor-run businesses” (Corbière et al., 2019, p. 39). In many employment models, organizations have explicitly situated disability inclusion as part of their organizational development strategies (e.g., Ndzwayiba & Ned, 2017). These organizations are typically profit-driven. In contrast to these organizations, social firms are explicitly organized to achieve social goals in addition to economic ones (Krupa & Lysaght, 2016).

Social firms can range from a workforce exclusively of disabled people to a workforce where disabled

people are integrated and work alongside non-disabled people. Another emerging model of employment is entrepreneurship where disabled people create their own businesses to meet generative and economic needs (Mandiberg, 2016; Shaheen, 2016).

Employment is intimately intertwined with health care access in the United States (US). US employers have typically offered health insurance as an employee benefit with employment-related health insurance operating as the most prominent gateway to health care access (Gorenstein, 2017; Knipsel, 2020). Health insurance access has facilitated affordable medical care and financial protection from unexpected health care costs (Office of Disease Prevention and Health Promotion, n.d.), however, the pairing of employment and health care access has proliferated the societal idea that health care access is a privilege rather than a right (Gorenstein, 2017; Knipsel, 2020). The Ticket to Work and Work Incentives Improvement Act of 1999 (TTW) was a federal policy that attempted to address disabled people's concerns about the loss of health insurance access due to employment. However, the outcome of the implementation has been limited in addressing this concern (Please see the "Key federal policies" section for further information on TTW). State-level initiatives have also been developed to help with concerns about loss of health insurance access with community employment.

Disabled people experience disparities in employer-sponsored health insurance access and coverage compared to non-disabled people in the United States. In 2019, approximately 46% of people with disabilities had private health insurance coverage compared to approximately 76% of people without disabilities (Rehabilitation Research and Training Center on Disability Statistics and Demographics, 2020). Although employment in higher wage firms can provide access to employer-sponsored health insurance, this access is much less common in low-wage jobs, where persons with disabilities have been disproportionately socially located (Antonisse & Garfield, 2018). For disabled people with employer-sponsored health insurance coverage, historically this coverage has not adequately covered their needs (National Council on Disability, 2009), and, for those in low-wage jobs, health insurance premiums can be unaffordable (World Health Organization, 2020). For those who are only able to work a part-time job, the employer may not offer benefits, including health insurance.

Supported work sites for people with intellectual and developmental disabilities often pay disabled people poorly. The connection between supported work sites and wage disparities reflects an ableist perspective to labor participation (Blonk et al., 2020). In other words, due to harmful attitudes concerning labor participation for people with intellectual and developmental disabilities, they are socially isolated in segregated work settings where subminimal wages can be enacted. Notably, the United States Commission on Civil Rights (2020) has advocated for the abolishment of supported work sites due to their practice of paying subminimum wages in segregated work settings, which has been rife with abuse and in conflict with civil rights laws. A cost study has shown that, compared to supported work site employment, support employment in non-segregated work settings has resulted in significant financial benefits for both the disabled person as well as taxpayers (Cimera, 2011).

## Housing

Despite The U.S. Supreme Court's Olmstead Decision of 1999, which determined institutionalized disabled people who were capable have the right to leave institutional care and live in community-based living spaces (Mackelprang, 2013), disabled people continue to face challenges in finding and maintaining these living spaces. Disabled people have been vulnerable to geographic concentrations of socioeconomic disadvantage when housing solutions failed to consider location and neighborhood context (Aitken et al., 2019; Callaway & Tregloan, 2018). In other words, disabled people experiencing this disadvantage undergo segregation in their communities. Initiatives have focused on housing accessibility without consideration of needs within neighborhoods and communities (e.g., Bhakta & Pickerill, 2016). Individual development accounts, accounts where individual savings are combined with matching funds through housing policy, have some evidence of a positive impact on home ownership for people with disabilities, especially among women of color and single parents who are disabled (Huang et al., 2016).

## Cultural Elements

The social identity of disability intersects with other identities in employment, housing, and poverty. The interaction of racial and ethnic identities, particularly Black identities, with disability status in employment has been examined. Bailey and Mobley (2019) identified that much of the Black experience has been shaped by an understanding of Black bodies as a productive labor force in the United States, which has been intimately intertwined with Black peoples' experience of slavery. The slave economy prioritized the value of Black bodies' utility to a white society. The impact of this white compartmentalization of value raised the stakes for Black people identifying as disabled since identifying as a Black, disabled person acknowledges a compromised relationship with labor and the ability to generate capital. This coupling of Black bodies and labor has made identifying as disabled an unviable option for most Black people (Bailey & Mobley, 2019). Black, disabled, and proud groups have been mobilizing to speak to this concern.[\[4\]](#)

Legal and cultural institutions have been reluctant to acknowledge the compounding and complex forms of employment discrimination experienced by disabled people of color, especially Black people with disabilities (Abrokwa, 2018). Evidence has shown the interaction of racial, gender, and disabled identities sort workers with disadvantaged identities into lower-level and part-time work in the United Kingdom (Woodhams et al., 2015). Disabled British mothers have also identified unsupportive managers as a barrier to maintaining employment (Skinner & MacGill, 2015). For example, mothers identified that managers gave their jobs to someone else when they returned from maternity leave and/or were inflexible about the hours the mothers could work, which made covering childcare difficult.

Miles (2019) identified an intersection between racial, gender, and disability identities with housing for African American women with physical disabilities in the United States. Using surveys and in-depth interviews with 32 women, Miles examined and explored participants' perceptions of barriers and facilitators to home

ownership. The application of a feminist intersectional disability framework to the data revealed participants' relationship to care strongly contributed to their self-concept. The "Strong Black Woman" schema (i.e., caregiving, resilient, independent, sacrificing, enduring, etc.) with its expectations influenced how participants viewed themselves and were viewed by others as receivers, managers, and providers of care. Receiving care was inconsistent with the schema, which resulted in decreased self-concept. Managing and providing care was consistent with the schema, which promoted a positive self-concept. The material reality of owning or not owning a home was not connected with self-concept appraisals.

## Key Federal Policies

Federal policies in the arena of employment, housing, and poverty reflect an evolution from a focus on social protection toward a human rights approach. Table 1, while not inclusive of every federal policy related to employment, housing, and poverty, highlights key policies illustrating this paradigmatic shift within the last century.<sup>[5]</sup> In the left column of the table, the year the policy was passed is presented. The middle column provides the name, and the right column provides a brief description of the policy relevant to the economic needs of disabled people.

Table 1.

*Key Federal Employment, Housing, and Poverty-Related Policies Relevant to Disabled People in the United States*

| Year | Policy   | Description   |
|------|--|---|
| 1917 | Smith-Hughes Act   | Established federal-state vocational rehabilitation programs for disabled veterans  |
| 1918 | Smith-Sears Veterans Rehabilitation (Soldier's Rehabilitation) Act | Expanded federal vocational rehabilitation programs to veterans of World War I  |
| 1920 | Smith-Fess (Civilian Rehabilitation) Act                           | Began vocational rehabilitation for all disabled Americans. Patterned after the Smith-Sears Veterans Rehabilitation Act.  |
| 1935 | Social Security Act  | Made federal vocational rehabilitation programs permanent. Provided an income maintenance system to people who were unable to work. Included provisions for "crippled children".  |
| 1936 | Randolph-Sheppard Act  | Gave states the authority to license qualified persons with blindness to operate vending stands in federal buildings.   |
| 1938 | Wagner-O'Day Act   | Required federal government to purchase designated products from workshops for persons who were blind.  |
| 1943 | Vocational Rehabilitation Amendments (Bardon-LaFollette Act)       | Made substantial changes in the federal/state program of rehabilitation. Broadened the program's financial provisions, and expanded services to include physical restoration, and each state had to submit a written plan for approval by the federal agency as to how federal/state dollars would be used. Expanded services included, on a limited basis, persons who were mentally handicapped and mentally ill. Fostered separate agencies for general rehabilitation and rehabilitation of persons who were blind. |
| 1954 | Vocational Rehabilitation Amendments                               | Reshaped roles of federal and state government in rehabilitation programs. Increased federal funding to states, and increased services to persons with mental retardation or mental illness.  |
| 1965 | Vocational Rehabilitation Act Amendments                           | Expanded services to include persons with socially handicapping conditions, such as alcoholism, lack of education, and prison records. Established a National Commission on Architectural Barriers, deleted economic needs as a general requirement for services.   |
| 1968 | Vocational Rehabilitation Act Amendments                           | Added follow-up services for maintaining a person with a disability in employment.  |
| 1968 | Architectural Barriers Act   | Required federally funded or utilized buildings to be accessible to the "handicapped".  |
| 1973 | Rehabilitation Act   | Provided protections to people with disabilities in federally involved programs including hiring practices, architectural, and transportation barriers and employment as well as extended and revised grants to states for vocational rehabilitation services   |
| 1978 | Rehabilitation Act Amendments                                      | Provided for the establishment of federally funded Centers for Independent Living to be directed by people with disabilities.   |
| 1986 | Rehabilitation Act Amendments                                      | Defined and established supported employment as an acceptable goal for vocational rehabilitation services.  |
| 1988 | Extension of the Fair Housing Act                                  | Although established in 1968, the Fair Housing Act was amended in 1988 to prohibit discrimination in housing based on disability.   |



|      |   |  |
|------|---|--|
| 1990 | Americans with Disabilities Act                         | Civil rights law that mandated equal access and nondiscrimination in employment and hiring practices, public accommodations, telecommunications, and societal services (e.g., insurance) in all areas of society.  |
| 1992 | Rehabilitation Act Amendments                           | Emphasized employment as the primary goal of rehabilitation, and stated that eligible individuals must be provided choice and increased control in determining their vocational rehabilitation goals and services. |
| 1999 | Ticket to Work and Work Incentives Improvement Act      | Created private-sector employment networks to provide vocational services to disabled people.  |
| 2008 | Americans with Disabilities Act Amendments              | Revised definition of “disability” to encompass impairments that substantially limit a major life activity.  |
| 2014 | Centers for Medicare & Medicaid Services, Settings Rule | Ensured Medicaid-funded Home and Community Based Services (HCBS) provide people with disabilities opportunities, to live, work, and receive services in integrated community settings.                             |

*Note.* Sources for this table were Colorado State University (n.d.), Findley (2020), and Mackelprang (2013)

As shown in the table, initial policies focused on disabled veterans, who were considered “worthy” of societal support (Mackelprang, 2013). Subsequent policies expanded how disability was defined and focused, for the most part, on rehabilitative services and supports. With the passage of the Architectural Barriers Act of 1968, Congress took a first step in ensuring physical access in housing and employment venues for disabled people (Findley, 2020). The table also shows a number of amendments to the Rehabilitation Act of 1973 moving from a focus on protections to people with disabilities in employment to employment as the primary goal of services and service participant choice in services. Although the extension of the Fair Housing Act in 1988 prohibited discrimination in housing based on disability, this type of discrimination has continued to be a significant problem throughout the United States (Findley, 2020).

The Americans with Disabilities Act (ADA) of 1990 has been considered the most significant disability civil rights law since it expanded rights to disabled people in all areas of society rather than just governmental entities and organizations receiving government funds (Mackelprang, 2013). The ADA acknowledged the pervasive discrimination and lack of access in employment and public housing that disabled people experienced. Although the ADA expanded civil rights, the policy did not provide entitlements to support its implementation or guarantee benefits. The policy left it to the individual person with the disability to identify their disability and accommodation needs and left no financial support to businesses to make workplace or housing modifications. As well, the fact that “reasonable accommodations” and “undue hardship” were not defined within the act left people with disabilities in a vulnerable space when negotiating accommodations. The ADA has been criticized as hardly reducing discrimination at all and disappointingly ineffective in reducing workplace discrimination (Findley, 2020).

The Olmstead legal case was a precedent-setting interpretation of the ADA. The Supreme Court’s ruling held that Georgia’s unnecessary and undesired institutionalization of two women with developmental

disabilities and mental health conditions was discriminatory (*Olmstead v. L. C.*, 1999). More broadly, state and local governments were required to administer services in the most integrated setting appropriate to the needs and wishes of individuals with disabilities. The Olmstead decision has received scholarly attention in the areas of aging (Bartels, 2011; Bartels et al., 2003; Bartels & Van Citters, 2005; Palley & Rozario, 2007; Yong, 2007; Zendell, 2007). State implementation of the Olmstead decision was a significant challenge as many states were not financially or procedurally prepared to transition disabled people from institutional to community-based care (Bartels & Van Citters, 2005; Jackson et al., 2003).

Although the social work profession has played an important role in the implementation to the Olmstead decision (Yong, 2007; Zendell, 2007), Flynn (2010) identified United States health policy should move from a focus on cost-driven compliance with the Olmstead decision to a rights-based health service system in alignment with the ADA. The Olmstead decision has transformed the Medicaid program, which has been noted to have a bias towards institutional services (Milne, 2012), with a push to expand home and community-based services (HCBS). Olmstead related cases have continued to be litigated since the original decision and used to encourage states to expand community-based services and move people out of institutions (Ng et al., 2014). Cremin (2012) identified that advocates and individuals with disabilities are applying the Olmstead decision's interpretation of the ADA integration mandate to non-residential institutions as well such as sheltered workshops, child protective services, and assisted outpatient treatment.

The Ticket to Work and Work Incentives Improvement Act of 1999 (TTW; *Public Law 106-170*) is a federal policy related to employment for people with disabilities. The intention of the policy was to address the low incidence of disability insurance beneficiaries returning to work (Dean et al., 2003; Thornton & O'Leary, 2007), with a crucial piece of the legislation being the creation of a large, diverse supply of active private-sector rehabilitation service providers, called employment networks (ENs), that would essentially compete with existing state vocational rehabilitation agencies (SVRAs; Dean et al., 2003; Silva, 2007). Although the act was authorized in 1999, the TTW program was not initiated until April 2002 (Dean et al., 2003). Disabled people and disability advocates voiced several concerns about the program. One concern was that people with significant disabilities, which were costlier to support in employment, would be tracked into SVRAs rather than ENs due to the outcome-contingent funding structure of TTW. This funding structure would create two separate but unequal service systems (Blanck et al., 2002). Disabled people feared that participating in the program would result in the loss of existing medical and cash benefits (Hanson et al., 2019; Hernandez et al., 2007). People with disabilities reported feeling overwhelmed with the amount of the informational materials they received on the TTW program (Hanson et al., 2019). TTW implementation was challenged by the recession of 2001-2002 (O'Day & Revell, 2007), and the supply of ENs was low during the initial years of implementation due to the perception by providers that the program was too risky and cumbersome relative to potential payments offered (Silva, 2007; Thornton & O'Leary, 2007). In 2008, the Social Security Administration revised TTW regulations to address implementation barriers. However, although provider and beneficiary participation increased substantially after the revision, the proportion of participants forgoing benefits for work declined (Hyde & Stapleton, 2015).

## Disability-Related Debates from the Perspective of Disabled People in the Arena of Employment, Housing, and Poverty[\[6\]](#)

People with disabilities have identified a concern that the disability benefit systems (e.g., Medicaid, SSI, SSDI) in the United States trap them into poverty. Interviews with disabled people living with HIV and/or type 2 diabetes revealed the people interacted with a complex, inflexible, and bureaucratic disability benefit system that resulted in their destitution (Whittle et al., 2017). “Brian”, a type 2 diabetes participant of the study, disclosed:

The shit that Social Security puts a person through, and you can type that word ‘shit’ in there, is inhumane. The first thing, they deny you. Then you wait two-and-a-half years. The waiting period is, like, ridiculous. You know, and all these hoops you have to jump through. Well, in that period of time that you’re waiting, some of us can’t work. And there it went. So I went from a fantastic with a totally cool income, living in my own home, and I do mean home, having everything, to that...I went to \$80, \$86 a month, actually, in cash [GA], you know, and food stamps of \$127, or something like that. Those food stamps were very handy. But needless to say, I was on the street, and so on and so forth (Whittle et al., 2017, p. 185).

Cyr (2019), one of this chapter’s authors, a disabled woman, public health professional, and advocate, has discussed the dehumanizing process to determine eligibility for Medicaid, which is essential for access to critical medical services for disabled people. She reported her demoralizing experience of the Medicaid eligibility assessment in her blog, after going through the process independently as an adult for the first time. She wrote:

In my life, my illness is not at the forefront. My LIFE is. I power on, day-to-day, working to change the healthcare system for others in similar situations. I network, I spend time with my family, I get coffee with my friends, I watch mindless reality TV, I do things every other 25 year old does. Then at the end of the day before heading to bed, I happen to get hooked up to an IV for 12 hours when I sleep. No big deal. Another day in the life...But when it comes time to prove eligibility it’s ABOUT being sick – not able to be independent or successful. It’s not about proving how hard you have worked to achieve a good level of health and independence. It’s playing a game, to see if you “win” the services you need to ultimately be independent and alive (Cyr, 2019, para. 7 & 8).

Disabled women living with fibromyalgia have also discussed a struggle in having their chronic pain legitimized by disability benefit bureaucrats, especially Black women who encountered the intersection of sexism and racism (Pryma, 2017). In contrast to several of the white women involved in the study who reported their claims were legitimized when backed by extensive medical documentation, “Candace”, a working-class Black woman diagnosed with fibromyalgia reported she was only able to break through to her disability judge about the pain and disability she experienced by sharing her graphic story of sexual assault and trauma. She reported:

So they kept on denying me...Well I went further on my own and filed my own second appeal. And it wasn’t until I got graphic with my life story, I feel, that they awarded me my long term disability...I had written appeals

before. I had kept it very professional. I had...you know...I didn't disclose a lot of personal details of myself or my life or anything of that nature. And then I finally just went...went totally graphic. And once I went totally graphic then they awarded it...Doesn't look like I was raped, doesn't look like I was molested, but yet I was. You know, I don't look like a lot of things, and this illness doesn't look like I'm sick. But I am. And I...I need this (Pryma, 2017, p. 71).

Disabled people have argued they want to work, but they encounter ambivalence to their inclusion in employment settings. Some people have argued their contributions in open employment settings were not socially valued (Rustad & Kassah, 2021). Other disabled people have identified they have encountered barriers to maintaining their employment including narrow and dismissive attitudes from coworkers and supervisors, and experiences of stigma and discrimination in the workplace (Meltzer et al., 2020). “Mindy”, an intellectually disabled, Australian woman in sheltered employment<sup>[7]</sup>, discussed how employers' assumptions about her ability to effectively complete her role negatively affected her search for work in open employment. She said:

I got knocked back a lot because of employers. That was a bit more challenging. Maybe because of people's attitudes...just looking at my disability, thinking that you are not able to do the job. Not listening. That kind of stuff (Meltzer et al., 2020, p. 94).

Disabled people have identified additional challenges. Challenges include inefficient systems to provide accommodations to their needs (Scanlon et al., 2020), and employer's unwillingness to provide accommodations for their disabilities in the work setting (Blajeski, 2020). Black disabled workers with sickle cell disorder have reported they have been pushed out of employment because employers have disregarded the self-care needed to manage the condition (Dyson et al., 2021).

People with disabilities have argued they experience economic segregation in the housing market. In most areas, the amount of money a person receives from SSI, or is allowed to have in order to be eligible for services, is frequently not enough to pay market rent, let alone buy any type of property. Interviews with intellectually disabled people, their family members, and support service workers identified a number of people were not able to choose where they lived and with whom they lived due to disability support packages that failed to include housing costs (Fisher et al., 2021). People with intellectual and developmental disabilities (IDD) and their advocates have reported the coupling of housing and support services needs to be broken, that they are not included in broader discussions of affordable housing, and that a lack of individualized funding support to personalize housing opportunities limits their housing choices (Verseghy et al., 2019). A significant reason this coupling of housing and support services occur is because housing options for people with IDD often include group settings that could be based on level of need and are often paid for by government entities like Medicaid, which, as mentioned previously, has a bias towards institutional care. Living with family members who serve as caregivers is a common alternative if other supports cannot be identified. These forced options can segregate disabled people into rural or more suburban areas that are away from community support and resources like public transit. These barriers are all components that exacerbate the social and economic inequities for disabled people.

Disabled people, their families, and their advocates have identified that people with disabilities are experiencing a housing crisis (The Arc, 2021). In response to this housing crisis, the Arc, a national community-based organization advocating for and with people with IDD, state their overall position on this issue as follows:

People with intellectual and/or developmental disabilities (IDD), like all Americans, have a right to live in their own homes, in the community...Adults should control where and with whom they live, including having opportunities to rent or buy their own homes, and must have the freedom to choose their daily routines and activities (The Arc, 2021, p. 24).

Most housing structures are not designed to be accessible for those who use mobility devices or have physical limitations. Several “loopholes” allow buildings to get by without meeting ADA accessibility requirements. For example, buildings whose construction commenced prior to January 26, 1992 do not have to meet accessibility guidelines (Department of Justice, 2010). Buildings, including housing, designated as historical properties have been granted exceptions to accessibility requirements if the alterations to meet accessibility guidelines are not feasible, or threaten or destroy the historic significance of the building. Minimal modifications can be made that may make the building compliant but may not truly meet the needs of a disabled residents.

The Fair Housing Act requires Federally-assisted new-construction housing developments with 5 or more units to design and construct 5% of the dwelling units, or at least 1 unit, whichever is greater, to be accessible for persons with mobility disabilities. However, the policy does *not* require that those units be rented to or reserved for tenants who have disabilities (United States Department of Housing and Urban Development, n.d.). This makes it even more difficult for disabled people to find and secure truly accessible housing.

The interaction of disability status along with other social identities impact outcomes related to employment, housing, and poverty for disabled people. Class, gender, and racial identities have explained how people with disabilities experience economic discrimination differently in their daily lives (Guerrero-Arias et al., 2020). Concerning employment, research has shown that the intersectional effects of gender, ethnicity, and disability sort disadvantaged men into lower-level and part-time work alongside women who experience gender discrimination (Woodhams et al., 2015). Additionally, veteran status has been shown to negatively impact on requests for accommodations within the workplace (Gonzalez et al., 2020). Military norms aligned closely with masculine gender norms may influence a stoic response to work limitations and independent problem solving of work-related limitations.

## Policy and Practice Implications for Working with Disabled People in this Arena

This section focuses on the application of the theoretical perspectives and the practice model from chapter 2 to the arena of employment, housing, and poverty. Social identity-related practice implications are presented.

### Application of Theoretical Perspectives

#### Critical Cultural Competence

When working with disabled people in the arena of employment, housing, and poverty, social workers need to recognize the personal and positive elements that disability culture brings to the workplace and community. At the same time, social workers need to align with the social model of disability in its critique of ableist employment, housing, and poverty systems. In working with individuals and families in this arena, social workers must attend to the power dynamics inherent in hiring and working phases of employment. Differences in the power between property owners and landlords need to be accounted for and the influence disability benefit bureaucrats wield needs to be kept in mind. Continual self-reflection and critical examination are necessary to recognize one's own values and biases related to who is deserving of employability, access to safe, accessible, visitable housing, and disability benefits. Social workers must avoid essentializing disability experiences, identities, and contexts within the workplace and community.

#### Intersectionality

Social workers should apply a comprehensive appreciation and understanding of a person's and communities' experiences when working with disabled people in the arena of employment, housing, and poverty. A disabled person has personal and social identities. These identities impact their lived experience and economic realities. Individuals with disabilities may or may not identify as disabled or understand the role their disability plays in their identity. A disabled person's social location determines advantages and disadvantages in employment, housing, and experience of poverty. Interlocking systems of oppression, such as ableism, racism, sexism, heterosexism, and ageism, often exclude disabled people from workplaces, housing options, and economic resources. Disabled people are often defined by non-disabled people in employment and housing settings through an ableist lens, which puts their disability in the forefront at the expense of other personal and social identities.

## Anti-Oppressive Practice

Recognition of ableism in discourse and practice are vital in the arena of employment, housing, and poverty. Ableism prevents the full inclusion and the economic participation of disabled people in our society. Recognizing multiple oppressions, including ableism, and working with disabled people to challenge these oppressions allows social workers to practice anti-oppressively within this arena. Social workers need to deconstruct dominant notions of the employability, housing needs, and economic entitlements while centering on individual, community, and societal change. Specific practices in this arena include: critical consciousness raising; deconstruction; viewing disabled persons as experts on their economic needs; empathy; addressing grief and loss in employment and housing as well as other arenas as they intersect and emerge; reframing employment and housing difficulties; advocacy; mediation to address economic barriers; peer support; and community engagement. The contributions disabled people and communities bring to the workplace and community need to be recognized and emphasized to disrupt ableist narratives.

## Application of the Practice Model

### Pre-Engagement

A focus on self-reflection and self-assessment of the employability and housing rights of disabled people is crucial for this step of the model. Social workers recognize and disrupt dominant cultural paradigms about who can work, who deserves safe, accessible, and visitable housing, and who is entitled to disability benefits. Although pre-engagement is an initial step, social workers assume this self-reflection and acknowledgement continue throughout the other steps of the model.

### Engagement

This step begins with the recognition of the limits of the social worker's knowledge on the employability, housing needs, and eligibility for disability benefits. This recognition spurs the social worker to connect with key players and systems to learn about what is needed to access services. The social worker arrests their preconceived notions of disabled people's capacities and meets the disabled person where they are at in terms of their identity as an individual with a disability. Being open to learning from disabled people is critical to this step. The social worker applies inter-identity/inter-cultural engagement techniques in this step.

### Assessment

Social workers need to center the client's narrative when considering employability, housing needs, and disability benefit eligibility. Recognizing that disability and intersecting social identities are socially constructed



and play out in the arena of employment, housing, and disability benefit systems is vital. Social workers should routinely identify circles of support, both formal and informal, when working in the arena of employment and housing.

## Intervention

Interventions must respect the dignity of risk and support self-determination in employment and housing decisions. Engagement of the circle of support is crucial to the provision of social work services in this arena. Securing employment and housing would be considered initial goals and workplace and community inclusion should be fostered. Social workers must remember: “nothing about us without us” in employment and housing services and prioritize the individual’s goals, desires, and interests when considering an intervention.

## Termination

Social work services need to honor the dignity of risk in terminating services in the arenas of employment, housing, and poverty. When at all possible, disabled people should be allowed to decide when they are ready for services to end. Social workers should recognize power dynamics and imbalances between and among the worker, client, and employment, housing, and disability benefit institutions.

## Evaluation

Measures of progress or success in these arenas need to be co-constructed with clients. The client’s narrative of their experience needs to be at the forefront when evaluating employment, housing, and poverty-related services.

# Social Identity-Related Practice Implications

## Race and Ethnicity

For Black people with disabilities, the recognition of the multigenerational sociohistorical experience of slavery is paramount to practice in the arena of employment, housing, and poverty. Social workers need to assess for and address historical and current grief and loss associated with Black people’s continuing economic discrimination. Practitioners need to assess for the Black client’s comfort with identifying as disabled given their experience of racial discrimination in this arena and work with these clients to engage circles of support that can assist them in locating their identity within the disability community. The narratives of legal and cultural institutions that have been reluctant to acknowledge the compounding and complex forms of

employment discrimination experienced by Black disabled people need to be deconstructed. This deconstruction needs to extend to corporate discourses that disproportionately relegate Black disabled people to low-skill, low-pay, stagnant jobs. Social workers need to promote the social value to employers of hiring Black people with disabilities. Finally, for Black people with sickle cell anemia (or sickle cell disease), employers need to be pushed to respect the self-care needed to manage the condition. In the arena of housing, practitioners need to be sensitized to the Strong Black Woman schema and work to engage circles of support that can assist women socialized to this schema to allow them to receive support in addition to giving care to others. Finally, the chronic pain experienced by Black women with fibromyalgia needs to be consistently legitimized by disability benefit bureaucrats.

The social identities of Indigenous people and people of color are critical in social work practice in the arena of employment, housing, and poverty. Social workers need to advocate that disabled Indigenous people and people of color be given equitable access to high-skill, high-pay, dynamic jobs that enhance their quality of life. The consciousness of employers to the impact of the disability hierarchy on hiring for Indigenous people and people of color with disabilities needs to be raised. Legal and cultural institutions that engage in employment discrimination need to be held accountable. Housing that is affordable and accessible needs to be provided in proximity to employment rather than spatially segregated by race. For clients who have a goal of home ownership, individual development account access is needed.

## Gender

The awareness of patriarchy is integral in addressing the needs of disabled people within the arena of employment, housing, and poverty. Social workers need to raise the consciousness of employers and clients to the influence of gender within the disability hierarchy in the hiring and working phases of employment. The elimination of the influence of this hierarchy is needed. Practitioners need to mediate between employers and disabled women and non-binary people who are primary caregivers to support these people with maintaining their employment. Advocacy for primary caregivers to keep their jobs when they return from family leave as well as flexibility in their working hours to accommodate child care needs are also imperative. Social workers need to recognize family medical leave policies are a benefit used by disabled people with chronic conditions who may need extended leave, not just in the instance of child birth. Although cisgender women experience sexism in the workplace that results in their disproportionate allocation to lower-level and part-time work, social workers must also be vigilant to this disparity in cisgender and transgender men with disabilities, transgender women, and those with non-binary gender identities. Client and class advocacy are vital to addressing problematic state and federal housing policies that spatially concentrate disabled individuals who have fewer financial resources, particularly cisgender women who are heads of the household. When working with cisgender and transgender women and non-binary disabled people who are in the process of applying for disability benefits, social workers need to be sensitized to how their chronic pain has been rejected

within the disability benefit system and work with these people's circles of support to advocate for their voices to be heard by bureaucrats.

## Sexual Orientation

Disrupting heterosexism within the arena of employment, housing, and poverty is an important aspect of anti-oppressive social work practice with disabled people. Social workers need to raise the awareness of employers to the social value of lesbian, gay, and bisexual people (LGB) as employees. LGB disabled people may be vulnerable to closeting their sexual identities, particularly in institutionally-based housing settings, due to fears of structural and physical violence.

## Case Study

**Scenario:** *You are social worker in a supported housing program serving people with co-occurring disabilities. The program provides rental assistance and case management services to clients. Here are the details of the case:*

Judy was recently admitted to the supported housing program, and you were assigned as her social worker. Judy was referred by her clinical social worker at the outpatient clinic after she was terminated from her part-time job as a clerk at the local grocery store due to excessive absenteeism. Judy was diagnosed approximately 10 years ago with fibromyalgia and recently had a “flare up” where her the pain got so bad she was not able to go to work. Judy receives services from the outpatient clinic for Post-traumatic Stress Disorder (PTSD) and depression. Between taking medication for her mental health conditions and attending weekly therapy with her clinical social worker, Judy's mental health has been stable for the last couple of years. The clinical social worker made the referral because Judy discussed that she would like to work again as she feels better and wanted to keep her current apartment.

You meet with Judy for an initial session to explain the services provided by the supported housing program and to learn about Judy's goals. Judy answers the door and navigates to her living room as she walks using a cane. She makes a wincing face as sits in a recliner and motions for you to take a seat on the couch. Judy is in her early 40s and white. She identifies her preferred pronouns as “she” and “her.”

After explaining the supported housing program to Judy, you ask what goals she would like to discuss. She states she would like her old job back and that she misses her work friends. She lets you know that she wants to stay in her current apartment. This is her “home.” Exploring the idea of the job a bit further with her, you ask her about her aspirations in the arena of employment. She says, “stay right there,” gets up, and walks slowly with her cane into a different room. You notice she stumbles at points when making the turn out of the room into a hallway. You think to yourself, “If only there was a handrail in that hallway, she probably would get around much easier.” Judy returns a couple of minutes later with a dark brown cupcake with mocha-colored frosting on a small plate. She encourages you to take a bite, you do, and taste a sweet, chocolate/coffee/mocha

confectionary masterpiece. As you remark about the fabulous flavor, Judy says, “I always dreamed of opening a small business where I could sell my cupcakes.”

Over the next couple of meetings with Judy, you learn more about her history. She had a relationship with a significantly older man, Rusty, in her late teens and had two daughters, Jessica and Jenna. Initially, her relationship with Rusty was happy, and they got along well. However, over time, he became increasingly jealous, possessive, and physically violent. She was able to leave the relationship and put a restraining order in place against Rusty. For her, leaving the relationship was about protecting her girls. Her girls are now adults, and since that time, Judy has primarily had relationships with women and a couple of men. She currently has a girlfriend, Sofia, who she spends time with frequently. Judy reports she receives Medicaid and SSDI due to her mental health conditions and her fibromyalgia, but she says she needed to “fight like a dog” to get the SSDI with the assistance of a lawyer since “no one believed me about the fibro.” “I even had to fight with my doctors for them to see I was in a ton of pain.”

Since Judy says her PTSD and depression are in a good place, you ask her more about her experience of living with fibromyalgia. She says, “I experience the ‘fibro fog’ almost all the time. The challenging thing is the pain, it’s all over my body, and I have good and bad days. I’m tired a lot, but I can’t get good sleep when I have a flare up. I have trouble getting things done and the migraines can be over the top! When the flare ups get bad, I can only stand or walk for an hour or two before I need to sit, but even when I sit, I can’t be down for a long time due to the pain and stiffness. I have difficulty reaching things. Look around this apartment, I can’t reach the top cabinets in the kitchen or the boxes of food on the bottom cabinets. I also use my cane since I can tumble if I am not careful. Getting around can be a real hassle.”

## As the social worker, how would you respond to the following questions?

1. What might be a dominant cultural paradigm concerning who should work or who deserves safe, accessible, and visitable housing that you might self-reflect on and be prepared disrupt?
2. What are some limits of your knowledge on the employability and housing needs of people with PTSD, depression, and/or fibromyalgia?
3. Who might be members of Judy’s circle of support?
4. How could you engage Judy’s circle of support to assist her with achieving her employment and housing goals?
5. What power dynamics and imbalances might occur among you, Judy, and the employment and housing institutions surrounding her? How would you address them?
6. What might be some measures of progress that could be co-constructed with Judy in alignment with her goals?

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[1] The language of “disabled people” and “people with disabilities” are both utilized within this chapter to reflect that identity-first and person-first language has been utilized in social work practice with the disability community.

[2] SSI provides cash to meet basic needs for food, clothing, and shelter. To be eligible for SSI, a person needs to be age 65 or older, blind, or disabled, and have limited income and resources. To learn more about SSI, please read the following overview: <https://www.ssa.gov/ssi/text-over-ussi.htm>

[3] SSDI provides cash benefits to people who have a substantial work history and have a medical condition that prevents them from working for at least 12 months or is expected to end in death. Since SSDI requires a

significant work history, many people are unable to qualify, especially people born with disabilities. For more information on SSID, please see the following overview: <https://www.benefits.gov/benefit/4382>

[4] Some examples of these initiatives include the National Black Disability Coalition (<https://blackdisability.org/nbdc.info/>), the HCBU Disability Consortium and AHEAD (<https://www.blackdisabledandproud.org/>), and the National Black Deaf Advocates (<https://www.nbda.org/content/college-youth>)

[5] Although key federal policies are reviewed in this section, the reader should also note the importance of state policies and programs, which are beyond the scope of this section to review. Federal policies provide a basic skeleton for policy to support employment, housing, and poverty, but the bulk of supports are facilitated via state-level policies and programs. Therefore, readers are encouraged to explore policies in this arena in their own locale for more specific information.

[6] In alignment with the practice model of this textbook, this section centers on the voices of disabled people in these debates rather than the voices of policy and service providers. Policy makers and service providers also have pertinent debates (e.g., how to move from segregated to integrated employment, how to plan for employment beginning in the transition years, how to best support real choice in living arrangements). Readers are encouraged to explore beyond this chapter to identify policy maker and service provider debates in employment, housing, and poverty.

[7] The term “sheltered employment” is used here in alignment with the source of the information, which is a study from Australia. The reader should note that the terminology used in the United States for this type of employment is different. This type of employment is commonly referred to as a “sheltered workshop” setting.

## 11.

# DISABILITY AND THE CRIMINAL LEGAL SYSTEM

Sandra Leotti and Elspeth Slayter

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## Learning Objectives:

- To describe the disproportionate involvement of disabled people in criminal legal systems
- To analyze the ways in which ableism and sanism impact the experiences of disabled people involved in criminal legal systems
- To categorize approaches to anti-oppressive practice in the context of criminal legal systems

## Introduction

This chapter explores the connections between disability and criminal legal systems. Throughout this chapter we use the terms “criminal legal system” and “carceral system” rather than “criminal justice system” to describe policing, prosecution, courts, and corrections in the United States. This is more than just an issue of semantics or political correctness. Language is inherently political, and it shapes how people think. The phrase “criminal justice” reifies taken for granted assumptions that justice can be found through punishment and confinement. Furthermore, as activists and scholars have shown, contemporary carceral systems are a product of racialized and ableist historical processes and do not deliver justice but rather perpetuate injustice for the most marginalized among us. Also, throughout this chapter, we use the terms disability and disabilities to refer to people with all types of physical, sensory, cognitive, emotional, or psychiatric disabilities, including people with mental health conditions. While at times we shift between person-first and identity-first language, we primarily



utilize identity-first language to refer to disabled people as a group or class., practices of imprisonment, and law enforcement in the United States.

In this system, social workers are often referred to as “forensic” or legal social workers. The [National Organization of Forensic Social Workers \(NOFSW\)](#) describes this field as having an application of social work to questions and concerns relating to the law and legal systems (criminal and civil) (NOFSW, n.d.). In this field, where possible, forensic social workers practice to empower disabled individuals within socio-legal environments and try to change socio-legal environments for the better. This work can range from enhancing disabled clients’ functioning and problem-solving to brokering resources for them. At the mezzo and macro levels, respectively, this can look like working to develop or improve service systems for disabled clients or developing policies that promote [disability justice](#). Within this sphere, forensic social workers commonly function as clinicians, consultants, case managers, advocates, trainers, and brokers, among other roles (Maschi & Leibowitz, 2018). This chapter primarily focuses on practice with disabled clients in criminal legal settings.

Social workers in practice with disabled clients may be involved in preventative and advocacy efforts, such as jail diversion, to keep clients out of correctional facilities or to ensure their protection and rights if they are in these facilities. Social workers may also participate in policing, which is a controversial area of practice. Additionally, in the context of criminal courts, social workers may practice in prosecutor’s offices as victim witness advocates or forensic interviewers or in specialty problem-solving courts. Defense attorneys may also partner with social workers under attorney-client privilege as part of the legal representation of defendants. Within delinquency placements or correctional settings, social workers may work as case managers, clinicians, or in other staff roles. Re-entry programs may also hire social workers in these roles. Given the overrepresentation of disabled people among those who are involved in criminal legal systems (as we will outline below), social workers in these settings need to develop a critical awareness of disability culture.

## General Context

In the United States today, there are over 2.3 million adults behind bars in **jails** and **prisons**, and just under 2,000 young people are locked in facilities for youth (Sawyer & Wagner, 2020). Mass incarceration has increased in the U.S. to such a degree that we are known globally for holding more people in correctional facilities than any other country in the world. However, when we think of mass incarceration, we would be remiss if we did not include the more than 4.5 million people who are under some form of community supervision. Community supervision includes parole, probation, and pretrial supervision (Jones, 2018). Understanding mass incarceration beyond prisons and jails and including community supervision is important because it gives us a more complete picture of punishment in the United States and shows the expansive reach of the criminal legal system.

It is relatively well known that certain populations, such as poor people and people of color, are disproportionately impacted by mass incarceration. For example, Native women are disproportionately



overrepresented in jails and prisons. In 2010, they constituted 2.5% of women in prisons and jails yet were just 0.7% of the total U.S. female population (Wang, 2021). Rarely discussed is the impact of the criminal legal system on disabled people. However, Americans with disabilities disproportionately fill the space in jails and prisons and are overrepresented at all points of interaction with the criminal legal system, in both youth and adult settings (Oberholtzer, 2017). Disability, situated alongside other intersecting lines of stratification such as race, class, and gender, is central to understanding the complexities of mass incarceration today.

Historically, disabled bodies have been policed in various ways, resulting in a disproportionate number of people with disabilities being confined in carceral spaces, be it institutions or prisons (Appleman, 2018; Chapman, 2014). While many large state institutions for people with psychiatric or intellectual disabilities closed in the 1980s and onward as a result of deinstitutionalization, they reopened in many states as prisons and detention centers (Ben-Moshe, 2011). Notably, this occurred alongside a broader and rapid increase in incarceration. Next, we will discuss the social and political mechanisms that spawned the mass incarceration of disabled people.

## Historical Overview

The 1970s marked a period of systematic mass imprisonment and heavy reliance on formal social controls targeted primarily at marginalized populations (Sokoloff, 2005). Mass incarceration can be largely attributed to three intersecting phenomena that emerged in the latter half of the twentieth century (Leotti, 2020). The first is the war on drugs, which began in the 1970s and brought about punitive social policies and sentencing enhancements, such as “three strikes, you’re out” laws and mandatory minimums. Sentencing enhancements have been adopted on both the federal and state level and inflict harsh penalties for both drugs and public order offenses. Public order offenses are violations deemed to interfere with public life. Prostitution, public drunkenness, loitering, and sleeping on the street are examples of public order offenses, which are commonly associated with drugs (Zhang et al., 2009). Mandatory minimums have replaced treatment and community service options when drugs are involved and reflect a policy choice to treat substance use and addiction as a criminal issue rather than a public health problem (Mauer & King, 2007). Such sentence enhancements have increased the number of people in prison, as well as the amount of time they spend there (Muehlmann, 2018). The second issue is the growth of the prison industrial complex, which, simply stated, is a complex web of relations between carceral institutions, policymakers, and for-profit prison corporations that results in financial gain through the incarceration of marginalized populations. The third of these phenomena is neoliberal globalization, which has brought about a fundamental shift in the role of the state. Neoliberal transformations in the economy have contributed to poverty in the United States and have brought an increasing number of poor and marginalized people into contact with the criminal legal system (Wacquant, 2009).

Resting on the central tenets of individualism, choice and responsibility, market-driven economics, and minimal government, neoliberal ideology has driven shifts in policy agendas from a Keynesian approach, which

saw government as necessary to ensure the basic social well-being of all, to one of deregulation and privatization (Abramovitz & Zelnick, 2018). Neoliberal ideology thus erodes government commitment to social welfare in favor of policies that focus on individual responsibility and market-based rationalities, and it brings with it a hyper focus on the individual as both the cause of and solution to social problems (Brown, 2015). Consequently, neoliberal policies have produced an increased reliance on disciplinary measures to manage manifestations of social exclusion, such as poverty and homelessness (Wacquant, 2009). Mass incarceration has thus occurred concurrently with decreased spending in the areas of social services, education, and health care.

There is a direct relationship between these three phenomena—sentence enhancements, growth of the prison industrial complex, and neoliberal globalization—and the increased criminalization/incarceration of disabled people. The past six decades have seen widespread closure of state mental hospitals and other institutional facilities that serve people with disabilities—a shift often referred to as deinstitutionalization. While deinstitutionalization should be seen as a positive development, it was not accompanied by the public investment necessary to ensure that community supports were made available for people with disabilities to live independently in the community. As a result, many disabled people, particularly those with mental health conditions, have been swept up into the criminal legal system, often for non-violent and minor infractions such as sleeping outside (i.e., homelessness) and atypical reactions to social cues which become interpreted as disorderly conduct. We use the term criminalized rather than “criminal” or “offender” to indicate that “crime” is a social, political, and historical construct defined by policy and the prevailing sociopolitical and economic climate rather than by faults and deficiencies located within individuals. In other words, crime is not a natural or stagnant category, but rather one that changes across time and across cultures. For instance, cannabis continues to be criminalized in some states (and on the federal level), while in other states, it is perfectly legal. Behaviors sometimes related to disability, such as substance use, can be a method of self-medication for disability-related conditions.

The historical processes of ableism, capitalism, and racism have pushed disabled people to the economic margins of society. Historically, people with physical and psychological behaviors and appearances that do not conform to dominant norms have been segregated and isolated and have been more vulnerable to shifting mechanisms of surveillance and control (ableism). Disabled people have thus been shunted out of the labor market and into institutions (capitalism). The current day iteration of exclusion manifests itself in the mass incarceration of the same people once shut away in institutions for psychiatric and developmental disabilities. Furthermore, the people in these institutions do not represent all segments of society – the majority are poor and people of color (racism). This historical (and ongoing) exclusion from the labor market (using processes of segregation and institutionalization) alongside the onset of neoliberalism has had a profound impact on the material well-being of disabled people. Currently, more than half of disabled people live in long-term poverty (Purnell, 2021). Poverty is known to create a number of disabling conditions and to be linked to behaviors that are commonly criminalized, such as petty theft or sleeping on the street (Chapman, et al., 2014). Coupled with an increasing divestment from public services (e.g. health care, housing services, employment protections, and other social welfare entitlements), disabled people have been disproportionately

swept up in the criminal legal system. Such a material historical analysis helps us counteract the often taken-for-granted assumptions about criminality (those that deviate from ableist understandings of how body-minds are “supposed” to look and behave) that have been attached to disabled people for centuries. Furthermore, it helps us see that criminalization is a product of social and economic processes rather than that of individual deviance and pathology.

## Prevalence of the Disability Community in the Criminal Legal System

As discussed previously, disabled people are disproportionately impacted by and involved in the criminal legal system (Oberholtzer, 2017). While disabled people make up 26% of the population in the United States, they represent up to half of people killed by police, over 50% of incarcerated adults, and up to 85% of incarcerated youth (Purnell, 2021). We also know that people with intellectual disabilities are at a higher risk of wrongful convictions and death sentences in part due to a higher likelihood of false confessions or less capacity to participate adequately in their defense (American Civil Liberties Union, 2022). This problem persists despite the 2002 Supreme Court ruling that the execution of this population violated the Eighth Amendment to the Constitution, which relates to cruel and unusual punishment.

People with disabilities come into contact with the criminal legal system as suspects, defendants, incarcerated persons, victims, and/or witnesses. Compared to people without disabilities, people with disabilities are more likely to experience victimization, be arrested, be charged with a crime, and serve longer prison sentences once convicted. These trends are even more profound for disabled people with intersecting marginalized identities, such as people of color, women, poor people, and those who identify as LGBTQ (Vallas, 2016).

According to the Bureau of Justice Statistics, people incarcerated in prisons and jails are three to four times more likely than the general population to report having at least one disability, with an estimated 30-40% of incarcerated individuals reporting at least one disability and about 15% reporting multiple disabilities (Bronson et al. 2015). Disability types included hearing, vision, cognitive, psychiatric, and mobility disabilities. Among the most commonly reported disabilities among inmates are cognitive disabilities (e.g., Down syndrome, autism, dementia, intellectual disabilities, and learning disabilities). In fact, incarcerated individuals are four to six times more likely to report a cognitive disability than the general population. Mobility disabilities are reported among 10% of incarcerated people, and between 5 – 10% are vision and hearing disabilities. Mental health conditions are also highly prevalent among the incarcerated population, with about 50% of inmates reporting a psychiatric disability (Schlanger, 2017). In addition, 40% of inmates report having a chronic medical condition such as diabetes, cancer, heart disease, etc. (Schlanger, 2017), and over 50% of incarcerated disabled people report having a co-occurring chronic condition (Bronson et al., 2015).

In addition to being overrepresented in **carceral** facilities, disabled people are more likely to experience

violence at the hands of criminal legal officials, including prison guards and police officers (Guy, 2016; Vallas, 2016). Indeed, many high-profile instances of police brutality and police killings, such as those of Freddie Gray, Eric Garner, and Sandra Bland, involve people with disabilities. It is estimated that one-third to one-half of all people killed by police are disabled (Perry & Carter-Long 2016). Police use of force against people with disabilities is a widespread yet under-discussed issue. Perry and Carter-Long (2016) found that the media often ignore disability identity when reporting on police violence. Understanding disability as a factor shaping interactions with police is important because it intersects with other factors, such as race, class, and sexuality, to amplify stigma, discrimination, and the risk of police violence. Including an analysis of disability provides more holistic accounts of the lives of victims of police brutality, a more nuanced understanding of the problem, and allows new solutions to emerge.

To illustrate the importance of considering intersectionality when analyzing disability and the criminal legal system, Vallas (2016) states:

The interplay of disability with race, poverty, sexual orientation, and gender identity further complicates the link between disability and the criminal justice system. There is a disproportionate incidence of intellectual and developmental disabilities among low-income racial and ethnic minority populations, which have higher rates of police involvement in their neighborhoods than in higher-income neighborhoods. In 2015, black men between the ages of 15 and 34 were nine times more likely than Americans of other races to be killed by police officers. And a 2014 report found that 73 percent of LGBT people and people living with HIV had had in-person contact with the police in the past five years. Of those individuals, 40 percent reported verbal, physical, or sexual assault or hostility from officers. (p. 6)

## Criminal Legal System Trends, Cultural Concerns, and Relevant Policies

The unique needs and challenges of disabled people are often overlooked or neglected when they come into contact with the criminal legal system. Once entangled in this system, disabled people face unique challenges, including biases, inaccessible services, and lack of accommodations, which further perpetuate the length and consequences of criminal legal involvement. Despite long-standing federal disability laws, such as the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act that mandate “equal access to programs, services, and activities” (Department of Justice, 2010, p. 110) for people with disabilities while in custody, people with disabilities are often deprived of medical care, as well as necessary supports, services, and accommodations while interfacing with law enforcement, the courts, and while incarcerated (Oberholtzer, 2017; Vallas, 2016).

Legal and law enforcement professionals often lack experience and accurate knowledge about disability, which can lead to misidentification of disability, inaccurate assumptions about competency and credibility, and a heightened risk of violence (Oberholtzer, 2017). Lack of knowledge regarding disability among these professionals may also lead to false confessions, lack of necessary accommodations, inappropriate placement

in institutions, and inadvertent waiving of rights. Furthermore, poor conditions in jails and prisons, as well as inadequate access to health care and mental health treatment, can exacerbate existing conditions and lead to new physical and mental health problems (Chandler, 2003). For example, limited access to regular physical activity, a common condition of confinement, has been shown to be detrimental to overall health and to intensify existing physical disabilities (Morgan, 2017).

## Policing and Law Enforcement

Symptoms of psychiatric, intellectual, physical, or sensory disabilities are often mistaken for non-compliant or hostile behaviors by law enforcement professionals who are not trained in recognizing the signs of disability or intervening in disability-related crisis situations. For example, in 2009, the police were called on Antonio Love, a d/Deaf man. According to Carol Padden and Tom Humphries, in *Deaf in America: Voices from a Culture* (1988): “We use the lowercase deaf when referring to the audiological condition of not hearing, and the uppercase Deaf when referring to a particular group of deaf people who share a language – American Sign Language (ASL) – and a culture. The members of this group have inherited their sign language, use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society. We distinguish them from, for example, those who find themselves losing their hearing because of illness, trauma, or age; although these people share the condition of not hearing, they do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people. For example, in 2009 the police were called on Antonio Love, a d/Deaf<sup>[1]</sup> individual, for loitering in the bathroom at a Dollar General store (Perry & Carter-Long, 2014). After knocking on the bathroom door, ordering Love to come out, and getting no response, the officers pepper sprayed under the door, forcibly opened the door, then repeatedly tasered Love. While the officers viewed Love’s non-response as non-compliance, the reality was that Love could not hear the officers.

<sup>[1]</sup> According to Carol Padden and Tom Humphries, in *Deaf in America: Voices from a Culture* (1988):

We use the lowercase deaf when referring to the audiological condition of not hearing, and the uppercase Deaf when referring to a particular group of deaf people who share a language – American Sign Language (ASL) – and a culture. The members of this group have inherited their sign language, use it as a primary means of communication among themselves, and hold a set of beliefs about themselves and their connection to the larger society. We distinguish them from, for example, those who find themselves losing their hearing because of illness, trauma or age; although these people share the condition of not hearing, they do not have access to the knowledge, beliefs, and practices that make up the culture of Deaf people.

d/Deaf people cannot be expected to respond to commands of police, for example, when delivered out of sight. Their inability to do so heightens their risk of violence when interacting with the police. Many d/Deaf people also use their eyes, hands, and body to communicate. Police officers often misunderstand these components of d/Deaf culture as threatening and aggressive – once again intensifying the risk of violence (Lewis, 2014). The

ADA mandates that law enforcement officers take appropriate steps to communicate effectively with d/Deaf people by providing sign language interpreters and/or auxiliary aids. Yet there is a disquieting number of law enforcement assaults against d/Deaf people that occur on a regular basis (Lewis, 2014). There is an urgent need for police officers to better understand Deaf culture and how to communicate with members of the d/Deaf community.

People with intellectual and developmental disabilities, such as autism and Down syndrome, are more likely to encounter the police and often have trouble understanding, responding to, and obeying police orders (Hurst, 2015). This may be misinterpreted as defiance and often results in unnecessary use of force and arrest. For example, in 2012, deputies in California assaulted and wrongfully arrested Antonio Martinez, a Latino man with Down syndrome who they suspected might be involved in a domestic violence (DV) dispute (Stapleton, 2012). Martinez had no involvement in the DV incident and was simply walking between his home and his family's bakery while wearing a hoodie. When he did not respond to the police commands, the police pepper sprayed him and beat him with a baton before arresting him. The sheriff's department defended their actions as a way "to gain compliance and prevent a possible escape" (Stapleton, 2012, para. 8). In 2011, another man with Down syndrome, Gilberto Powell, was walking home one evening when he was stopped by Miami police because they saw a "bulge" in his pants and assumed it might be a firearm (Perry & Carter-Long, 2016). The bulge was a colostomy bag. While attempting a pat down, Powell attempted to flee and was beaten on the grounds of resistance and non-compliance. Similarly, individuals exhibiting symptoms of certain conditions such as epilepsy, cerebral palsy, and diabetes are often mistaken as threatening or drunk and subjected to inappropriate and hostile police encounters (Perry & Carter-Long, 2014).

By far, the most common types of interaction between law enforcement and disabled people involve psychiatric disabilities (Vallas, 2016). Due to a lack of appropriate community resource systems for calling for help (other than 911), the police are often the first responders to a person experiencing a mental health crisis. It is estimated that up to half of officer shootings involved someone in a mental health crisis (Perry & Carter-Long, 2016). In many of these cases, 911 was explicitly called to help a person get medical treatment, not for the police. Despite their frequent involvement in mental health crises, police responses are inadequate and harmful (Oberholtzer, 2017). Certainly, police need better training to recognize and handle mental health crises. One common training used in over 2,700 US communities is the Crisis Intervention Team (CIT) model (Hurst, 2015). CIT is a 40-hour training that teaches officers how to deal with and de-escalate mental health crises when they encounter them (Hurst, 2015; Singal, 2014). The training also includes a component preparing officers for situations in which people do not respond to commands, which may be common among neurodivergent people or intellectually disabled people. While such interventions are a timely and necessary step in the right direction, given the militarization of the police and racial and ableist biases among officers, CIT trainings are unlikely to create a police force that is adequately equipped to deal with mental health crises and the needs of individuals with intellectual and developmental disabilities. In fact, there are documented cases in which officers trained in mental health procedures continued on to kill disabled people (Purnell, 2021).



Therefore, we argue that police involvement in mental health crises should be reconsidered entirely. Time and again, we see instances in which police escalate situations to the point of deadly force, resulting in disabled people, particularly disabled people of color, disproportionately and pointlessly, losing their lives. It is estimated that anywhere between 20 – 50% of people killed by police have a disability (Morgan, 2022). Social workers, mental health response teams, and other trained professionals are more appropriate than a militarized police force in handling mental health crises. Indeed, research shows that accessible and comprehensive social services and mental health treatment systems could divert disabled people from criminal legal involvement and prevent the criminalization of people with mental health disabilities (Vallas, 2016). Such services should include not only crisis services but clinical treatment; medications; substance use treatment; community support services, such as intensive case management; safe and affordable housing; and vocational support. However, these services are only as effective as their availability and, unfortunately, few communities in the United States have the funding for this level of comprehensive services. Spending on the criminal legal system continues to outweigh spending on many other critical services and programs, including education, mental health and substance use services, housing, and infrastructure (Lazere, 2021).

## Court Systems

After interaction with law enforcement, disabled people experience enormous barriers in the court system. At every stage, from arraignment to sentencing, disabled people face a lack of accessibility and are often not provided with necessary accommodations resulting in inadequate representation and misunderstandings regarding the consequences of sentencing or plea agreements. As discussed in this book's policy chapter, The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of disability and mandates that people with disabilities be provided with equal opportunity to participate in all aspects of life. Title II of the ADA applies to public and governmental entities and the programs and services they provide, including court services and court proceedings (Department of Justice, 2010). The law requires that reasonable accommodations are provided when needed. For example, courts must provide "effective communication," for example, in the form of qualified sign language interpreters to all persons participating in court processes, including witnesses, litigants, jurors, and companions, and support people of persons participating in the legal process (Department of Justice, 2010).

Still, lack of access and accommodation is widespread in the American court system (National Center for Access to Justice, 2020). According to the 2020 Disability Access Index, half of the states do not provide information regarding requesting accommodations on their state judiciary websites (National Center for Access to Justice, 2020). Only about 30 percent of states provide funding and conduct training for judges and court staff on how to assist people with various disabilities, and just five states require any type of ongoing training for judges and court staff on the legal requirements for providing equal access to disabled people. Eleven states do not require that service animals be permitted in courthouses at all times and without advance notice. In 16 states, courts can charge disabled people for necessary auxiliary aids (for example, large print



documents, braille printing, closed captioning on television monitors in public areas, mobility devices, etc.). Also, courts in a handful of states are still permitted to charge those who are d/Deaf or hard of hearing for their own sign language interpreter, in violation of the ADA (National Center for Access to Justice, 2016, 2020). While not captured in the 2020 access report, as of 2016, less than 30 percent of courts listed psychiatric disability on their websites as a basis for providing needed accommodations (National Center for Access to Justice, 2016). Given the prevalence of mental health conditions among those who come into contact with the legal system, this is especially troubling.

When defendants with disabilities are deprived of necessary accommodations and communication access, they are left unable to understand or participate in their own cases and are more susceptible to wrongful arrests and convictions. For example, in Arlington, VA, Abraham Zemedagegehu, a d/Deaf immigrant man whose first language was Ethiopian Sign Language, was held in county jail and was not provided access to an interpreter during his time awaiting trial or while he was in court. Lack of appropriate representation led him to serve six weeks of jail time for a crime he did not commit (Zapotosky, 2015). Lack of training and knowledge for how to work with disabled people and how to provide accommodations often results in inadequate representation, denying individuals their constitutional right to a speedy trial, legal representation, and being informed of the accusations against them. Importantly, the failure to provide accessibility in the court system impacts not only disabled people who are charged with crimes but also those who are victims of crimes, those who are litigants, those who serve on juries, and those who work in courtrooms.

## Therapeutic Jurisprudence

There are significant obstacles and serious ethical concerns for social workers when considering work in criminal legal settings. Courts are run by legal professionals, while other carceral facilities and programs are run by security staff according to rules never designed for or intended to ‘help.’ Therefore, social workers planning for a career in criminal legal settings, be it with youth or adults, need to be aware of the therapeutic jurisprudence framework used in specialty courts and the movements that have been connected to it domestically and internationally in court-based systems.

A primary aim of this framework is to better meet the needs of people involved with criminal legal systems – especially people who are repeatedly caught up in those systems (Arstein-Kerslake & Black, 2020). This is a philosophy and practice that considers both the therapeutic and anti-therapeutic properties of laws. Therapeutic jurisprudence also considers public policies (such as sentencing guidelines), legal institutions, and legal and dispute resolution systems. Overall, the goal of therapeutic jurisprudence is a healthy outcome – emotionally and physically – for the criminalized person in all interactions related to the legal case, and in the case itself. In order to obtain this healthy outcome, the court needs to provide healthy options that do “not conflict with other normative values of the legal system” (Rottman & Casey, 1999, p. 12). It is important to note that the therapeutic jurisprudence framework is different from the restorative justice concept, which is often used outside of the court context, such as in schools. We think about restorative justice as a process that

strengthens relationships, fosters a sense of belonging among program participants, and provides a system of collective accountability – all of which helps to repair the harm that has been caused by individual or group behaviors.

In the course of the therapeutic jurisprudence process in specialty courts, the role of an interdisciplinary team of judges, court personnel, lawyers, and, often, forensic social workers, are all seen as therapeutic agents while interacting with the criminalized individuals. The major argument for taking this approach is that taking care of a person's needs in addition to the needs of the legal case results in more effective case dispositions. As we have discussed above, many of those who are involved in the criminal legal system are disabled (Baldry, 2014). When we look at courts following therapeutic jurisprudence frameworks, such as mental health courts, an even higher percentage of people are disabled as these systems are established specifically for addressing the needs of those with disabilities (Spaulding et al., 2000). Therefore, disability often plays an outsized role in systems that embrace therapeutic jurisprudence, whether it is explicitly recognized or not (Arstein-Kerslake & Black, 2020). The therapeutic jurisprudence concept has been recommended as laudable as an approach to empower criminalized individuals with intellectual and developmental disabilities through the creation of a specialty treatment court in the Canadian context (Marinos & Whittingham, 2018). However, others have raised concerns about the ways in which therapeutic jurisprudence may prioritize the decisions and processes of professionals as well as simultaneously undermining the self-determination of disabled people involved in the criminal legal system (Arstein-Kerslake & Black, 2020). Additionally, the therapeutic jurisprudence model is not applied to all people being processed by the courts; it is only applied to those who have been selected for access to specialty services – often excluding people involved in more violent crimes. More consideration is needed regarding how this framework is to be applied to different members of the disability community.

For social workers interested in advocating for administrative and legislative changes on behalf of disability justice principles, Rottman and Casey (1999) discuss the ways in which this framework is applied at that level:

Therapeutic jurisprudence may also be practiced at the organizational level of the court by devising new procedures, information systems, and sentencing options by establishing links to social service providers to promote therapeutic outcomes. For some areas of law and court policy, the practice of therapeutic jurisprudence principles requires changes to state statutes or to court rules, policies, or procedures that apply across courts. (p. 12)

## Jails and prisons

As with every part of the criminal legal system in the US, prisons and jails are ill-equipped to meet the diverse needs of people with disabilities and often perpetuate horrendous discrimination and abuse. At the point of entry into jails and prisons, it is well-documented that there is either a lack or under-use of disability screening (Murphy, Gardner & Freeman, 2017). This results in the under-identification of this population as well as their basic health and disability-related needs. Living in a carceral facility entails activities of daily living (ADLs) that are particularly challenging for people with physical or developmental disabilities—so much

so that disabilities that can be easily navigated in a community setting can become serious barriers to health and safety while in prison. For example, in addition to regular ADLs such as bathing and dressing, prison life often involves additional ADLs such as dropping to the floor for alarms, enduring excessive background noise, jumping up and down from an upper bunk, and being able to hear and promptly follow orders (Blanck, 2017). States have a responsibility under the ADA to offer accessible programs and services and to provide reasonable accommodations and effective communication for people with disabilities. Yet, aside from litigation, there appear to be few mechanisms of accountability for ensuring ADA mandates will be followed in America's jails and prisons.

Jails are locally operated, short-term holding facilities for individuals awaiting trial or sentencing or for those serving sentences of one year or less. Jails currently incarcerate large numbers of people who have not yet been convicted of a crime (Sawyer & Wagner, 2020). Individuals who cannot afford bail make up the vast majority of those detained in jails as a form of pretrial incarceration. Many disabled people who are detained in local jails are not awaiting trial; they are awaiting a transfer to a hospital or other health facility, most often a mental health facility, which may currently be overcapacity (Vallas, 2016). In this way, jails are being used as substitutes for mental health facilities (Rembis, 2014). However, unlike mental health facilities, jails do not have the resources or staff training to adequately address the needs of individuals experiencing psychiatric disabilities or mental health crises (Human Rights Watch, 2015).

Additionally, despite federal disability protections, jails often deprive disabled people of access to necessary medical care as well as needed supports and accommodations, which can worsen existing health and mental health problems (Pope et al., 2007). Take, for example, the case of Abreham Zemedagegehu, the d/Deaf Ethiopian immigrant discussed above. During his six weeks of jail time, he regularly missed meals because he could not hear the announcements for mealtimes. Because he was unable to communicate with the staff, he was essentially denied access to the medication he needed for chronic pain (Zapotosky, 2015). Obviously, the system of pretrial incarceration and using jails as holding cells for people in need of mental health care are negatively impacting disabled people, for whom targeted resources and services are more appropriate. A more robust health and mental health care system, as well as the eradication of pretrial detention and the cash bail system, would decrease the unnecessary and unjust detainment of poor people with disabilities.

Unlike jails, prisons are state or federally-run institutions that typically incarcerate individuals with felony convictions or those serving sentences longer than one year. As in jails, disabled prisoners are entitled to reasonable accommodations and equal access to programs, services, and activities under the ADA and Section 504 of the Rehabilitation Act. However, there are documented widespread and persistent failures to ensure accessibility and to provide needed accommodations in carceral facilities across the United States (Guy, 2016). Medical care and accommodations for disabled people in prisons are either inconsistent, sub-par or routinely denied (Blanck, 2017).

The Eighth Amendment, which prohibits cruel and unusual punishment, requires that mentally ill prisoners, including prisoners who become mentally ill while in prison, receive access to proper diagnoses and treatment. Nevertheless, widespread neglect of the mental health needs of incarcerated individuals appears

to be the norm (Morgan, 2017; Steinberg, et al., 2015; Seevers, 2016). From a paucity of qualified mental health professionals to withholding or discontinuing medications, to the inhumane use and overuse of solitary confinement, the human rights of people with psychiatric disabilities are inordinately violated while existing in a prison (Seevers, 2016). And for those who do not enter with pre-existing conditions, because of the violent and traumatizing nature of prison life, many people develop mental health diagnoses while incarcerated (Singal, 2014). The use of solitary confinement provides a profound case in point.

Despite the documented psychological harms of segregation and solitary confinement, especially on young people and disabled people, it continues to be a prevalent practice in many jails and prisons, including facilities for youth (Guy, 2016). People who spend long stretches in solitary often experience depression, anxiety, and psychosis (Berman, 2016). Many disabled people are held in solitary confinement as a substitute for appropriate accommodations (Vallas, 2016). There have been countless reports of abuse and neglect of disabled people while in segregation and solitary confinement, including prolonged isolation, deplorable conditions, inadequate care, increased self-harm and suicide attempts, and death (Guy, 2016). The case of Kalief Browder serves as a tragic example of the harms of solitary confinement.

Sixteen-year-old Browder spent three years on Rikers Island awaiting trial for an alleged robbery, only to have his case dismissed. During his time at Rikers, he spent almost two years in solitary confinement and suffered abuse from the officers and other prisoners. While in solitary, he made several suicide attempts which were disregarded as attempts to manipulate the officers (Berman, 2016). When he was released, he suffered from symptoms of Post-Traumatic Stress Disorder (PTSD) and, within two years, committed suicide (Bonnerman, 2015). Kalief's family explains his suicide as a byproduct of the torment he experienced on Rikers from which he could not escape after he left (Berman, 2016). Advocates argue that the imposition of restrictive conditions on inmates with disabilities and those with a mental illness violates the Eighth Amendment prohibition of cruel and unusual punishment, the Americans with Disabilities Act, and Section 504 of the Rehabilitation Act of 1973. As social justice minded social workers, we must participate in the fight for eliminating the use of segregation in our nation's jails and prisons.

Doing time is difficult and traumatizing for everyone. Jails and prisons are violent, chaotic, and overcrowded facilities. One can imagine how difficult it is to maintain emotional and physical well-being in the context of exploitation, lack of control and privacy, a paucity of meaningful activities, and limitations on contact with family and friends. The difficulties of maintaining one's health and safety while incarcerated are particularly difficult for disabled people. They have unique needs for special programs, facilities, and extensive and varied health services that often go unacknowledged or unmet. When formal accommodations are absent, incarcerated people with disabilities must often resort to obtaining informal accommodations such as paying other prisoners for help with ADLs (e.g., pushing a wheelchair or signing for a d/Deaf person) (Blanck, 2017).

Research shows that prisoners with disabilities are at an increased risk for safety threats and inadequate services while incarcerated (Blanck, 2017). For example, prisoners with disabilities have higher rates of injuries compared to prisoners without disabilities. In addition, incarcerated people with disabilities are more vulnerable to exploitation and victimization by other incarcerated individuals and prison staff. Furthermore,

the widespread lack of reasonable accommodations means that disabled people are less able to engage in programs and activities that are offered to other prisoners. Poor and often inhumane conditions in jails and prisons, combined with inadequate access to reasonable accommodations and health care, often exacerbate existing conditions and lead to further physical and mental health problems that did not exist prior to incarceration (Chandler, 2003). As such, incarceration itself can be understood as creating disabling conditions (Chapman et al., 2014); it is “both detrimental for people with disabilities and responsible for creating new experiences of disabilities” (Ware et al., 2014, p. 164).

Blanck (2017, p. 320) outlines seven best practices for prisons that may help ensure appropriate accommodations for incarcerated people with disabilities. These include:

- 1) ADA self-evaluation plans: develop and adopt a system-wide ADA self-evaluation plan.
- 2) Disability identification and monitoring: identify and track inmates with disabilities, their accommodations, and ADA grievances, and evaluate accommodation requests with consideration of the inmate’s preferred accommodation.
- 3) Accommodation implementation: implement an ‘Inmate Helper and/or Aid’ certification training program to assist in the provision of accommodations for inmates with disabilities.
- 4) ADA training: provide staff training on ADA disabilities.
- 5) ADA coordinators: designate facility ADA coordinators with accountability for monitoring and sustaining ADA-related outcomes.
- 6) ADA notice: disseminate information in accessible formats to inmates about their ADA rights and responsibilities.
- 7) ADA accountability: state prison leaders foster staff accountability with respect to the rights of inmates with disabilities under the ADA.

Practices such as those listed above are crucial, given the disabling effects of incarceration. They are also practices that social workers can be active in implementing, facilitating, and monitoring.

## Reentry

Most disabled people who are incarcerated are eventually released, and their experiences of reentering society have uniquely challenging dimensions, especially when they are denied access to vocational and release planning while incarcerated. The challenges disabled people face in reentry can be formidable as the culture of punishment and exclusion continues post-incarceration.

Incarcerated people, in general, face significant barriers upon re-entering society, including stigma, lack of resources, and a plethora of “collateral consequences” while reintegrating into their communities— “laws and regulations that serve to diminish the rights and privileges of those convicted of crimes” (Travis, 2002, p. 16). For example, formerly incarcerated people are legally discriminated against in employment and housing and are denied access to public benefits, such as student loans and social welfare assistance (Brown & Patterson, 2016). In most states, they are refused the right to vote (Miller & Stuart, 2017). Further, research shows that

being imprisoned for one year reduces a person's life span by two years (Wildra, 2017) and reduces annual wages by 40% (Pew Charitable Trusts, 2010). In effect, collateral consequences serve to restrict the mobility of 'offenders,' limit options for survival, and reinforce their 'criminal' status. When these barriers are compounded by disability, people with disabilities face almost insurmountable obstacles while attempting to re-enter their communities after being incarcerated.

Some correctional programs and services, such as vocational and pre-release planning programs, have been shown to facilitate a smoother and more successful reentry experience for individuals upon release from jail or prison. However, similar to their widespread lack of access to health and mental health treatment, disabled people are often denied access to such programs while incarcerated or are placed in programs without accommodations (Seevers, 2016). For example, many incarcerated people with psychiatric disabilities are often released with no plan for reintegration, including no prescriptions for medications and no referrals for mental health services or housing support (Rembis, 2014). The difficulties formerly incarcerated disabled people face are compounded by a lack of pre-release assistance in applying for necessary social supports such as Medicaid and SSDI, which can take months to become eligible for on the outside. Additionally, the absence of reasonable accommodations for prisoners with disabilities in educational, vocational, work-release, and reentry programs, is associated with increased levels of recidivism (Blanck, 2017). In this way, ableism in prisons perpetuates discrimination and lack of access for the disabled when released and creates the conditions for re-incarceration.

## Voices/Perspectives of Disabled People in the Criminal Legal System

Given the disempowering nature of involvement in the criminal legal system and the virtual silencing and invisibility of disabled people in carceral spaces, it is crucial that we amplify the voices of disabled people. This section provides a variety of links to videos that focus on the voices and experiences of criminalized disabled people. We encourage you to peruse their stories in order to humanize the data presented throughout this chapter.

### Voices of Disabled Prisoners

This section includes three short video clips of disabled prisoners. Each person shares their experience of incarceration and the consequent disability specific challenges. Most members of the general public will never enter a prison or jail and will have no firsthand knowledge of how disabled inmates fare inside them.

In the first clip (02:24) we hear from Brenda Charity who is an older adult with a mobility disability. Brenda discusses the experience of having needed accommodations taken away while in prison.

<https://www.youtube.com/>

[watch?v=3gRSKZ5Xr3w&list=PLLSb3deWSkYzNa3NrRAIMFpNkEAfipY3W&index=13](https://www.youtube.com/watch?v=3gRSKZ5Xr3w&list=PLLSb3deWSkYzNa3NrRAIMFpNkEAfipY3W&index=13)



In this second clip (03:04), Tyrone Gathings shares some of the challenges with having a vision disability while in prison, and his struggles with getting accommodations in order to participate in services and programming.

<https://www.youtube.com/watch?v=mixJAS2bJxs&list=PLLSb3deWSkYzNa3NrRAIMFpNkEAfipY3W&index=14>

In the final clip, we hear from Ricardo Rodriguez who has a psychiatric disability. Ricardo discusses his experience of being punished, rather than treated, for self-harm and suicide attempts while in jail.

Ricardo Rodriguez (4:41): [https://www.youtube.com/watch?v=a0Q\\_4y6YCSQ&list=PLLSb3deWSkYzNa3NrRAIMFpNkEAfipY3W&index=18](https://www.youtube.com/watch?v=a0Q_4y6YCSQ&list=PLLSb3deWSkYzNa3NrRAIMFpNkEAfipY3W&index=18)

Voices from Segregation:

This next section includes four short clips which include the voices of disabled people who have experienced segregation and solitary confinement while incarcerated. They all discuss the torture of solitary and the enduring impact of being locked alone in a small space for a long period of time.

Eldorado Brown (02:56): <https://www.youtube.com/watch?v=swKsb-ichxA&feature=youtu.be>

Daniel Perez (02:54): <https://youtu.be/zmzSjbKu6UI>

Justin Rueb (03:56): <https://youtu.be/6e-DKlt-90Q>

Five Mualimm-ak (03:36): <https://youtu.be/DJZQAd5dkOs>

## Voices of Inmates with Mental Health Disabilities

In this section, we look at the experience of navigating a psychiatric disability while incarcerated. This eight-minute clip from the Amplifying Voices of Inmates with (AVID) Jail Project presents images and stories that bring attention to the crisis of mental health in the criminal legal system. We hear from both advocates and inmates with mental illness.

<https://www.youtube.com/watch?v=Hjfu2VR62tY&list=PLLSb3deWSkYzNa3NrRAIMFpNkEAfipY3W&index=21>

## Voices on Release and Reentry

This short documentary (34:22), “On The Outs: Reentry for Inmates with Disabilities”, is produced by the AVID Prison Project. On The Outs follows three inmates with various disabilities, including vision impairment, brain injury, and a mental illness, through all stages of the reentry process. The documentary depicts each person’s experience at three points: in prison prior to release, on their release date, and life on the “outs” after release. The film is intended to raise awareness of people with disabilities in prison, inspire communication about much-needed reentry reform, and encourage collaborative relationships among inmates, prison systems, advocates, and other interested stakeholders to address this issue.

<https://www.youtube.com/watch?v=7WukbvDKTdk>



## Application of Theoretical Perspectives and Practice Model

In the introductory chapter of this textbook, you learned about the core principles of empowerment-oriented social work practice with the disability community: community inclusion, self-determination, dignity of risk, circles of support, and “nothing about us without us.” We argue that these principles are important when practicing with people involved in criminal legal systems, albeit in ways you might not immediately think about. In fact, these guiding principles are even more crucial for social workers to embrace in practice in these settings, given the disempowering nature of the criminal legal system.

When we talk about community inclusion, we are talking about the idea that disabled people are valuable members of their communities who have a right to live and work in the community inasmuch as that is possible. We know that the disability community has traditionally experienced more institutionalization and that this has been even more of an issue for disabled people of color. When we think about community inclusion in the context of social work with disabled people involved in the criminal legal system, our first instinct might be to focus on pre-trial or sentencing work that addresses either keeping people in the community or getting people back into the community. This could be accomplished through alternatives to incarceration placements, for example, or through simple bail arrangements. Alternatives to traditional courts, such as mental health courts, could also be a more helpful and inclusive way of dealing with disabled people’s criminalized behaviors. Compared to traditional courts, mental health courts have been shown to increase quality of life, decrease psychological distress and reduce recidivism among criminalized individuals with psychiatric disabilities (Steinberg et al., 2015). We might also think about fostering community inclusion at the parole stage, when people have the opportunity to apply to return to the community before the end of their sentence. Within jail and prison settings, we might also think about whether disabled people are placed in general units or segregated units, or in solitary confinement units, as this relates to community inclusion as well.

Self-determination is another core principle for empowerment-oriented disability social work practice that, at first blush, may not feel relevant in a carceral setting. This principle is thought of as the process of making something happen in one’s own life. We want people to be self-determined in the sense of having an opportunity to make their own choices, set their own goals, solve their own problems, and make a range of decisions for themselves. At the pre-trial stage, legal teams of which social workers are a part can offer disabled clients self-determination in the form of making decisions about the path a case will take. If a social worker is engaged in practice with someone living in a correctional facility, opportunities for self-determination may be very tiny, but looking for those tiny opportunities may be very important for maintaining the humanity of the client in the midst of an oppressive system.

Disability advocates and scholars have written about the importance of the “dignity of risk” for the disability community. The term was coined in the early 1970s and posits that much can be learned through experiencing

everyday, or greater, risks (Perske, 1972). Indeed, for disabled people involved in acts viewed as delinquent or involved in activity that is criminalized, such as substance use, this is often the case. For example, one of the authors' forensic social work practices involved regularly co-representing clients with disabilities in cases involving public drinking from a bottle in a brown liquor store bag – with judges giving out harsher sentences for this population than for non-disabled people. At the core of honoring the dignity of risk is the respect for a person's right to make their own choices – be they small, medium, or large. Allowing someone to live with the consequences of their choices is vital to this process, even if a social work professional feels that they could endanger the client regardless of the presence of support on the side. Social workers in practice with disabled clients in the legal system need to be mindful of the opportunities for the dignity of risk just as they would be in any other setting – perhaps with greater attention to discussing the risk that an offender would experience within the carceral system given their choices.

Connected to practicing the dignity of risk is the idea of circles of support. Circles of support are the groups of supportive people that surround a disabled client. In practice, circles of support are a mixture of formal staff, family members, friends, or neighbors. For people living in the carceral system, this may involve people who live in the jail or prison with them, as well as people on the outside with whom they have telephone contact or family visits. Telephone contact is often difficult due to exploitative practices related to the cost of prison-based telephone calls, therefore limiting access to circles of support.

The final principle to consider in social work with disabled people involved in the criminal legal system is “nothing about us without us.” This phrase originally emerged as part of the disability civil rights movement. It gets across the idea that no decision about a disabled person should be made without the input of the disabled person. In the pre-trial phase, the structure of the legal representation system allows for this, although the sentencing decision-making process does not. While most decisions about an inmate's life behind bars will not allow for input along the lines of “nothing about us without us,” social workers should look for the small opportunities where they do have the opportunity to empower their clients in this way.

While this narrative has focused on applying these principles in direct, clinical, and case management-oriented practice in the criminal legal system, these principles also have applications in the policy realm. Social workers who are crafting legal legislation or other policies can “check” their writing against these principles to make sure they are doing what they can to empower the disability community.

Also discussed earlier in this textbook, in the theoretical practice model chapter, is the practice model for intersectional, anti-oppressive, and critically culturally competent work with disabled clients. Using the intersectional lens to understand your client's experience of the criminal legal system will be important. So, too, will be the use of the critical cultural competence lens in examining your positionality in relationship to your client. Although your practice in the context of a (very likely) highly oppressive organizational culture will prove challenging vis-a-vis the practice of anti-oppressive practice, you should look for small opportunities in which power sharing, for example, can be accomplished.

Your practice for disabled clients may not all be targeted at the clients themselves. Sometimes you may have opportunities to engage in systems change at the mezzo level. You may be able to help your agency conduct

accessibility audits to look at how people with visual, hearing, physical, cognitive, sensory, and other disabilities are able to access services and facilities. You can challenge the ways in which disabled people's behaviors, which may not align with dominant social norms, get interpreted as threatening or dangerous. You may also be able to consider how the system unconsciously uses ableist language. Sometimes change is made in small ways, over time, with lots of patience.

Social workers can also serve as powerful advocates for protecting the rights of disabled people in the criminal legal system. For example, social workers may consider working as part of the protection and advocacy (P&A) system. The P&A system was enacted by Congress in the 1970s to protect and advocate for the rights of disabled people (Guy, 2016; Seevers, 2016). P&A's have the authority to monitor settings where disabled people live, even the most segregated settings such as prisons. As more disabled people have become incarcerated, P&As have taken an active role in monitoring and advocating in prisons (Seevers, 2016). P&A work in prisons typically ranges from providing information and assistance to incarcerated individuals to monitoring conditions on the inside, to large-scale litigation. In prisons, where very few outsiders are ever given access, P&As serve a crucial role in making public the conditions of confinement and helping improve the lives of prisoners. A brief overview of the history and work of P&As can be found in this short video: [https://www.youtube.com/watch?time\\_continue=139&v=m3vYxSe3s4M&feature=emb\\_logo](https://www.youtube.com/watch?time_continue=139&v=m3vYxSe3s4M&feature=emb_logo)

While some people believe that social workers can help mitigate the harmful impacts of the criminal legal system, many argue social work's alignment with carceral systems is not an effective approach for social-justice-oriented practice. Such critics argue that carceral social work distorts "social work practice and values, while particularly harming BIPOC and communities; poor people; immigrants; queer, transgender and gender non-conforming people; youth and the elderly; and people with disabilities" (Jacobs, et al., 2021, p. 52). As such, another practice model to consider that aligns more closely with NASW's commitment to social justice is that of anti-carceral social work (also known as abolitionist social work), which "seeks to divest from the carceral arm of the state... and elevate community voices, community practices, and community problem solving" (Jacobs, et al., 2021, pp. 53-54). The logic of anti-carceral/abolitionist social work rests in a framework of non-reformist reforms (Hereth & Bouris, 2020; Kaba & Duda, 2017). In contrast to reformist reforms, which "serve to resolve the crisis of the carceral state through carceral accommodation" (Kim, 2020, p. 319), and thus support the status quo, non-reformist reforms work to "imagine a different horizon and are not limited by a discussion of what is possible at present" (Ben-Moshe, 2020, p. 16). For example, fighting for the safety of disabled people in prisons is supported by abolitionists and considered a necessary non-reformist reform (Davis, 2003). In contrast, other seemingly progressive initiatives, such as the uptake of community-based electronic monitoring, are considered reformist in that they strengthen and expand, rather than displace, the reach of carceral systems (Ben-Moshe, 2020).

Engaging with anti-carceral/abolitionist social work does not imply that social workers cannot or should not provide individual-level supports and treatment, but there are ethical issues we must grapple with regarding how we can provide effective support when we are bound by the rules of a highly oppressive system rooted in individualizing and pathologizing discourses (Leotti, 2021). Therefore, we encourage you to claim a space

for radical imagination in your practice – a space in which you imagine possibilities for life-affirming practices that encourage accountability, repair harm, and promote healing outside of carceral systems. Models such as transformative justice and restorative justice are generally considered to fall under the rubric of anti-carceral social work.

Now, let us turn our attention to a case study where we can apply these theories and principles to a real-world situation from one of the authors' case practice experiences.

## Case Study with Discussion Questions

You are a forensic (legal) social worker partnering with public defense attorneys in adult criminal court. You are practicing during a “law and order” era, where the city’s mayor has ordered zero tolerance for criminal activity, even petty misdemeanors. However, the mayor’s crackdown on crime is unevenly administered in low-income neighborhoods such as the ones in which your court is based. This means that the court is constantly overloaded with cases, resulting in the intake/arraignments court needing to function on a 24-hour, 7-days-a-week basis. You are seeing people brought in for minor crimes that used to be handled through the issuance of a ticket or citation. You are also seeing people charged with crimes who really should not be charged with crimes – this is one such case. It is important to know that the sociopolitical context in which each court resides can impact how cases are chosen for prosecution and that this can differ from jurisdiction to jurisdiction. This case is exemplary of the approach taken by prosecutors in many jurisdictions during the 1990s phase of the War on Drugs and the rise of the prison industrial complex. Unfortunately, the racism, sexism, and ableism present in this case remain in our system and in the types of situations forensic social workers can see in practice today.

Your job today is to interview newly arrested people to learn about what is going on for them in order to help attorneys identify social service needs that may support people’s legal cases. You are tasked with meeting a new client who is charged with manslaughter for the accidental death of her two children in a fire. You always start your shift by walking into the smelly, cramped holding cell in the back of the arraignment court. There is an open toilet and a row of hard, metal benches that people sit and lie down on, depending on how many people are crammed into the space. You notice someone’s hair extensions on the floor from the fight that happened yesterday – nobody has been in to clean the space in 24 hours. Several people are lying in the corner, going through heroin withdrawal. You have learned not to get upset about this because you can’t do anything about it at this moment. People are sleeping and talking but are generally clearly not happy to be there. Despite that, you get a sense of camaraderie, with people advising each other on their charges. There are several pools of vomit on the floor that you are careful to avoid as you walk toward the interview area.

You call out your new client’s name, “Rina Q.” but get no response. You call out again, and again get no response. Consulting a corrections officer, you learn that your client “can’t hear that well” and “has the purple and pink shirt on, the one in the solitary cell because she’s causing problems.” Further, the court officer lets you know her opinion saying, “But you don’t want to spend too much time with that one – you know how

those illegals are, and she let her babies die after all.” Ignoring the comment and the ire rising up in you about it, you immediately see your client weeping uncontrollably, rocking her curled-up body back and forth, sitting in the cramped cell of the arraignments court in the South Bronx. As you walk up to the sole solitary cell in the arraignments holding area, you see that Rina’s purple and pink shirt has a Wiccan symbol on it and has fresh burn marks on it. Assuming your client identifies as a woman based on the case file (but remembering that you need to check that), you wonder why she isn’t wearing a coat in the middle of the winter – Did the police not give them a chance to find a coat before they arrested her? “Wouldn’t be the first time I’ve seen that,” you think to yourself. As you approach your client and call her name, you notice that she doesn’t seem to respond at all.

You are always hesitant to touch a client, but after several verbal attempts to connect, you place your hand gently on her shoulder. Looking up, you see that your client’s face is tear-stained and covered in black smoke. She has dark brown skin and looks to you to be of indigenous Latin American origin. “You want me?” Rina says in hard-to-understand English. You invite Rina to join you at the interview table across the way, noticing that Rina’s voice has an unusual sound and accent to it that you can’t quite place. As you sit down, Rina says something you can’t understand and begins gesturing with her hands. You quickly realize that Rina is indicating that she can speak, but she is either hard of hearing or d/Deaf and uses sign language. You instantly think, “How did she care for two young children if she was d/Deaf?” but move on from the thought. You switch to using pencil and paper for writing. You write a brief introduction about who you are on your case file notepad and pass it across the desk. Rina’s head shakes “No.” Taking the pen, Rina writes “Español mejor” or “Spanish better.” You use the little bit of Spanish you have to explain your role and explain that you will order an interpreter and will be back. Rina nods with wide, sad eyes and grimaces as the smell wafts over from someone throwing up again in the corner.

After ordering both an American Sign Language interpreter and a Spanish language interpreter, (because you are not sure which you really need and you don’t have a lot of time to think about it), you sit down to check in with your attorney partner. You are told by the attorney that the police report indicates that Rina has said she left her infant and toddler alone to go upstairs to borrow a cup of rice. Privately, you question her judgment about leaving young children alone and wonder again about her capacity to parent as a d/Deaf person. You think, “Would she have been able to attend parenting preparation courses that would have warned against doing such a thing because of her impairment?” You learn that there was a fast-moving fire that engulfed her apartment before she could get back to the children. Although the police report indicates that a number of neighbors witnessed Rina trying to run through the flames to get to her children, she was still arrested on the spot and apparently given no grief counseling. Or, at least, that is what the file says; the attorney hasn’t been able to interview Rina himself due to a lack of an interpreter. As the arraignment is required to happen within 24 hours, the judge is going to call the case soon, so your team needs to figure out what to do as soon as possible even though you have not been able to talk with the client.

At this point, a court officer taps you on the shoulder and lets you know that Rina’s mother is in the courtroom and would like to speak to you. From the mother, you learn that Rina is very hard of hearing, not completely d/Deaf, and uses something called Argentinian Sign Language, which you have never heard

of before. She is a legal Argentinian immigrant who is 24 years old. Rina left school in Argentina at age 16 to pursue employment in the U.S. in order to help the family by sending money back to Argentina. She recently moved into an illegal basement apartment. The apartment was one of four in the basement of an 8-unit apartment building, but the walls were very thin due to shoddy construction. For example, the mother described seeing electrical wires hanging here and there all through the basement. She said, “You can see why a fire would be so likely in a space like that.” You learn that Rina moved into the apartment because it was an affordable place for her and her two children to live on her meager housecleaner’s salary. She had just left an abusive relationship with a much older man, a father figure who allegedly “practiced witchcraft.” Apparently, Rina had to get an order of protection against this man, but he had also filed an order of protection against her. The partner had wanted Rina to engage in sex work to make additional money on top of her housecleaning work, and this had led to conflict. You think about how d/Deaf people may be more likely to become victimized, further encouraging your thoughts about the appropriateness of d/Deaf people as parents. You also learn from the mother that Rina had experienced physical abuse at the hands of her partner. This led to a hospitalization, and due to challenges with communicating with hospital staff about how to get in touch with her mother, the children had been placed in foster care for a short period of time. You find yourself thinking, “Maybe the children would have been better off in foster care rather than with this d/Deaf parent, or with their grandmother.”

Clearly, you think, Rina has been through some significant trauma and is in need of care as soon as possible. Rina’s mother concludes her take on Rina by saying that Rina is a generally “good girl,” but that she just needs to come back to the “Christian family ways.” Further, she explains this is the only way she will take her daughter in if released by the court and “Wouldn’t you please send her that message?” Demurring on that request, you learn that Rina’s mother does not speak Argentinian Sign Language very well, and mostly communicates with her daughter on paper, which apparently causes a lot of conflict in their relationship.

Before you finish your interview with Rina’s mother, a minor miracle occurs. The American Sign Language interpreter shows up at the same time as the Spanish language interpreter. This never happens in the resource-poor and understaffed criminal court. You consider yourself lucky. You and the attorney hustle back into the holding cell to talk to Rina for the first time. But within moments, it is clear that there is a problem. You feel dismayed at your thinking about how to handle this because the American Sign Language Interpreter can’t understand Rina’s Argentinian Sign Language and quickly disappears. You revert to using the Spanish language interpreter who helps you to pass notes to Rina back and forth across the table, which takes up precious time, and leads to great frustration on Rina’s part. You try to put yourself in your client’s shoes, expressing your thoughts, feelings, and experiences on a piece of paper, slowly, with an interpreter, after just losing your children in a fire, for which you are charged criminally.

You confirm the details of the story about borrowing the rice and trying to get back to the children through the flames. It is clear that Rina’s remorse runs deep and that the pain of losing her children in this horrible way will torture her for the rest of her life. The attorney explains the charges and how the case will proceed if Rina wishes to plead not guilty. Rina asks when she can get out of jail, and the attorney explains that this is unlikely



because of the seriousness of the charges, which is upsetting to her. He tries to explain what her choices are at this juncture in the case, but there are not many. Communicating via pen and paper clearly does not help the situation and causes her more frustration, leading her to throw the pen across the room as she cries out, “Doesn’t anyone know I just lost my babies?” Rina ends the interview by walking away and sitting back in the solitary cell, where she starts crying and rocking anew. At this moment, the judge calls the case.

- 1) What might anti-oppressive practice techniques look like as part of the interviewing process in the arraignments interview with Rina?
- 2) How would the therapeutic jurisprudence principle assist Rina in this case? What would the implementation of therapeutic jurisprudence look like in an ideal scenario for Rina?
- 3) How would you handle the comment from the court officer about “illegals?” Would you confront the court officer in some way?
- 4) How can the principles of self-determination, community inclusion, and “nothing about us without us” be used to inform case practice in this setting and in this moment?
- 5) Ableism is defined as “the belief that because persons with disabilities are not typical of the non-disabled majority, they are inferior. Ableism precipitates devaluation, while the results of devaluation, including exclusion, ostracism” and a lack of privilege, can reinforce the attitudes, behaviors, and government actions of those who oppress. Four manifestations of oppression characterize ableism, “containment, expendability, compartmentalization and blaming the victim” (Mackelprang & Salsgiver, 2015, p. 105). As a reflective and reflexive practitioner, how would you address both the personal and structural ableism present in this case?
- 6) If this case took place in a rural area, how would the dynamics of the situation change? Would you approach your work differently?
- 7) What would your next steps be in this case?

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## 12.

# AGING, END-OF-LIFE, AND THE DISABILITY COMMUNITY

Alexandria Lewis

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## Learning Objectives:

- To explore how disability is framed in gerontological social work
- To inform practice with disabled people who are aging
- To understand the potential for positive disability identity development with elders

## Introduction

This chapter explores the process of aging with a disability and acquiring a disability while aging. The chapter starts with a historical context of the field of gerontology and disability. Next, demographics of older disabled adults are examined, including several approaches to categorizing age. Service trends discussed consist of the medical model, access to services, and aging in place. Cultural elements, including quality of life, disability perspectives on medical aid in dying laws, and advance care planning, are examined. Key aging policies and programs relevant to disabled people in the U.S. are discussed. The chapter also includes disability-related debates in aging and practice implications. The chapter concludes with a case study and discussion questions.

Absent from traditional gerontology textbooks is the inclusion of details about aging with a disability; when disability is mentioned, the focus is on older adults who acquire a disability in late life (Putnam et al., 2021; Westwood & Carey, 2019). Putnam et al. (2021) defined *persons ageing with disability* as: “Individuals who experience the onset of disability in early life or mid-life who continue to experience disability over the life course” (p. 3). Also, disability studies do not always incorporate the experiences of individuals who acquire a disability in late life, focusing instead on younger populations with disabilities (Kahana & Kahana, 2017;

Putnam et al., 2021). The goal of this chapter is to help fill in the gap in the literature by considering disability, aging, and end-of-life.

Challenges in exploring the intersection of gerontology and disability include the differences in how disability is discussed in the field of gerontology. Gerontology tends to view disability among older adults through a medical model (Kahana & Kahana, 2017; Putnam et al., 2021). Gerontology textbooks tend to focus discussions on disability as related to activities of daily living (ADLs) and instrumental activities of daily living (IADLs), and there is little discussion on disabled persons who age with disability. Whereas traditional gerontology concepts such as “successful aging” have focused on the goal of avoiding disability in late life, “successful aging” through the lens of a disabled person is viewed differently. Since aging is multidimensional and intersectional, one chapter cannot address all the nuances of aging and disability. Therefore, we should re-envision how we view aging because this population is diverse, and the changing landscape of our aging society is critical to consider.

## Historical Context

From a historical standpoint, the separation of disability from aging can be seen in the approaches gerontology developed in the mid- and late 20th century to address stereotypes and discrimination against older adults. In this context, ageism and ableism are essential to understand since ageism and ableism influence how disability is viewed in late life. Ageism is discrimination and prejudice based on age, and ableism is discrimination and prejudice towards disabled persons. Butler (2005) coined the term ageism in 1968 based on his observations of the treatment of older adults in society. He witnessed negative language used about older adults when he was in medical school and when he worked in nursing homes during the 1950s and 1960s; as he explored the abuse of older adults in the 1960s, he witnessed the negative reactions of people in his community when housing was being built for older adults. Butler (2005) recognized ageism could take place at any age; however, due to the extent that society mistreated older adults, he emphasized ageism as the discrimination of older adults. Ageism can be individual or institutional, also referred to as structural. Structural ageism is defined as “the discrimination directed against older persons by policies of institutions and the actions facilitated with them” (Levy, 2022, para. 2). Institutional ageism includes employment discrimination, health care policies based on age (e.g., organ transplantation), and negative portrayals of older adults on television shows and commercials (Nelson, 2005). Institutional ableism has been discussed in other chapters, such as employment discrimination, quality access to health care, and access to accessible housing— [See Chapter 10].

One way the field of gerontology sought to address ageism was by presenting aging in what was perceived as a “positive light,” which included conceptualizing terms like successful aging, productive aging, active aging, and aging well (Urtamo et al., 2019). Concepts such as successful aging emphasized the absence or avoidance of disability in late life. For instance, Urtamo et al. (2019) noted, “[the concept of successful and healthy ageing](#) has been generally associated with longevity, and the absence of disease and disability” (360).



Kim and Park (2017) conducted a meta-analysis of the “correlates” of successful aging, and they organized themes into four categories. The first category related to the “absence” of disease and disability; another type was connected to “high” functioning. Bowling and Dieppe (2005) found some older adults associated their level of physical functioning, psychological functioning, productivity, accomplishments, and social roles with “successful aging.” Unfortunately, the “positive light” of aging was presented as the absence of disability. From a historical perspective, the unintended consequence of the field of gerontology reframing aging to address ageism has been to segment disability as something that does not happen to most older adults; thus, attempting to reassure nondisabled people that aging for most folks is “disability-free.” Disability late in life is presented as unfavorable and something to avoid (Kahana & Kahana, 2017). Disability *and* aging have not been co-considered until relatively recently (Kahana & Kahana, 2017).

## Prevalence and Life Expectancy

An important consideration in understanding populations and implementing service delivery is prevalence data. Sometimes demographics about older adults use language that describes the population increase of older adults in a fatalistic manner, presenting the older adult population as a crisis. Terms like “aging tsunami” and “the graying of America” present aging as something that will quickly take over the landscape and damage society. This message sends a negative image of aging. The FrameWorks Institute (n.d.) emphasizes the importance of solutions and avoiding fatalism due to the message it sends to the public. Prevalence data should also be viewed through an intersectional lens. As demographics evolve, using a solution-focused lens instead of a problem-based lens can help shift the narrative about living in an aging society.

The disability status prevalence for any disability in the U.S. in (2022) was 43.6% for persons 65 years and older (Disability and Health Data System, n.d.). Disability types included self-care (6.1%), cognitive (9.9%), hearing (16.2%), mobility (27.7%), vision (7.4%), and independent living disability (9.9%). Independent living is the ability to complete tasks (e.g., errands, transportation, cooking, cleaning) in the community without assistance, also referred to as instrumental activities of daily living (IADLs). Mobility disability had the highest prevalence (27.7%), and self-care disability comprised the lowest prevalence (6.1%) of the other functional disability types. Self-care is similar to activities of daily living (ADLs) (e.g., dressing, bathing, eating). Disability prevalence among older adults tends to focus on IADLs and ADLs. The 2018 National Center for Health Statistics age-adjusted percentages showed 68.6% of adults 65 years and older experienced “any level” of functional difficulties, 45.6% reported “some difficulty,” and the third category was “a lot of difficulty or cannot do at all,” with 23% responding in this category (NCHS, 2021).

Approximately 54 million persons in the U.S. were 65 years and older in 2020 (Administration for Community Living [ACL], 2021). In 2020, there were 6.6 million adults 85 years and older (ACL, 2021). Approximately 40% (2 in 5) of adults 65 years and older have a disability (Disability and Health Promotion, n.d.). Chapter One of this textbook discussed the overall prevalence of disability. Over the last century, the

overall prevalence of disability has increased, and the prevalence of disability increases as individuals age (Kraus et al., 2017; Campbell & Putnam, 2021). Also, the prevalence of having more than two disabilities increases with age.

Life expectancy at birth in the U.S. was 77 years in 2020; females had a higher life expectancy of 79.9 years, whereas males had a life expectancy of 74.2 years (Murphy et al., 2021). There are differences in life expectancy when comparing geographic location and race/ethnicity. The U.S. state with the highest life expectancy was Hawaii at 80.7 years, and the lowest life expectancy was 71.9 years in Mississippi (Arias et al., 2022). The highest life expectancy for race/ethnicity was non-Hispanic Asian, and the lowest was 67.1 for Non-Hispanic American Indians or Alaska Natives. The COVID-19 pandemic has impacted overall life expectancy, especially for non-Hispanic Black men and Latino men, who experienced a 2.9-3 year drop in life expectancy (Perry et al., 2021). In 2020, the leading causes of death for adults 65 years and older were heart disease, cancer, and COVID-19 (National Center for Health Statistics, 2020).

## Race and Ethnicity

Of the 54 million population of older adults in 2020, around 24% comprised racial or ethnic minoritized persons: African American (non-Hispanic) 9%, Hispanic origin 9%, Asian American (non-Hispanic) 5%, American Indian and Alaska Native (non-Hispanic) 0.6%, Native Hawaiian/Pacific Islander (not Hispanic) 0.1%, and two or more races 0.8%. Overall (all ages), one in ten Asian Americans, three in ten American Indians and Alaska Natives, one in six Native Hawaiian and Pacific Islanders, one in six Hispanic Americans, and one in four Black Americans live with disability.

## Sexual Orientation and Gender Identity

Because of a lack of national data, population estimates about LGBTQIA+ older adults vary (Choi & Meyer, 2016). Most LGBT data about older adults primarily explores gender identity and sexual orientation (Choi & Meyer, 2016). There are around 1.75 to 4 million LGBT older adults 60 years and older (Choi & Meyer, 2016). Approximately 8.1% of persons 65 years and older identified as LGBT, and 8.6% of persons 55-64 identified as LGBT (U.S. Census Bureau, 2021).

Fredericksen-Goldsen et al. (2011) conducted a nationwide community-based survey of more than 2,500 LGBT adults ages 50-95; 44% were age 50-64, 46% were 65-79, and 10% were 80 years and older. Of the 2,500 survey respondents, 44% reported physical or mental problems that limited their physical activities. Around 20% of the participants in the survey reported using durable medical equipment (e.g., special beds) and assistive devices. About 47% of respondents had a disability; of that 47%, older adults who are transgender had the highest percentage of disability (62%), and LGB adults 50 years and older had higher rates of disability than

heterosexual older adults (Fredericken-Goldsen et al., 2011). Women were more likely than men to report disability, and disability increased with age (Fredericken-Goldsen et al., 2011).

Victimization of LGBT older adults was connected to poor mental health, including depression (Choi & Meyer, 2016). In addition, internalized stigma was associated with increased depression and disability. In comparison to heterosexual older adults, LGBT older adults are at higher risk of disability, physical limitations, and mental health diagnoses. LGBT adults with HIV have higher rates of disability than LGBT adults who do not have HIV (Choi & Meyer, 2016).

## Poverty and Income

This section provides an overview, whereas Chapter 10 details employment, housing, and poverty. There are several variables that impact poverty rates in old age, such as race/ethnicity, gender identity, financial assets, access to employment with pension plans, financial investment resources, home ownership, and household size. Since disability in late life is often described based on ADL and IADL functioning, economic data about this population does not typically separate poverty and disability data.

Poverty data can be challenging to understand due to how poverty data are calculated and the purpose of the data. Poverty data is issued by the U.S. Census Bureau (poverty thresholds) and by the U.S. Department of Health and Human Services (poverty line/guidelines). Poverty guidelines are used for eligibility for some government programs, and the purpose of poverty thresholds is to calculate data about persons in poverty. The U.S. Census Bureau also produces the supplemental poverty measure, which takes into consideration shelter, utilities, and food expenditures. In contrast, the poverty threshold is based on a decades-old calculation of the minimum food diet in 1963. The official poverty threshold measure is gross income (before taxes); the supplemental poverty measure (SPM) subtracts taxes, work expenses, child support paid to a different household, and medical expenses. Since the SPM provides a better view of poverty, this discussion of poverty information will focus on SPM.

The 2021 poverty threshold for a 65-year-old householder who resided alone was \$12,996 (U.S. Census Bureau, n.d.). In 2019, 8.9% of older adults were below the 2019 poverty line, also referred to as the poverty threshold (ACL, 2020). When the supplemental poverty measure (SPM) is applied to persons 65 years and older, the poverty measure was higher at 12.8% in 2019 (ACL, 2020). The difference in the rates between the SPM and the poverty line was due to out-of-pocket medical costs (ACL, 2020). In 2017, 30.1% of persons 65 years and older (15 million) experienced poverty below 200% of the poverty line, and using the supplemental poverty measure, this percentage increased to 42% of older persons (21.4 million) living 200% below the SPM poverty line.

Poverty rates among older adults increase with age for both poverty threshold and supplemental poverty measure rates. Forty percent of adults 80 years and older (4.6 million) had incomes below 200% of poverty, in contrast to 24.9% of adults 65-69 years (Cubanski et al., 2018). The poverty percentages increase when applied to the supplemental poverty measure, with 52.6% of adults 80 years and older (6.1 million) with incomes below

200% of poverty, in comparison to 35.8% of adults 65-69 years. Health status (fair/poor, good, and excellent/very good) indicate differences in poverty rates (Cubanski et al., 2018). The rate of poverty below 200% of poverty based on SMP almost doubles for older adults with fair or poor health (56.9%), in contrast to 30.9% for adults with excellent or very good health.

Older women experience higher rates of poverty than men (Cubanski, et al., 2018; ACL, 2020). Based on the supplemental poverty measure, 46% percent of women 65 years and older (12.6 million) had income considered below 200% of poverty. In the same age category, 37% of men (8.3 million) had incomes below 200% of poverty (Cubanski, et al., 2018). Men 65 years and older also had a higher median income (\$36,921) than women (\$27,398) 65 years and older (ACL, 2020). African American older women (31.7%) and Hispanic women (32.1%) living alone had the highest poverty rates (ACL, 2020). Sixty percent (60.3%) of Black women (2.6 million) and 65.6% of Hispanic women 65 years and older (2.7 million) had incomes below 200% of poverty using the SPM.

Poverty rates also vary based on geographic location for older adults, and these are also essential to understand. For example, there were 11 states where 45%-51% of older adults lived below 200% of poverty based on the SMP: New York, New Jersey, Washington D.C., Mississippi, Massachusetts, Louisiana, Kentucky, Georgia, Florida, Arkansas, and Hawaii (Cubanski et al., 2018).

Chapter 10 of this text addresses employment, housing, and poverty in greater detail. Employment, housing, and poverty impact people as they age with disability. The accumulation of financial wealth is impeded when disabled people are discriminated against in the hiring process, paid lower wages, charged more for accessible housing, etc. Approximately 2.3 million adults 65 years and older receive an average of \$468 a month for Supplemental Security Income (Social Security Administration, 2021b). To qualify for Supplemental Security Income (SSI), individuals “must be disabled, blind, or at least 65 years old and have limited income and resources” (Social Security Administration, n.d.).

Overall, for older adults, sources of income consist of Social Security, pensions and retirement accounts, employment earnings, and property, to name several. Forty-eight percent of households 55 years and older did not have retirement savings in 2016, a 4% decrease from 2013 (U.S. Government Accountability Office, 2019). The average monthly benefit for Social Security retirement benefits in December 2020 was \$1,497: females received an average of \$1,322 and males an average of \$1,689 (Social Security Administration, 2021a). The average monthly survivor benefits for disabled widow(er)s were \$770: females received \$787, and men received \$588. Older adults with lower income obtain most of their income in old age from Social Security retirement and Supplemental Security Income (Thompson & King, 2022). In comparison, older adults with higher incomes receive more of their income from retirement plans, pensions, and financial assets other than federal government-subsidized retirement accounts (Thompson & King, 2022). Therefore, discrimination and oppression can significantly impact a person’s earnings, which is magnified for persons who age with disability due to the discrimination they receive in employment.

## Categorization of Aging

Using chronological age to describe older adulthood is challenging because each person has a unique life course with diverse life experiences. Functional age (also referred to as functional status) is distinct from chronological age. The focus is on impairments and disability, which some suggest is more relevant for eligibility for some service delivery (Morgan & Kunkel, 2016). Life stage relates to changes and transitions, including retirement, raising grandchildren, and health changes (Morgan & Kunkel, 2016).

There are several approaches to categorizing age, such as chronological age, functional age, and life stages (Morgan & Kunkel, 2016). Perspectives about older adulthood will continue to shift as the social construction of aging evolves. Context is useful when examining aging concepts because how society views and discusses aging will continue to evolve. For example, Bernice Neugarten is recognized in the field of gerontology as coining the terms “young-old” (55-75 years old) and “old-old” (75 years and older) in the 1970s (McCoyd et al., 2019; Settersten & Godlewski, 2016). Neugarten (1974) noted the challenges of using chronological age to categorize older adulthood and separated the age categories based on financial resources, educational attainment, and health status. It is essential to note the demographics she examined were White men and women in 1970. To illustrate, Neugarten (1974) referred to the “young-old” as those “who are relatively healthy, relatively affluent, relatively free from traditional responsibilities of work and family and who are increasingly well educated and politically active” (p. 187). Additional age categories include “young-old” (65-74 years old), “middle-old” (75-84 years old), “old-old” (75-84 years old), and “oldest-old” (85 years and older) (Settersten & Godlewski, 2016; Corr et al., 2019; McCoyd et al., 2019).

## Service Trends

### Medical Model

The medicalized focus on aging services, versus a social model approach, has influenced the field of gerontology. Bowling and Dieppe (2005) concluded, “The medical model is so dominant that few health professionals are aware of psychosocial aging. The result is a focus on the burden of old age, the decline and failure of the body” (para. 2). Unfortunately, there is a lack of information about how people with disabilities in late life can live fulfilling lives (Kahana & Kahana, 2017). There is an absence of research about the experiences of disabled people in aging and end-of-life services and individuals coming into disability identity as they age. The view of disability in late life is focused on IADLS and ADLs, and the emphasis on “successful aging” has placed more emphasis on the “avoidance” of disability, leaving out information about how to live well with a disability in late life. People with disabilities live with dignity and have quality of life, which should not be defined by non-disabled individuals. In reality, institutional ableism has treated disabled people in ways that affect their ability

to live well and with dignity. It is imperative to move past the medical model to support disabled people as they age and nondisabled people who acquire a disability in later life.

## Opening Access to Services

### Telehealth

Older adults with disabilities deserve universal access to programming, and the adaptation of virtual services needs to continue moving forward. During the COVID-19 pandemic, the Centers for Medicare and Medicaid Services (CMS) expanded telehealth services under a waiver that increased access to remote care and services. The CMS changes allowed Medicare payment for telehealth visits in the home, which previously were only approved for designated sites (e.g., clinics, medical facilities, hospitals) in rural areas (U.S. Department of Health and Human Services, n.d.). Providers could bill for video and audio-only services, similar to in-person services. The CMS waiver encouraged providers to implement the use of telehealth to provide service delivery, including medical consultation, nutrition counseling, eye exams, routine health care, wellness visits, and mental health services. The expansion of covered telehealth services includes home visits, therapy services, initial nursing facility, discharge visits, and emergency department visits (U.S. Department of Health and Human Services, n.d.). The CMS will continue to allow billing for telehealth (mental health) services through the year 2023 (American Psychological Association, 2021). One positive of the pandemic has been the flexibility of service delivery, granting access to persons in their homes. Disabled older adults deserve to receive universal access to services in the home, and there is no evidence that telehealth services are not capable of providing quality services.

### Senior Centers

The COVID-19 pandemic required service providers to quickly adapt their in-person services. While in-person interactions are different from virtual interactions, older adults with disabilities can benefit from virtual service options. Around one million older adults receive services from senior centers (Wacker & Roberto, 2019). Most senior centers are funded by the federal government and offer home-delivered meals, legal services, transportation services, congregate meals, information and assistance, benefits counseling, recreational and social activities, and health and fitness programs (Wacker & Roberto, 2019). The National Council on Aging ([NCOA], n.d.) surveys senior centers, and senior centers adapted service delivery because of the pandemic. Forty-eight percent of respondents indicated an increase in the number of older adults they served since fall 2020. Some of the services introduced or increased were home-delivered meals, virtual education on chronic disease and falls, benefits counseling, and take-home meals, to name several (NCOA, 2021a).

Marmo et al. (2021) examined virtual services offered by senior centers. In their study of SAGE, a senior center with five locations in New York City that provide service delivery for older LGBTQ adults, Marmo



et al. (2021) found that there was no significant difference between in-person senior center participation and virtual participation (sample size 113) for LGBTQ older adults who attended senior centers. Most of the older adults (82.7%) already had established friendships with at least four friends from the senior center, and they continued these friendships during the pandemic. The senior center offered various virtual programming, including fitness classes, support groups, meditation, social meet-ups, and arts-related programming, to name several. The top program attended was the exercise program; around 52% of the older adults participated in these programs. The main barriers to virtual services were access to Wi-Fi, and some older adults do not have devices (e.g., computers, tablets, smartphones) equipped to connect virtually (Marmo et al., 2021). In addition to these barriers, accessibility is also essential, such as language access (e.g., closed captioning, interpreting). For instance, when there are virtual support groups and social meet-ups, these programs should have an interpreter so persons who communicate using sign language can fully participate in the groups.

The NCOA (2021b) received a three-year \$750,000 grant from the Administration for Community Living (ACL) to help modernize senior centers through the development of the Modernizing Senior Centers Resource Center. The goal of this grant is to assist senior centers as they adapt to a changing society. The NCOA will offer senior centers training and technical help and share resources to innovate programming. As the NCOA supports the modernization of senior centers, continued access to virtual services is critical.

## Aging in Place

“Aging in place” is not a one-size-fits-all approach. The disabled older adult’s service preferences should be centered when determining their choice to remain at home and live with dignity. “Aging in place” consists of the social environment (e.g., personal assistance, programming that helps reduce socialization) and physical environment (e.g., transportation, home modification, technology safety monitoring devices, assisted devices) supports, which influence whether a person can age well at home (Gitlin et al., 2013). The focus of “aging in place” models is functioning (ADLs and IADLs).

An example of an aging-in-place model is the Community Aging in Place: Advancing Better Living for Elders (CAPABLE) program developed by Sarah Szanton at John Hopkins University, which seeks to support older adults with low income who prefer to remain in their community (John Hopkins University, n.d.). CAPABLE provides the support of a registered nurse, occupational therapist, and a home-repair professional for four to five months (Gitlin et al., 2013). CAPABLE aims to provide short-term assistance using assessment and goal-setting, in which the disabled older adult determines their own goals (Szanton et al., 2014). CAPABLE consists of education, home modification, fall prevention techniques, pain management, medication management, and problem-solving skills (Szanton et al., 2014). Most older adults reside in the community, and “aging in place” programs are essential in supporting older adults with disabilities in meeting their goals. Programs like CAPABLE have been found to improve quality of life and are more cost-effective than long-term care facilities (Szanton et al., 2014).

People who age with disability can and do take an active role in directing their care, including choosing care



professionals. Kahana and Kahana (2017) used the term “care-getter” to refer to the active role of consumer-driven disability services. Their expectations will be unique to adults who acquire a disability when they age, whereas in late life, there tends to be more emphasis on caregiving vs. care-getting. Aging in place needs to be at the forefront to ensure disabled older adults receive optimal community-based care.

## Cultural Elements

### Quality of Life

Ableism and the medical model influence perceptions about older adults with disabilities and what constitutes “quality of life.” In a survey of 714 physicians, most (82.4%) believed nondisabled persons have a better quality of life than disabled persons (Iezzoni et al., 2021). Disability perceived as a burden is detrimental to the quality of care for older adults with disabilities. Jacob et al. (2016) concluded, “The effects of healthy lifestyle factors on the proportion of future lives lived free of disability indicate that the disabled period can be compressed, given the right combination of these factors” (section: Conclusion). These views about the quality of life affect how disabled older adults are treated in the health care system.

### Disability Perspectives: Medical Aid in Dying Laws

Medical aid in dying laws, also referred to as physician-assisted suicide and death with dignity, are not without controversy. There are 11 jurisdictions in the U.S. with medical aid in dying laws (Death with Dignity, n.d.). Death with Dignity Acts allow an adult with a terminal illness (six months or less to live) deemed competent to receive a prescription for a lethal dose of medication (Corr et al., 2019). There are differing opinions on whether physician aid in dying should be legal. Rarely considered are the perspectives of disabled advocates about physician-assisted suicide.

Not Dead Yet (NDY) is a disability rights group that views medical aid in dying laws through the lens of the historical oppression of disabled people. Historically, disabled persons have experienced forced sterilization that was codified into law in many U.S. states, and the U.S. Supreme Court upheld the sterilization of disabled people. Also, medical treatment decisions made by some medical professionals are based on disability status, such as COVID-19 protocols in many hospitals (Kliger and Steinbach vs. Healey and O’Keefe, 2022). NDY and other disability groups are involved in a recent amicus brief in an assisted suicide case. In this brief, Kliger and Steinbach vs. Healey and O’Keefe (2022) outlined the discrimination of disabled individuals in medical settings, the implicit bias of medical professionals, and the primary reasons for assisted suicide laws being related to disability. The NDY movement points out that being disabled should not be a legal reason for suicide, and they view disability “as the heart of the assisted suicide debate” (section: Unacceptable Losses).

In an Oregon Death with Dignity Act report, primary end-of-life concerns were disability-related: losing

control of bodily functions (37.6%), the burden on family, friends/caregivers (53.1%), loss of dignity (71.8%), losing autonomy (93.1%), inability to engage in activities for life enjoyment (94.3%), concern about pain control or “inadequate pain control,” (32.7%), and medical care costs for treatment (6.1%) (Public Health Division Center for Health Statistics, 2021). Disabled persons have fears of how disability-related experiences are labeled as reasons for physician-assisted suicide.

## Disability Perspectives: Advance Care Planning

Advance care planning is a process that can include selecting a health care proxy who can speak on behalf of a person if they are unable to communicate their health care decisions, or it can be completing an advance care planning document such as a living will and advance directive. Advance care planning is defined as:

a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness. (Sudore et al., 2016, section: Results)

Unintentionally, ableism is embedded in how the quality of care is discussed, and some of the content in advance care planning centers on disability. An example of statements in an advance care planning document for when a person is “seriously ill”: “I would not want medical treatments to try and keep me alive if I could no longer: live without being permanently hooked up to a breathing machine, recognize family and friends, talk to family and friends, feed, bathe or take care of myself, live without severe pain or discomfort, and live well enough to make everyday decisions” (UCLA Health, n.d., p. 2). At the end of this section, there is an option to check “None of the above apply. My life is always worth living, no matter how sick I am” (UCLA Health, n.d., p. 2).

A disability perspective is rarely infused into information about advance care planning. Coleman (2012) emphasized the importance of viewing advance care planning through a balanced perspective to ensure a person’s wishes are respected, asking “Are advance directives always to refuse treatment, never to request it?” (p. 10). Coleman (2012) highlighted a comparison of futility policies vs. advance directives, wherein futility policies are based on biases about quality of life and predictions about prognosis, and driven by the medical team instead of the patient/family. Coleman (2012) mentioned the importance of designating someone to make healthcare decisions due to the process that occurs when there is no healthcare proxy documentation available. Some states have surrogate decision-making laws when a person does not have an identified healthcare proxy, and these laws have a hierarchy for who can make decisions for the person, typically (1) married partner, (2) adult child, (3) parent, and (4) adult siblings (Coleman, 2012). Coleman (2012) discussed a problem with this hierarchy because the person given priority might not necessarily be the best person to make these decisions, such as patients who experience intimate partner violence or abuse from their adult children.

There must be a balance when discussing advance care planning to ensure the person’s wishes are respected

and not the wishes of the persons making the decisions (Coleman, 2012). The perspectives of disabled persons are vital to finding balance in end-of-life decision-making. Coleman (2012) emphasized the balance as “recognition that concerns about overtreatment must be balanced with protections against undertreatment” (section: Conclusion).

## Policies

There are entire textbooks that focus on aging and disability policies, and the goal of this information is to provide a general overview of policies related to Medicare, Medicaid, and home and community-based services. Chapter four of this text offers more information about health and personal care services.

## Social Security Act Overview

The Social Security Act has 21 titles and covers disability insurance, retirement, temporary assistance for families with low income, maternal and child health, blind and visual impairment, supplemental security income (SSI), health insurance for disabled individuals and older adults, a children’s health insurance program, medical assistance programs, unemployment insurance, and social services grants, to name several.

## Medicare Overview

Adults 65 years and older who pay into Medicare through payroll taxes are eligible for Medicare Part A (hospital insurance) and Part B (medical insurance). Medicare premiums for adults 65 years and older will depend on how many quarters (calendar quarters of coverage) they have paid through their Medicare payroll taxes (Congressional Research Service, 2020). Adults 65 years and younger who receive social security disability cash benefits for two years are eligible for Medicare Part A, and persons with end-stage renal disease of any age are eligible for Medicare Part A (CRS, 2020). In 2020, approximately 54 million older adults and nine million disabled adults were covered by Medicare (CRS, 2020). In addition, about 7.2 million older adults with low income are enrolled in Medicaid and Medicare, referred to as dual eligibility. The total Medicare revenue for the fiscal year 2019 was 794 billion dollars (CRS, 2020).

Medicare consists of four parts: Part A (hospital insurance), Part B (supplemental medical insurance), Part C (Medicare Advantage), and Part D (optional prescription plan). Medicare Parts A and B are typically referred to as Original Medicare (CRS, 2020). Medicare Part A covers inpatient hospital care, hospice care, home health care, and nursing home short-stay rehabilitation care. Medicare Part B covers durable medical equipment, ambulance services, mental health (inpatient and outpatient), and some outpatient prescriptions. Medicare Part C is optional and considered a private plan. Medicare Part D is also optional. Medicare requires

deductibles and coinsurance for inpatient services, and Part B has a deductible (annual) and coinsurance (20%) for services (CRS, 2020).

## Medicare and Home Health

Medicare does not cover long-term home and community-based services. Medicare Parts A and Part B cover short-term home health rehabilitation-related services. Medicare requires a physician or other “allowed practitioner” to certify that beneficiaries need one or more rehabilitation-related services (e.g., physical therapy, occupational therapy, skilled nursing care, medical social services, speech-language pathology, short-term personal care). Another requirement of Medicare home health is “homebound status” (i.e., the beneficiary requires assistance to leave their home, due to illness or injury). Medicare homebound status can also apply to persons with a mental health diagnosis where they are unable to leave their home, and a physician/allowed practitioner evaluates the person as not safe to leave their home without assistance (CMS, 2022). Medicare home health does not cover 24-hour nursing services, home-delivered meals, or help with IADLs. In addition, Medicare does not provide personal care if personal care is the only service requested. Home health companies that are eligible to bill for Medicare are required to be certified by Medicare (CMS, n.d.-a).

## Medicare and Nursing Home Care

Similar to Medicare home health services, Medicare does not provide long-term nursing home coverage. Instead, Medicare covers short-term skilled rehabilitation services (e.g., speech-language pathology, occupational therapy, skilled nursing, physical therapy) in certified nursing homes with eligibility requirements: (1) Three-day “qualifying stay” in a hospital, (2) Medicare Part A, (3) physician assessment that the individual needs skilled services, (4) or the benefit period has days left for skilled services (CMS, n.d.-a). Medicare pays 100% for days 1-20, but for days 21-100, there is a \$194.50 daily coinsurance. After 100 days, Medicare beneficiaries are responsible for total costs (CMS, n.d.-b). The coinsurance is not a fixed rate and typically will increase each year.

## Medicaid Overview

Medicaid is considered a means-tested health care program (e.g., eligibility, income) and is regarded as a voluntary program. All U.S. states and the District of Columbia participate in Medicaid, and the federal government and state government fund Medicaid. Via the use of federal funds, U.S. states and the District of Columbia have the option to expand the coverage of Medicaid under the Affordable Care Act to adults with income of up to 138% of the federal poverty level. As of February 2022, the District of Columbia and 39 states expanded Medicaid (Kaiser Family Foundation [KFF], 2022). While states administer Medicaid and are allowed some choices in administering Medicaid, there are federal requirements for mandatory services. For

example, inpatient hospital services, outpatient hospital services, long-term nursing home services, physician services, home health services, rural health clinic services, and laboratory and x-ray services are some of the mandatory services required by the federal government (CMS, n.d.-c).

Medicaid provided coverage to around seven million disabled adults under 65 (Musumeci & Chidambaram, 2019). Total Medicaid expenditures for the fiscal year 2019 were 627 million dollars across all 50 states and the District of Columbia (CRS, 2021). Medicaid expenditures for older adults and disabled adults were 54% of Medicaid expenditures in the fiscal year 2017 (Congressional Research Service, 2021). Medicaid is considered the primary payee for Long-Term Services and Supports (LTSS), paying approximately 44% of home and community-based services and nursing home care (CRS, 2021). The 2018 estimated national LTSS spending was \$379 billion, and Medicaid LTSS spending was 52% of the overall federal LTSS spending at \$196.9 billion (Watts et al., 2020).

## Community-Based Services

The 1999 *Olmstead vs. L.C.* case is considered a critical Supreme Court decision, ruling that the Americans with Disabilities Act prohibited the segregation of disabled adults in institutions and that community-based options should be made available when appropriate. The *Olmstead* case is based on Elaine Wilson and Lois Curtis, who remained undischarged from a state-run psychiatric unit for several years even though their treatment was completed. This monumental ruling has set a positive precedent for other cases to be filed against entities that do not provide community-based services where appropriate. For instance, in 2016, the Department of Justice indicated Louisiana was in violation of the Americans with Disabilities Act because services were not delivered in community settings for people with serious mental illness; they were being admitted into nursing homes instead of the community (U.S. Department of Justice, n.d.).

## Medicaid Home and Community-Based Services

Home and community-based services (HCBS) are vital to “aging in place.” The only requirement by the federal government for home and community-based services for Medicaid is home health services. Optional HCBS services include personal care services (assistance with household and self-care), Community First Choice (attendant services for persons who qualify for institutional services), Section 1915 (i) (e.g., case management, rehabilitation, respite services, homemaker services, home health aide, personal care services, adult day health services, and mental health), Section 1915 (c) and Section 1115. Sections 1915 (c) and Section 1115 are referred to as Medicaid HCBS Waivers. Waivers provide some flexibility in how states can tailor their programs. Most states offer optional HCBS services, and most Medicaid HCBS spending is for optional services (CRS, 2021). HCBS 1915 (c) provides the same services as Section 1915(i). In addition to these services, states can implement enrollment caps, target specific populations, implement geographic limits, and waive income and asset limits. Eligibility requires individuals who would also meet the requirements for institutional care (Watts

et al., 2020). Under Section 1115, states can implement HCBS enrollment caps and use Medicaid funding for demonstration projects and pilot programs that the federal government would not usually fund under Medicaid. HCBS Section 1915(c) enrollment was the highest at 1,806,600 enrollees (48 states). The total enrollment of Waiver programs for the fiscal year 2018 was 2.5 million (Watts et al., 2020). The enrollment numbers show the importance of HCBS programs, and these programs need to be expanded to provide support to disabled older adults. In 2018, there were an estimated 185,774 disabled older adults on waiting lists for enrollment in Medicaid Section 1915(c) HCBS waiver programs (KFF, n.d.).

As mentioned in the aging in place section, disabled adults who age with a disability are used to self-directing their care. How many individuals participate in HCBS self-directed personal care plans is unknown because not all states report these data. However, in 15 states out of the 20 that reported these data, around 700,000 people engaged in self-directed personal care state plans. These plans allow individuals to take an active role in their service delivery by hiring their direct care workers, terminating their direct care workers, and determining the hours of their direct care workers.

## Money Follows the Person

The Money Follows the Person (MFP) program is a demonstration program created under the 2005 Deficit Reduction Act (Section 6071). The MFP gives grants to help states improve home and community-based services, to increase access to HCBS for Medicaid recipients who might otherwise reside in an institution, and to support people on Medicaid who want to move from institutions to the community. The underlying premise of the MFP is for Medicare recipients to have the opportunity to reside in the community instead of in an institutional setting. When the MFP was first established, 1.75 billion dollars was allocated for a five-year period to offer grants to states (Hargan, 2017). Participation in the MFP is voluntary, and states apply for grant awards to participate in the MFP.

The institutions for eligibility are hospitals, nursing homes, intermediate care facilities for persons with intellectual disabilities (ICF/ID), inpatient psychiatric facilities with patients 21 years and under, and “institutions for mental diseases” for older adults (65+). In addition, the MFP has specific parameters on what constitutes a “qualified residence”: (1) Housing owned or leased by the individual or their family; (2) Residing in an apartment that requires a lease directly with the landlord (individual lease), an exit to the outside (egress), ability to lock the apartment, and control over their living space; and (3) Small group homes (four unrelated residents and under). The Deficit Reduction Act initially used a residence time frame of six months in an institutional setting as part of the eligibility parameters; however, the Affordable Care Act reduced the residence requirement to 90 consecutive days. The residence requirement has since been reduced to 60 straight days, and short-term rehabilitation days can now count towards the 60-day timeframe (Colello, 2021).

The MFP participants can receive HCBS through Section 1915(c), and demonstration services are services participants cannot access under their HCBS services (Hargan, 2017). For instance, demonstration services may include assistance with assistive technologies and additional personal care services. The goal of the



demonstration services is to support individuals through the adjustment process of moving from an institutional setting to a community setting; the demonstration services are short-term (Hardan, 2017). According to the law, Medicaid cannot pay rental costs for participants, and some participants experience barriers to locating housing due to rental costs and availability (Colello, 2021). After participants transition into the community, they can receive support from the MFP program for one year (Liao & Peebles, 2019).

The MFP has successfully assisted more than 100,000 individuals in moving from institutional settings into the community from 2008 to 2019 (Congressional Research Service, 2021). States can choose populations to target their MFP demonstration project, and states can decide which institutional settings to focus on (Liao & Peebles, 2019). In total, 44 states have participated in the MFP demonstration project. Oregon, Wyoming, Utah, Arizona, New Mexico, Florida, and Alaska do not have MFP programs (Musumeci & Chidambaram, 2019).

The MFP has helped enhance the quality of life of disabled individuals who prefer to reside in the community, and the program is more cost-effective than paying for institutional placement (Gottluch, 2021). To illustrate, the average monthly cost of a nursing home is \$7,698 for a private room and \$6,844 for a semi-private room (Administration for Community Living, n.d.). Nursing home costs vary depending on geographic location and amenities offered. Funding for the MFP has continued to be extended, and funds appropriated through various legislation such as the Affordable Care Act and Medicaid Acts. The Coronavirus Aid, Relief, and Economic Security Act extended the MFP funding through the end of November 2020. Recently, the Consolidated Appropriations Act extended the MFP funding through the end of September 2021. The total funding appropriated for the fiscal year 2021 through 2023 is \$1.35 billion, which amounts to \$450 million each fiscal year (Colello, 2021).

## Residential Care Communities

In [year], around 918,700 older adults, ages 65 years and older, resided in residential care communities (Caffrey et al., 2021). The grouping of residential care communities consists of assisted living facilities, adult foster care, personal care homes, and board care homes. Most residents who lived in residential care communities were female (67%), non-Hispanic White (89%), and 85 years and older (55%). Most residents (61%) in residential care communities received assistance with three or more ADLs: eating (26%), toileting (49%), dressing (62%), walking (69%), and bathing (77%). States have different licensing rules and regulations for assisted living care facilities. When a type of residential setting is licensed with a state, there will be specific regulations these settings need to follow. The Centers for Medicare and Medicaid Services do not regulate state-licensed-only facilities. Some assistance with ADLs is typically provided in assisted living facilities. Some states have more specific requirements for assisted living facilities than others, such as the ability for the individual to leave the building independently without staff assistance. Depending on the state, some older adults with disabilities may not be eligible for certain levels of care based on the assistance provided by the type of residential setting.



Some of these types of residential settings are private pay and do not accept Medicaid; however, some states allow the use of Medicaid funding in assisted living facilities.

## Senior & Disability Housing

Some geographic locations have public housing apartments tailored for disabled and older adults. Usually, these apartments are means-tested, and there is a certain percentage of rent individuals pay. Some housing accepts vouchers, such as Section 8 (Jurkowski, 2019). These residential settings are tailored to older adults and adults with disabilities, so they are required to meet environmental accessibility standards (e.g., apartment layout, bathrooms, elevators).

## Long-Term Care

There were approximately 1.7 million licensed nursing home beds, and 15,600 nursing homes in 2016 (National Center for Health Statistics, n.d.). In 2020, 1.3 million (1,290,177) people resided in certified nursing facilities (KFF, n.d.-c). Nursing home care as a long-term level of care requires adults to meet specific criteria for admission, such as some level of assistance with ADLs and IADLs, and assistance with medication administration (National Center for Health Statistics, 2019). Some nursing homes provide short-stay rehabilitation. Approximately 83.5% of persons who live in nursing homes are 65 years and older, and 38.6% are 85 years and older. Additional demographic characteristics of individuals who use nursing homes long-term (100 days or more) show 67.9% were women, 75.6% were White (non-Hispanic), and 85.1% were 65 years and older (National Center for Health Statistics, 2019). The top diagnoses of individuals who had long-term stays were high blood pressure or hypertension, Alzheimer's disease (58.9%), depression (53%), heart disease (38.8%), diabetes (32.2%), and arthritis (29.7%). Nineteen percent of persons who resided in nursing homes in 2016 experienced a fall before their nursing home admission (National Center for Health Statistics, 2019). Medicaid is considered a primary financial funder of nursing home care, spending 55 billion dollars on nursing home care in 2015 (KFF, 2017).

## Hospice Care

The National Hospice and Palliative Care Organization (NHPCO) does not present data on disability in its annual reports. Therefore, there is a lack of information about persons who age with a disability who receive hospice care. Hospice is a philosophy of comfort care and support for patients with a life-limiting illness (i.e., prognosis of six months or less). Hospice is a benefit of Medicare, and hospice providers certified by Medicare have regulation guidelines that govern the range, level, and as well as staffing requirements, and quality of services offered to patients and families. The hospice team comprises an interdisciplinary group of social workers, physicians, nurses, chaplains, bereavement counselors, and hospice aides. The goals of

hospice care include symptom management, pain management, medication management, family education, and psychosocial and spiritual support of the patient and their family. The four different levels of care provided are routine hospice care, continuous home care, inpatient respite care, and general inpatient care. Most hospice care provided to patients is routine hospice care offered in the location a hospice patient identifies as home (e.g., nursing homes, assisted living, and private residences). The majority of persons who receive hospice services are 85 years and older. The primary diagnoses related to the hospice patient's life-limiting illness were Alzheimer's/Dementia/Parkinson's (one category), cancer, severe malnutrition, circulatory/heart, stroke, and kidney disease (NHPCO, 2021). In 2019, 1.61 million Medicare beneficiaries received hospice care, and Medicare paid \$20.9 billion for hospice services in 2019 (NHPCO, 2021).

## Disability-related Debates in Aging

### Voices of Disabled Individuals

The voices of disabled individuals are essential to consider when exploring these topics. Here, we share a few of them.

Lankasky (2004) mentions that successful aging starts during childhood in learning how to live in a society that doesn't include disabled people, learning how to "fall and get back up," and building self-esteem. Lankasky (2004) also mentioned the importance of having supportive parents who allow them to make mistakes and grow. When Lankasky (2004) started experiencing additional disability, they asked one of the following questions: "How do I give up the social status that this society seems to assign to standing straight and walking tall?" (p. 17). Lankasky (2004) shared they were not always included in healthcare decision-making: "I am the primary expert when it comes to knowing what is different about my body and my functioning today compared with yesterday. I have incredible valuable input to add to the corpus of information so much of my health care is based on" (p. 16).

Judy Heumann is a well-known international disability rights activist, and she is the author of *Being Heumann* and *Rolling Warrior*. Her [linktr.ee webpage](#) includes her website, newsletter, podcast, and YouTube channel, among other means of communication. Judy has asserted that instead of using the term "able-bodied," we should use the word "nondisabled" because anyone at any time can become disabled. This language can help to shift the narrative of disability as something foreign and reduce the "othering" of disability.

Alice Wong is a well-known international disability rights activist and the founder and director of the online community [Disability Visibility Project](#). She is a writer and editor of *Disability Visibility: First-Person Stories from the Twenty-First Century*. Alice Wong shared her experiences living with a disability during the COVID-19 pandemic. In this [Vox article](#), she discussed medical rationing and problems with the concept of "quality of life." Alice Wong aptly stated:

Even the notion of ‘quality of life’ as a measurable standard is based on assumptions that a ‘good’ healthy life is one without disability, pain, and suffering. I live with all three intimately, and I feel more vital than ever at this point in time, because of my experiences and relationships. (Wong, 2020, para. 8)

## Older Adults and Disability Identity

More research is needed to explore disability identity in adults who acquire a disability when 65 years and older and in aging people who have acquired a disability earlier in life. First and foremost, social workers should be respectful of how people self-identify. Being aware of the nuances of disability identity in late life is helpful in gaining insight into how people view their experiences. Some older adults who may be classified as disabled due to activities of daily living do not necessarily identify as disabled. The reasons they might not identify as disabled are not fully understood. Kelly-Moore et al. (2006) suggested some older adults might view their experiences as part of normal aging (as cited in Williamson and Fried, 1996). Some older adults who were nondisabled throughout their life course may not see a connection to “disabled” as part of their identity and life experiences since they have been nondisabled for most of their lives. The authors (2006) noted, “disability carries negative social meaning, and little is known about when (or if), in the process of health decline, persons identify themselves as disabled” (p.126).

Kelly-Moore et al. (2006) conducted a four-year panel study of 1,000 residents from three Florida retirement communities. The residents they examined were 72 years and older and most were White. An interesting aspect of this study is that Kelly-Moore et al. (2006) explored disability identity and whether there were changes to self-identification as disabled. They noted men were less likely than women to view themselves as disabled. The population of older adults more likely to view themselves as disabled was individuals with cognitive impairment, more limitations in functioning, and more health conditions. How nondisabled people who acquire a disability in late life perceive disability is unique from those who age with a disability. For instance, the inability to drive and the need to receive home health services increased an older adult’s “perceived disability.” Even when an older adult did not have functional status problems, they were more likely to identify as being disabled if they had several health conditions. In addition, if someone had strong social support, including family, they did not necessarily view themselves as disabled.

While there is a lack of research on the experiences of nondisabled adults who acquire a disability in late life, it can be hypothesized that they will experience disability differently than persons who age with a disability (Kahana & Kahana, 2017). Persons who acquired a disability as a young adult or middle-aged adult are more likely than someone who acquired a disability in late life to have disability pride as part of their identity. Conversely, those who become disabled in late life may reject their disability identity (Kahana & Kahana, 2017). Some disabled persons experience the internalization of ableism, resulting in attempts to hide their disability from others, and some persons with disabilities may distinguish themselves from persons with different disabilities (Nario-Redmond, 2020). Some people might use a few strategies to distance themselves from their disability, such as not disclosing their disability to others and not using assisted devices (Nario-

Redmond, 2020). For instance, some older adults who do not identify as disabled or who want to hide their disability may choose not to use assistive devices or refuse assistance at home (Kahana & Kahana, 2017). Some older adults choose not to use hearing aids because they do not want others to know they have a hearing impairment. For instance, there are hearing aid companies that advertise their hearing aids are discreet, and their commercials emphasize that others will not know when hearing aids users are wearing them. This messaging contributes to ableism, as if there is something wrong with a hearing impairment that people should hide from others.

## Life Course Perspective

There is a lack of research on disability and aging across the life course (Kahana & Kahana, 2017). Disability should be viewed through a life course perspective lens because individuals with disabilities are not homogenous and have different life experiences. As Kahana and Kahana (2017) noted, “The way that illness and disability affect daily life is embedded within the life course” (p. 77). Disabilities acquired in late life can be transitions or turning points for people who have lived as nondisabled for most of their lives. People can also be affected by timing specific to societal norms about disability. To illustrate, if the messaging people receive is disability is to be avoided, this messaging impacts how some people view acquired disabilities. More research should explore how people with disabilities in late life can live fulfilling lives (Kahana & Kahana, 2017).

Chronological age cannot be viewed in isolation because aging occurs across the life span and life course. The life course perspective considers cohort, transitions, life events, trajectories, and turning points as contributing to a person’s life experiences (Hutchison, 2017). For example, the *Healthy Brain Initiative* for Alzheimer’s disease and other dementias uses a life course perspective from birth to death, reflective of a lifelong development approach to examining Alzheimer’s disease (Alzheimer’s Association & Centers for Disease Control, 2018). Human agency recognizes people actively engage in their own lives and make decisions on how to survive, despite the barriers they may face due to discrimination, oppression, and lack of opportunities (Wilmoth & London, 2013; Hutchison, 2017). Individuals, groups, families, and communities are affected by historical context. Within the life course perspective, timing (as opposed to chronological age) relates to when life events and transitions occur, and linked lives are connections like social relationships and interdependence (Wilmoth & London, 2013).

## Erikson's Ninth Psychosocial Developmental Stage

This section focuses on the 8th and 9th stages of Erikson’s psychosocial developmental theory. For information about stages 1-8, refer to the following resource: [Erikson’s Eight Stages of Development](#).

While Erikson and Erikson (1998) developed a 9th psychosocial developmental stage, this stage is not incorporated into some textbooks. Joan M. Erikson wrote the 9th psychosocial development stage based on

her collaboration with Erik Erikson (Erikson & Erikson, 1998). She mentioned they engaged in rethinking the last psychosocial development stage once they reached older adulthood. Erikson and Erikson (1998) did not feel the 8th psychosocial development stage captured adults 80 years and older, based on their own aging experiences. Reflection on one's life was the key component of the 8th stage of integrity vs. despair and disgust. Erikson and Erikson (1998) suggested older adults will experience despair if an older adult does not feel satisfied or fulfilled with their life experiences. Each psychosocial stage has a virtual and developmental task, and wisdom is the virtue of the 8th stage.

Erikson and Erikson (1998) indicated persons 80 years and older go through all the psychosocial stages (stages 1-8), with the developmental tasks reversed: mistrust vs. trust, shame/doubt vs. autonomy, guilt vs. initiative, inferiority vs. industry, identity confusion vs. identity, isolation vs. intimacy, stagnation vs. generativity, and despair and disgust vs. integrity. Erikson and Erikson (1998) did not use the language disability; however, their description of several of the tasks related to disability. To share several examples, they discussed the decline of the body and how some people may no longer trust in their physical capabilities, resulting in losing hope (mistrust vs. trust). In shame and doubt vs. autonomy, independence was discussed regarding autonomy over their life. For inferiority vs. industry, value to society was explored (Erikson & Erikson, 1998). In Western culture, the emphasis on productivity and achievement places more importance on what a person “does” and not on their personhood; this cultural aspect relates to ableism and ageism.

## Policy and Practice Implications

This section focuses on policy implications and the application of the theoretical perspectives and the practice model from Chapter 2 to aging, disability, and end-of-life care.

### Policy Implications

Beliefs, values, and ideologies shape how policies are implemented and funded. First, it is important for social workers to acknowledge institutional ableism and ageism and how these perspectives have impacted policy development to address discrimination and oppression. There are also other intersectionality layers (e.g., racism, sexism, heterosexism, classism) that impact service delivery for persons aging with disability and adults who experience disability in older adulthood. Social workers should examine policy through a human-rights lens that extends past a needs-based approach. Minimum standards for accessibility are not acceptable, and disabled individuals should not have to advocate to be treated equally. As Cox (2015) noted, “As social policies aim to address the needs of citizens, they should integrate standards that move beyond meeting basic needs to assure that fundamental rights are being met” (p. 13). The importance of a human rights perspective to policy cannot be overstated. Judy Heumann in the film *Crip Camp* (2020) captures the need to think beyond needs-based policies, saying,

“And I’m very tired of being thankful for accessible toilets, you know? I– I really am tired of feeling that way, when I basically feel that, if I have to feel thankful about an accessible bathroom, when am I ever gonna be equal in the community?”

Social workers should use more active language in discussing discrimination and oppression. Disparities occur because of discrimination and oppression. The systems that create disparities need to be discussed, which creates an active approach to examining systemic oppression, racism, sexism, etc., that results in disparities in the first place. Research should do more than repeat that disparities exist but seek to explore meaningful change through solutions.

Policy implications must include discussions about the importance of home and community-based services and financial support available for disabled older adults to remain in the community, where possible. The America Rescue Plan of 2021 Section 9817 provided additional funding for specific Medicaid expenditures (CMS, n.d.-c). The increased funding was around 12.7 billion dollars. While the time period is April 1, 2021, until the end of March 2022, states are able to spend the additional funding until March 31, 2024 (CMS, n.d.-d). The Build Back Better Framework (n.d.) focuses on the affordability and quality of home care services provided to older adults and disabled individuals of all ages. Funding home and community-based services should be permanent in federal and state government budgets. Social workers can play a significant role in exploring solutions to create meaningful changes through micro, mezzo, and macro work, which is intertwined-social work doesn’t take place in a silo.

## Practice Implications

Self-reflection and critical self-examination are vital to becoming aware of one’s own values regarding aging, disability, quality of life, and dignity. Social workers need to recognize how “care getting,” and “caregiving” have presented disabled individuals as passive receivers because society does not view them as contributing to society. The power dynamic inherent in some service delivery is the belief that disabled older adults are not capable of self-directing their own care. Social workers should be cognizant that disabled older adults are the experts of their own lives.

Because there is a lack of information about aging with disability and disability culture in late life, social workers should recognize disabled people who age with disability and nondisabled people who acquire a disability in late life have distinct life experiences. Some nondisabled older adults who develop a disability in late life do not identify as disabled, and they may view their disabilities as unfavorable. Nondisabled adults who become disabled in older adulthood might examine their functioning through a lens of internalized ableism. In contrast, persons who age with a disability and who have a strong disability identity will have different expectations. For instance, some disabled persons are used to directing their own care and advocating for themselves.

Anti-oppressive social work requires action and the ability to engage in the deconstruction of dominant narratives. The dominant narrative some disabled older adults experience is that disability is viewed as the



opposite of successful aging, disabled individuals cannot live with dignity, and disabled persons do not have a good quality of life. The need to reframe concepts like successful aging is paramount to deconstructing the historical narrative of what it means to age well. There needs to be more inclusion of disabled voices about their aging experiences for both disabled individuals who are aging with a disability and nondisabled individuals who experience disability in older adulthood. The concept of quality of life also needs to be deconstructed with a new narrative that disabled people have a good quality of life, value their life, contribute to society, and are more than their assistive devices. Some disabled older adults fear their lives will not be valued if they need acute health care services and that decisions will be made by health care professionals based on their disability. Social workers must acknowledge these experiences and reframe conversations about quality of life in the healthcare environment. Social workers can create opportunities for older disabled adults to connect with each other because peer support is valuable. Anti-oppressive social workers acknowledge and reinforce the value inherent in disabled older adults. Social workers must deconstruct these dominant narratives while working with individuals, groups, families, and communities in meaningful ways.

## Application of the Practice Model

### Pre-Engagement

The question introduced in Chapter Two, “How will my social identities impact client engagement?” is a thoughtful question because self-awareness can guide social workers to new ways of being and thinking. Self-reflection and introspection can also foster empathy for the client as a person. Self-reflection requires stepping back free from judgment while examining one’s own lived experiences and how those experiences shape one’s worldview.

Example: A hospital social worker, Amber Taplin (fictitious name), reviews the medical record of a patient, Roy E. Manns (fictitious name), before meeting the patient. In reviewing his electronic medical record, she learns Roy will be discharged from the hospital in three days. The worker notices Roy is a wheelchair user, a 75-year-old White male, and he recently broke his arm in several places. A nurse notes that the patient does not want to be discharged to a skilled nursing facility for physical and occupational therapy, but his goal is to return to his private residence with home health services. Another note by the physician indicates she wants the patient to be discharged to a nursing home because the patient is unsafe to be at home. Finally, a nurse’s note describes the patient as ‘non-compliant’ and not following the physician’s recommendations.

This vignette will be used for the following application of the practice model.

The social worker, Amber, can self-reflect on how a lens of ableism and ageism can shape how she views Roy’s capabilities of returning home. Amber recognizes she is nondisabled and lacks knowledge about social work practice with disabled individuals. Initially, Amber thought Roy would be safer to discharge to the nursing home but realizes her perspective is due to ableism and ageism. Amber envisions that Roy could feel



frustrated because the hospital staff are not listening to his preference to return home. The social worker can begin to empathize with what Roy might be experiencing. During this self-reflection, Amber can challenge her beliefs about disability and safety. This reflection process will help Amber be mindful of Roy's experiences, including intersectionality.

## Engagement

The social worker can center herself before entering the patient's room. Amber acknowledges to herself she is unfamiliar with the experiences of disabled persons who age with a disability; however, she recognizes Roy is the expert in his life. She decided to take cues from Roy. Before entering the room, she knocked on the door and introduced herself as the unit social worker. Roy became upset, thinking Amber would call Adult Protective Services (APS). Before Amber could explain her role, he expressed his frustrations about his preferences being dismissed by the hospital staff. Amber decided not to interrupt Roy to let him share his experiences. Roy continues by sharing that he has been disabled for 50 years and can care for himself at home. Roy's voice begins to rise, and he tells the social worker he is angry. The social worker validates his frustrations and lets him know she was not there to make an APS report. Roy remarks the nurses and physician never asked him about his goals and what assistance he currently has at home. He shared that directing his own care was very important to him. Amber asked him about his disability identity because disability seemed to be an important part of his identity. Roy shared his history as a disabled activist and how he was on the front lines pushing for home and community-based services. By asking about the patient's disability identity and validating his experiences, the social worker shows Roy that she views him as the expert in his life and capable of making his own decisions. Roy's voice softened, and he appeared more relaxed in speaking with Amber.

## Assessment

The application of the practice model varies in a social worker's professional work setting. For instance, in an acute hospital setting where the patient may only be admitted for several days, engagement and assessment might need to occur during the same visit or a few visits. In this scenario, Amber needs to engage in assessment on the same day she meets the patient. Amber recognizes some of the questions in the assessment about quality of life present as ableist, so she adjusts her assessment approach. In self-reflection, she acknowledges that some healthcare professionals view disabled individuals as having a lower quality of life. Amber does not want to cause further distress for Roy by asking insensitive questions. Initially, the physician wanted the social worker to assess Roy's "behaviors"; however, the social worker recognizes Roy did not have any "behaviors" that would warrant a behavioral health assessment. Roy was advocating for himself and not experiencing a mental health crisis. Amber used a strengths-based approach in assessing Roy's safety. Amber learned that Roy has a supportive network through the assessment process, and there are no safety issues in his home environment.

Amber writes her documentation in the electronic medical record using a strengths-based approach and explains directing his own care is essential to Roy's quality of life.

## Intervention

Amber's awareness about Roy's preferences for directing his own care led her to ask Roy if he would like to meet with members of his care team, including the attending physician. Roy is appreciative of the opportunity to meet with several care team members. Roy gave the social worker permission to start the meeting by highlighting her assessment of Roy as he preferred not to repeat the same information in the meeting to the team. The physician shares her concerns about Roy returning home, but after learning more about his experiences, the physician acknowledges that Roy is more than capable of returning home upon discharge. Roy discusses in the meeting his goals for care, and he also mentions he wants to choose the home health agency because he is aware of a few companies that had problems retaining staff. Roy creates a goal of returning home with home health upon discharge with physical and occupational therapy. Roy becomes more open to medical social work due to feeling heard. Rapport-building takes place throughout the different phases of social work practice.

## Termination

Amber has the opportunity to visit Roy several times during his hospital stay. A few hours before Roy is picked up by a friend to return home, Amber has her last visit with him. Roy asks Amber whether she would be conducting a home visit, and she realizes she has not been clear about her role in working with Roy during their first visit. Amber shares she will not be able to conduct a home visit to check in on him, but she does complete post-discharge calls to check in on people who are discharged to their private residences. Roy mentions he looks forward to speaking with Amber. She provided Roy with the home health agency's contact information, and Roy said he would call the home health agency to follow up.

## Evaluation

Amber uses her understanding of intersectionality to reflect on how ageism and ableism contributed to how some hospital staff treated Roy. When Amber conducted the post-discharge follow-up phone call with Roy, she asked Roy what went well with their visits together and what he felt could be improved. Evaluating one's social work practice requires humility and openness in listening to clients' perspectives. Amber learned Roy felt positive about his experiences with Amber, but he mentioned how he initially noticed she had some level of discomfort. Amber appreciates Roy's feedback realizing her discomfort was detectable by Roy. After her phone

visit with Roy, Amber self-reflected on ways she could continue to educate herself about people who age with a disability.

## Case Study

The following case study is fictitious, and all names have been created using a fake name generator.

Scenario: You are an adult protective services worker who has been assigned a case based on an incoming call to the Adult Abuse Hotline with the allegation of a 72-year-old disabled woman who is living alone in an ‘old house’ with no running water and no heat. The reporter is a hospital social worker.

## Case Details

Arlette C. McCrea returned to her home today from a two-day hospital stay where she was treated for dehydration. The hospital social worker made the hotline call because Arlette left the hospital against medical advice (AMA) and did not want to be discharged from the hospital to a nursing home for physical and occupational therapy. Your supervisor has assigned the hotline report to you to investigate. You call the hospital to speak with the reporter for more details. The hospital social worker shares Arlette is 72 years old and lives alone in an older home that is not habitable. She mentions Arlette has two above-the-knee amputations due to complications from her diabetes ten years ago. The social worker suspects Arlette has some dementia, but Arlette declined to participate in the mental status assessment. The social worker says Arlette “yelled” at the staff and refused to answer assessment questions. The hospital wanted to keep Arlette for several days and discharge her to a nursing home, but Arlette was adamant about not going to a nursing home. She notes Arlette threatened to call 911 if they tried to ‘kidnap’ her. After two days at the hospital, Arlette called a friend to take her home from the hospital. Arlette left the hospital AMA, and they are concerned for her overall health and safety. The hospital social worker explains she was able to speak with Arlette’s oldest daughter, who resides in Michigan. Her daughter was unable to visit her mother in the hospital because she could not take leave from work.

You arrive at Arlette’s home and knock several times, but there is no answer. After five minutes, Arlette opens the door. You tell her you are there to check in with her to see if she was doing okay. You ask her if you can come inside to check in on her to follow up on her visit to the hospital. You hold your identification badge for her to see. Arlette slowly opens the door with a hesitant look on her face. Arlette mentioned not being able to hear you clearly, so you speak louder. She tells you that you can come inside but only for a few minutes. You realize she is speaking loudly to you because she is hearing impaired.

As you enter the home, you observe the inside of her house. There is a large open area to the left side, and you notice a bed, recliner, and television in the middle of the room and a portable toilet in the corner of the room by a sliding glass door. The room has some dust, but you do not notice anything that makes the home

unsafe. There is a closed door to your immediate right and a large staircase down the hall. Arlette is using a manual older wheelchair, and you observe as she wheels herself slowly into the open area with the television, recliner, and bed. Arlette points to a folding chair and says you can sit there because no one was allowed in her recliner.

You ask Arlette what she prefers to be called, and she prefers to be addressed as Mrs. McCrea. You continue to do a visual assessment, noticing Mrs. McCrea's wheelchair was older and something might be wrong with one of the wheels. While the wheelchair has some problems, you observe Mrs. McCrea can propel the wheelchair. You notice there are two cats in the room. As a way to build rapport, you ask her the names of the cats. She responds warmly, sharing the names of her cats. She shares she acquired the cats 12 years ago from a friend. You notice Mrs. McCrea glance at a large photo of a couple in a wedding gown and suit, and you wonder if the picture might be her wedding picture. You ask if the picture was her wedding picture, and she shares the name of her husband, who died ten years ago. Mrs. McCrea states she does not want to talk about her husband. You respect she does not want to talk about him, so you share more details about your role and the purpose of the visit.

You mention someone shared concerns about her health and safety, and you wanted to check to see if she can meet her basic needs. She expresses concern about being checked on, and you validate her feelings. She propels her wheelchair into another room to show you the refrigerator. She opens the freezer, which is full of frozen meals. You ask her about her utilities, and she mentions her friend set up automatic payments for her bills. You notice she warms up to you, so you continue to let her take the lead during the visit. She wheels back slowly into her living space, but you notice she struggles to turn the wheelchair due to one of the wheels. You do not attempt to push her wheelchair or ask her if she needs assistance. After a few more attempts, she is able to turn the wheelchair.

Mrs. McCrea explains she was at the store with her friend when she passed out, and the store called an ambulance against her will. She said she was angry because she could barely hear the staff and was confused about what was happening and what they were doing to her. You ask Mrs. McCrea permission to come back tomorrow for another visit, and she says that would be okay. Based on the information Mrs. McCrea has been sharing, you realize that she does not present as having cognitive impairment.

You return the next day, and you ask Mrs. McCrea if there is anything you could help with, and she shares it would be helpful if someone could take a look at her wheelchair and mow her lawn. You share a local resource that has a wheelchair donation program, and you also share a local resource from an agency that has volunteers that do yard maintenance for disabled older adults. You ask her if she would like help contacting the agencies, and she mentions that she will have her friend help her with making the calls. You thank Mrs. McCrea for allowing you into her home. You want to check on her bathroom situation, and you ask her about the portable toilet in the corner of the room. She says she only uses the portable toilet for emergencies. She propels her wheelchair to the closed door off to the right and mentions this is her bathroom. You notice her hair is clean, she is wearing clean clothes, and you don't ask any more questions about her hygiene. You thank her again and remind her to give you a call if she needs any assistance.

## Discussion Questions

1. What are some ways you could pre-engage with Mrs. McCrea before you arrive for her home visit?
2. What power dynamics and imbalances may already exist or could occur between you and Mrs. McCrea?
3. How might you approach this case using an anti-oppressive practice lens?
4. What are some other ways you would engage with Mrs. McCrea?
5. What are some approaches you can take in showing Mrs. McCrea she is the expert of her life?
6. How might ableism and/or ageism play a role in the hospital's perception of Mrs. McCrea?
7. Why do you think the hospital wanted to discharge Mrs. McCrea to a nursing home?
8. In what ways could you engage in the evaluation of your work with Mrs. McCrea?
9. What is the role of critical cultural competence for the social worker in this case?

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13.

# VIOLENCE AGAINST PEOPLE WITH DISABILITIES: IMPLICATIONS FOR PRACTICE

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## Learning Objectives:

- To appraise the relationship between violence and disability
- To document barriers to services for disabled people experiencing violence
- To describe interventions for violence against members of the disability community

## Introduction

The abuse of people with disabilities is a historically under-examined and under-researched topic. While the percentage of people with disabilities in the United States (US) is 26% (Centers for Disease Control and Prevention (CDC, n.d.), the physical, sexual, emotional, financial, and disability-specific abuse of people with disabilities is exponentially higher compared to people with no disability (CDC, n.d.). While the specific prevalence of abusive acts remains unclear, the consensus of scholars in this area continually points to anywhere from 50 to 100 percent of people with disabilities being victims of some sort of violence. In fact, some scholars in the field have argued that having a disability will automatically make you a target for some form of abuse (Gilson, DePoy, & Cramer, 2001). Given these high percentages, it would seem logical

that more researchers and scholars would focus on interpersonal violence (IPV<sup>1</sup>) of people with disabilities (PWDs<sup>2</sup>). However, this is not the case. This chapter offers a journey through the study of IPV against PWDs by reviewing the current state of the research. The prevalence, forms of abuse, and risks that increase the propensity of abuse will be shared. Current interventions that have been established will be examined using a socioecological perspective. A specific focus on this history of policies created to address IPV in the United States is provided to address the Council on Social Work Education (CSWE) competencies that require a policy-practice approach. The authors conclude this section with how these policies impact PWDs who have been abused.

Given that PWDs have both similar and unique experiences of abuse compared to the non-disabled population, the authors will share information generally about this issue while also choosing to focus on people who are deaf/hard of hearing (d/Deaf<sup>3</sup>). This is in response to our awareness that no one definition and explanation can fully express what occurs to each individual PWD who is abused. A general approach reduces and simplifies this complex and multilayered issue. Suggestions for future research have argued that disability is not a monolith, and new studies must explore the impact of violence on people with specific disabilities and take into consideration the confluence of life experiences based on their unique place in the world (Plummer & Findley, 2012).

This is in response to our awareness that no single definition and explanation can fully express what occurs to each PWD who is abused. A general approach reduces and simplifies this complex and multilayered issue. Suggestions for future research have argued that disability is not a monolith. New studies must explore the impact of violence on people with specific disabilities and consider the confluence of life experiences based on their unique place in the world (Plummer & Findley, 2012).

Intersectionality is a critical concept in understanding the lived experience of PWD, and this chapter strives to discuss intersectional identities wherever possible. In *Care Work: Dreaming Disability Justice*, Piepzna-Samarasinha (2018) cites a list of principles of disability justice, leading with intersectionality. Another important aspect of disability justice is representation, as demanded by the statement “Nothing about us without us,” a call to establish that PWDs know what is best, are experts in their own lives, and that disability-related issues cannot, and should not be studied without the involvement of PWDs. One of the authors of this chapter is a Deaf woman who is a licensed clinical social worker and thus can adequately share her insights

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1. Interpersonal Violence (IPV)<sup>1</sup>, which may include physical assault, sexual assault, stalking, and domestic violence.

2. The authors will primarily use PWD in order to identify people with disabilities. Our language throughout will change from person-first language to identity-first language to recognize the changing ways we address disability.

3. In the Deaf community, lowercase d indicates someone who has hearing loss, but may not culturally identify as Deaf. Capitalized D Deaf indicates someone who knows and uses ASL and identifies as culturally Deaf. This chapter will use both terms.

beyond the current research based on her positionality<sup>4</sup>. The authors will share thoughts and suggestions that may be considered in the future to address this issue. Finally, a case study will be presented with various suggestions to address the needs of PWDs seeking support for their abusive situation.

## Abuse of PWDs Explored and Defined

### Prevalence

The statistics on the prevalence of violence against PWDs suggest that the scale and scope of the issue are significant. Data shows that having a disability not only increases the lifetime risk of experiencing interpersonal violence, but those with disabilities often experience violence for more extended periods of time. In a meta-analysis (Hughes et al., 2012), rates of abuse among PWDs were 1.5 times higher compared to people without disabilities. In their seminal article, Young, Nosek, Howland, Chanpong, and Rintala (1997) examined a community sample to compare rates of abuse between people with and without disabilities and found that disabled people who were abused experienced more forms of abuse for more extended periods compared to people without a disability. More recent studies suggest similar results, indicating that having a disability is associated with a greater risk of violence (Breiding & Armour, 2015), with some indicating a nearly double lifetime risk (Smith, 2007). While the numbers bear witness to a significant problem, it is notable that the field of social work has been slow to explore this issue. This lack of recognition may stem from a reflection of ableism, either intentionally or unintentionally. Ableism is discrimination against PWD in favor of able-bodied people. Ableist norms are easily seen in how social work has mainly viewed disability as a deficiency. As a result, in terms of many social work programs, PWD have been grouped into a singular identity, making it challenging to explore the issue's complexity (Slayter et al., 2022).

When viewing the experiences of PWD as individuals with intersecting identities, it is possible to unpack the unique risk factors and types of violence that contribute to the alarming statistics. PWDs are at high risk for all forms of abuse and violence in their lifetime, including disability-specific violence, such as withholding medications, over-medicating, and neglecting daily living needs such as toileting and bathing (Plummer & Findley, 2012). More recently, Hahn et al. (2014) found that those who identified as having either a mental health or physical disability were more likely to report having experienced interpersonal violence compared to the general population. Similarly, Haydon et al. (2011) reported that individuals with disabilities had significantly higher rates of forced sexual interactions. Research suggests that more than 80% of women with disabilities experience sexual assault during their lifetimes (Obinna, Krueger, Osterbaan, Sadusky, & DeVore, 2006; Stimpson & Best, 1991). Though men with disabilities experience higher rates of violence than both men

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4. Positionality refers to the social, cultural, political, and personal contexts that make up each individual's life experiences, power, and viewpoints.



and women without disabilities, the majority of research on this topic has focused on the prevalence of abuse of women with disabilities (Mitra & Mouradian, 2014; Plummer & Findley, 2012). While specific numbers may vary, it is believed that 39% of those who identify as female report they experienced rape during their lifetime. People who identify as males with a disability are similarly at higher risk of abuse, with an estimated one-quarter (24%) experiencing some form of sexual violence in their lifetime (CDC, n.d.). Likely a reflection of our cultural assumptions about who can be victimized, there remains a dearth of studies on the abuse of individuals that define themselves as male or nonbinary (Breiding & Armour, 2015). Individuals with multiple identities, such as those who identify as LGBTQ+ or BIPOC, may be further invisible in the data. Without academic exploration, our understanding of prevalence is reliant on self-report or uniform crime reports.

Interpersonal violence, in general, is often underreported. According to the Department of Justice, it is estimated that 2 out of 3 sexual assaults go unreported to police, and only half of domestic violence incidents are reported (2020). PWD may face additional barriers to reporting domestic violence, including lack of education about what constitutes violence, knowledge about individual rights or feeling empowered to exercise them, accessibility of resources, relationship to the perpetrator, or the setting where the violence is occurring. These factors may all compound a survivor's ability to choose to report.

Some PWDs may rely on the perpetrator for support in daily living, whether in their own homes or a community setting. For those abused in a community setting, institutions may be reluctant to respond. The violence experienced by PWDs may be aided by the systemic silence of the institutions in which abuse occurs. Hospitals, group homes, schools, and medical transportation companies are seldom held accountable for the acts of the individual abuser (Plummer & Findley, 2012). Instead, reports of violence are met with insensitive behavior by service providers and first responders (Swedlund & Nosek, 2000) or are faced with systemic barriers that impede their ability to obtain help (Gilson et al., 2001). Therefore, the issue often gets identified as a micro or singular issue, often framed as the act of a 'bad apple,' who is then fired. There is generally no follow-up, policy or procedure review, adjustment in hiring practices, or even a report to the police. This lack of follow-through is due to a need to protect the business or organization from potential lawsuits and a loss of revenue. The fear of news being shared about an incident and its impact on the company's bottom line prevents the institution's administration from disclosing violence and abuse. In turn, the individuals who abuse a patient/client/consumer are free to seek out new employment in similar settings, creating a new opportunity for them to harm others. For those experiencing violence in home settings, their experience may be further isolating. The uniqueness of each individual's experience further validates the need for an intersectional approach that includes the voices of PWDs.

## Forms of Abuse

Those who identify as disabled experience all forms of violence and neglect, all of which would be considered abusive. PWDs experience multiple forms of violence and neglect, including physical, emotional, psychological, economic, sexual, and disability-related/specific forms of abuse. Disability-related (disability-

specific) abuse can include withholding medications, denying access to mobility or communication devices, neglecting daily living needs, and barring access to medical services (Copel, 2006). This type of abuse focuses on the person's specific disability and assumed related vulnerabilities. An example would be a partner or family member who intentionally moves furniture and other household items without informing the person who is blind, causing potential accidents and injury. Another situation would be an abuser taking the battery from the scooter of a person who relies on it and placing it at a height the victim cannot reach, thus blocking their ability to utilize mobility aids to leave a dangerous situation. It is essential to consider that an individual with a disability may experience violence due to perceived vulnerability or become disabled due to violence. One example could be a traumatic brain injury caused by ongoing intimate partner violence or mental illness resulting from chronic trauma.

Sobsey pioneered awareness of sexual abuse and assault of PWDs with disabilities in the early 1990s and created the Sexual Abuse and Disability Project (Mansell et al., 1992). Sobsey focused primarily on people with developmental disabilities. Today we continue to see articles that confirm Sobsey's concerns that PWDs are experiencing sexual abuse and assault at high rates (Tomsa et al., 2021). Today we see that PWDs experience rape, sexual violence not identified as rape, control of reproductive or sexual health, stalking, and psychological aggression at rates higher than those without disabilities (Breiding & Armour, 2015). Sexual assault in all forms can result from intimate partner relationships and professional ones. Some doctors, nurses, care attendants, and transportation drivers have used coercion and threats to engage in intimate relationships (Plummer & Findley, 2012).

## Risk Factors

Risk factors for the victimization of PWDs may be experienced at the individual, relationship, community, and societal levels. Some factors include having a lack of independence (often defined as dependence) either physically or financially, isolation, a lack of identification of the abuse (especially if it is disability related), learned helplessness (which has been supported by some and deemed victim-blaming by others (Wanjiru, 2021), and the sheer number of people they interact with daily (Hassouneh-Phillips & Curry, 2002; Plummer & Findley, 2012). At the relationship level, PWDs are often asexualized and therefore do not receive education about consent, boundaries, or healthy relationships (Mailhot Amborski et al., 2021). Further, some PWD are not given autonomy to make their own decisions, including about their own bodies, and may internalize this helplessness. At the community level, PWD may face poverty compounded by being on a fixed income or may experience isolation due to a lack of resources or transportation. At organizational levels, there may be a lack of resources, limited experience or training, and implicit bias. At the societal level, bias and attitudinal barriers play a prominent role. Negative attitudes about people with disabilities and other marginalized identities, such as BIPOC and LGBTQ+ folks, dictate how individuals are perceived and treated. Survivors of IPV are often disbelieved; the same is true for survivors with disabilities.

Overarching all these factors and the most influential and damning risk factor, posited by the authors of

this chapter, includes the overall devaluation of PWDs in society. As Plummer and Findley (2012) succinctly state, “The scarcity of information about the abuse of women with disabilities suggests a continued reluctance of society to acknowledge that violence toward this population may be occurring” (p.15). The lack of acknowledgment of men’s victimization may be further compounded by cultural assumptions regarding who can be victimized. Generally, attitudes toward the disabled population have been historically negative (Hassouneh-Phillips & Curry, 2002). PWDs have always been marginalized, hidden in locked facilities, dehumanized, and made to feel like a stress and strain on the rest of the population (Cramer et al., 2003). Regardless of disability, PWDs are seen as burdens that must be dealt with rather than integrated into society (Cramer et al., 2003). This, in turn, creates a lack of attention and priority to an endemic that places PWDs at high risk of abuse in all areas of their lives, beginning in childhood.

Ultimately, the cause of IPV rests with the perpetrators of violence. While there are risk factors for victimization that require attention, there are also risk factors for perpetration that demand intervention to ensure that violence against PWD stops. Some individual risk factors for perpetration may include a lack of empathy or adherence to traditional gender roles or hyper-masculinity. At the relationship level, experiencing or witnessing abuse as a child or having an unsupportive family environment could be a risk factor for perpetration. At the community level, poverty, lack of resources, community support for violence, or weak sanctions for perpetrators could contribute. Norms that support violence, including patriarchy and weak policies related to violence and equity, may contribute to perpetration at the societal level. When examining interventions, it is essential to consider responses that address issues at all socio-ecological levels and also seek to prevent harm from occurring in the first place (CDC, n.d).

## Interventions

Interventions focused on IPV and PWDs tend to exclude clients’ specific and contextual needs and their unique experiences in the world (Plummer & Findley, 2012). Effective interventions require action at the individual, relationship, community, and societal levels and should target risk factors for victimization and perpetration. Following a public health model, primary, secondary, or tertiary interventions may occur. Primary interventions occur before violence has been perpetrated, secondary interventions focus on preventing escalation, and tertiary interventions are provided after violence has occurred. Within this model, a primary intervention could be educational programs aimed at preventing violence, a secondary intervention could be screening for violence, and a tertiary intervention could provide follow-up services or resources.

Often interventions for PWD focus on the tertiary level and are reactive. This supports the idea that PWDs need to be protected rather than empowered with information promoting a “response-to-risk approach to a broader approach encompassing safety as part of quality of life and human rights.” (Araten-Bergman & Bigby, 2020). These interventions usually focus on skills training for staff working in care settings or behavioral training for PWD on what to do if they experience violence. Secondary interventions such as screening tools for PWD are scarce, limited to physical disability, or center on women’s experiences (Curry et al., 2004;

McFarlane et al., 2001). Further, provider training on how to implement screening tools is limited. Existing primary interventions often seek to modify rather than build interventions with input from those with lived experience. For example, programming curricula that seek to prevent sexual, dating, and domestic violence exist; however, programs created for and with the input of PWD are severely limited, as are rigorous evaluations of the modified interventions that do exist (Mikton et al., 2014; Barger et al., 2009).

As noted, the experiences of PWD cannot be grouped into one monolith. Interventions must be developed to meet the individual needs of each survivor based on their experience and available resources or lack thereof. “A comprehensive, trauma-informed response to IPV for women with disabilities must begin by addressing the full constellation of disability-related risk factors and consequences of abuse, at both personal and structural levels” (Ballan & Freyer, 2017, p. 134).

It is relevant to consider that all program interventions are shaped by the implicit bias of the authors, which may limit the scope of content and frequently center women’s experiences. The exclusion of men, LGBTQ+ folks, and BIPOC from intervention development creates an added risk factor for these individuals. For this reason, those with lived experience must be included in the research, development, and evaluation of prescribed interventions. Cross-sector collaboration is also a vital community-level intervention that can propel sustainable change and ensure that victim service providers feel competent to serve PWD and those working in disability-focused agencies feel prepared to empower survivors. While the anti-violence movement and disability justice share tenets of equity and inclusion, they also share a divergent history.

## The History of IPV Policy

### Overview

Understanding the historical context of how the United States has addressed IPV from a policy and practice standpoint is essential. History offers insight into how a problem becomes a social issue at the forefront of national policy concerns. Public policy has been rooted primarily in attempting to address and respond to ‘violence against women’ and has only begun to address interpersonal violence more broadly within the last decade. Therefore, using the term ‘gender-based violence’ in public policy is intentional—currently, three significant federal policies focus on gender-based violence in the U.S. The following section will outline these policies, including how the legislation impacts survivor-focused programming for PWD locally. Further, there will be a brief discussion of Covid-era legislation and its impact on survivor communities, especially d/Deaf individuals and PWDs. Finally, this section will explore the Americans with Disabilities Act as it applies to survivors of gender-based violence, including opportunities for continued discourse and policy growth.

Federal policy plays a significant role in determining funding allocations and service provisions for survivors of gender-based violence. Federal policy also has the power to shape public discourse, shift perspectives, and generate systems change. To understand the role that public policy plays in the intersection of gender-based

violence and disabilities, it is essential to consider how the interpersonal violence field has gotten where we are and to examine how policy can shape where we are going.

## Policy Development and Research Trends

Although we now understand that gender-based violence results from intersecting individual, family, community, and societal factors, this understanding was not always widely held. Until the 1970s, in the United States, gender-based violence was viewed as an individual or private issue and was treated as such by the law. Gender-based violence is rooted in patriarchy or the belief that men inherently hold more power than and over women. Patriarchy presumes that there is some innate difference between genders and attaches power to that difference. Within this belief system, men are expected to be strong, aggressive, and dominant and may use violence to maintain that dominance. These same patriarchal views have been codified in law for centuries, from a Roman marriage, where a wife was completely under her husband's legal control, to marital rape—which was not made illegal in all 50 states until 1993. As of 2023, states' definitions of marital rape vary to varying extents (Kamp, 2020; Berger, 2006). It has taken decades of awareness-raising, advocacy, and, quite frankly, the death and injury of many individuals to shift gender-based violence into the public sphere, where it is now recognized as human rights violation (United Nations, Office of the High Commissioner for Human Rights, 1993).

Built on the foundation of Civil Rights, Black Liberation, and movements against war in the 1960s, the Women's Liberation Movement opened a space for survivors of gender-based violence to begin speaking up and working together in grassroots movements for change, except for survivors with disabilities (Evans, 2015). The voices of disabled individuals were often excluded in these spaces prompting the growth of Disability Rights as a parallel movement (Anti-Defamation League, 2018; Price, 2011). There is still an exclusion of PWDs from social movements focused on IPV, as seen during the rise of the #MeToo movement in 2018, prompting the #DisabilityToo movement in response (McNamara, 2018). Notably, women of color were and still are excluded from feminist spaces. Crenshaw (1991) posits that “because of their intersectional identity as both women and of color within discourses that are shaped to respond to one or the other, women of color are marginalized within both. Even the #MeToo movement noted above and birthed by Tarana Burke, a woman of color, did not gain traction until Alyssa Milano, a famous white woman, co-opted the hashtag. In response to the growth of #MeToo, Burke (2017) shared in a Washington Post article that:

What history has shown us time and again is that if marginalized voices — those of people of color, queer people, disabled people, and poor people — aren't centered in our movements, then they tend to become no more than a footnote. I often say that sexual violence knows no race, class, or gender, but the response to it does (para. 11).

Furthering the point, activist Vilissa Thompson highlighted the exclusion of women of color from the #DisabilityToo movement and responded with #DisabilityTooWhite, which reminded people that disability rights and civil rights are the same (Dunn, n.d.). The intersectionality of oppression is not a new concept, nor

is the whitewashing of people of color from mainstream movements. In her book, *Black Disability Politics*, Schalk (2022) reminds us that although the Black Panther Party (BPP) “understood disabled people, along with other people of color, people in poverty, women, and gays and lesbians, to be fellow oppressed members of society who had to fight for survival in an oppressive capitalist system”, this narrative is largely invisible in our understanding of the BPP or the disability rights movement (p.30).

During the 1960s, although grassroots activism was gaining national attention, individuals in the community were still being harmed, often behind closed doors. Advocates seeing the need in their communities began opening their homes to create safe spaces for survivors. By the early 1970s, acknowledging that the need was more significant than what individual homes could offer, advocates began to open community-based domestic and sexual violence programs (Fernandes-Alcantara & Billings, 2021). It is essential to consider that this grassroots movement continued to grow in response to community needs; however, there was still no federal legislation or intervention in place to protect survivors or prevent violence from occurring during this time. Additionally, while opened with good intentions, these community-based programs did not consider the unique needs of survivors with disabilities and were often inaccessible (Dubin, 2007). It was not until 1986 that Abused Deaf Women’s Advocacy Services (ADWAS) was founded in Seattle, Washington, to support and empower Deaf and DeafBlind survivors of domestic/sexual violence. ADWAS was the first agency of its kind in the United States. The Department of Justice later funded it in 1998 and 2009 to train other cities in their model (Abused Deaf Women’s Advocacy Services [ADWAS], n.d.).

The elevation of survivors’ voices during this time, as well as a growing national crime rate, prompted the federal government to pay greater attention to violence against women as a public health issue; however, the fight for dedicated funding and legislative change was hard-won. Despite data showing the prevalence of gender-based and family violence, gaining bi-partisan support was challenging through the 1990s. Although during the late 1970s, the Carter administration had secured a meager amount of funding for domestic violence shelters and founded an Office of Domestic Violence in the United States, that funding was later discontinued by the Reagan administration, leaving agencies and families to fend for themselves once again (Weldon, 2022, p.2; NY Times, 1983). With continued public discourse in 1984, the Department of Justice (DOJ) issued a report that examined the scope and impact of domestic violence in the US. This report recommended improvements in law enforcement and community responses to offenses which, in turn, prompted a series of congressional hearings during the late 1980s and early 1990s held to understand better the scope of domestic violence and other forms of violence against women in the United States (Fernandes-Alcantara & Billings, 2021).

While hearings and research continued to explore the scope of the issue, individuals were still being harmed. Critics of the lack of government intervention, like June Zeitlin, former Director of the Office of Domestic Violence under President Carter, seeing that lives were being lost at the expense of politics, noted that “these families need help, not more studies of the problem and election-year rhetoric (NY Times, 1983).” Federal policy cannot advance without bi-partisan support. Looking back at this period, Scholar Van Eck argues that it was a change in rhetoric by advocates from one of patriarchy to that of civil rights and equal protection



under the law that eventually pushed the movement forward (2017). For context, in 1984, out of 435 members of Congress, only 24 of those were women (*Congress Profiles*, n.d.; *History of Women in the US Congress*, n.d.). Seeking to garner bi-partisan support for legislation that a large percentage of Congress may have felt unaffected by or rhetoric they may have felt attacked by could have stalled support.

The three primary national policies focusing on gender-based violence that exist today are a result of ongoing legal battles, relentless advocacy fueled by the Women's Liberation Movement, research into the prevalence of the issues, and the bravery of survivors who put a face to the issue by sharing their stories during Congressional hearings. As noted, the voices of disabled people and people of color were silenced during the evolution of the mainstream Women's Liberation Movement. Conversations and meetings were often inaccessible or invisible in mainstream media (Price, 2011; Schalk, 2022). This systemic exclusion at the very root of the movement meant that disabled voices and Black, Indigenous, and People of Color (BIPOC) were left out of research, policy, and funding allocations. The far-reaching impact of ableism and racism, particularly in policy development and roll-out, is an ongoing concern.

## Family Violence Prevention and Services Act

The Family Violence Prevention and Services Act (FVPSA, Title III of P.L. 98-457) was the first federal law to address domestic violence. Initially enacted in 1984, FVPSA has been reauthorized multiple times, most recently through the fiscal year 2015. Although the act has yet to be reauthorized since its expiration, Congress has appropriated funds to ensure the continuity of programs. In October 2021, the House passed H.R. 2119, known as the Family Violence Prevention and Services Improvement Act of 2021, which, if authorized, would amend the existing FVPSA. As of May 2022, H.R. 2119 is still pending Senate action. Reauthorization would allow amendments to the law focused on increasing inclusion and access for individuals with disabilities.

In 1984, when FVPSA was enacted, it included both social service and law enforcement responses to preventing and responding to domestic violence. FVPSA focuses specifically on family, domestic, and dating violence, and it does not broadly address interpersonal violence or gender-based violence. The law authorized grants focused on providing services and shelter to survivors and training and technical assistance to law enforcement personnel nationwide. Over the years, the act has been amended to include support for children exposed to domestic violence and teen dating violence. FVPSA currently authorizes three primary activities: prevention programming, domestic violence services and support, and the national domestic violence hotline, which began in 1996. Training and technical assistance for law enforcement were later removed and brought under the Violence Against Women Act (VAWA) umbrella. The U.S. Department of Health and Human Services (HHS) Family and Youth Services Bureau (FYSB) administers funding for the hotline, domestic violence shelters, and direct services to survivors. The Centers for Disease Control and Prevention (CDC), also within HHS, administers the Domestic Violence Prevention Enhancement and Leadership Through Alliances (DELTA) programming.

When the FVPSA was last enacted in 2010 under the Child Abuse Prevention and Treatment Act



reauthorization, apart from ensuring the accessibility of hotline access, it did little to address the needs of disabled people explicitly. While it mentions underserved populations<sup>5</sup>, the act did not acknowledge the scope of violence against d/Deaf or disabled individuals or earmark funding to meet their specific service needs. Specifically, the 2010 reauthorization notes that applicants for FVPSA funding must demonstrate a commitment “to the provision of services to underserved populations, including to ethnic, racial, and non-English speaking minorities, in addition to older individuals and individuals with disabilities” and that the funded hotline program “shall provide assistance and referrals to meet the needs of underserved populations and individuals with disabilities” (pp. 47-48). Lastly, it mentions that education and planning should “recognize, in applicable cases, the needs of underserved populations, racial and linguistic populations, and individuals with disabilities” (p. 51). While the act requires a commitment by applicants to provide services for and meet the needs of disabled survivors, it does not offer funding to build agency capacity or support access needs (Family Violence Prevention and Services Act, 2010). This means that although anyone receiving FVPSA funding is committing to serve individuals with disabilities, they may not know how or have staff who feel competent to serve and may not be able to access training. Further, they may be unable to ensure that their facilities, outreach, or services are accessible. As another example, this could mean not being able to develop linguistically or visibly accessible outreach materials or being able to hire a certified interpreter.

Being committed to providing services for disabled people is not the same as being competent or able to provide service. As noted, a primary exception to this is a relationship forged between the National Domestic Violence Hotline and Abused Deaf Women’s Advocacy Services (ADWAS). In 2003, the National Domestic Violence Hotline partnered with ADWAS to roll out the Deaf Hotline. Since 2017, The Deaf Hotline has been available 24/7. Their website “offers safe, confidential advocacy services for Deaf survivors and service providers [and] resources and education about the need for Deaf abuse outreach programs.” (n.d.) This program, however, is not codified in any law but instead supported with discretionary funding.

Contrary to the limitations of the current FVPSA as enacted, bills have been presented in the last few years to amend the act, addressing the erasure of individuals with disabilities from the legislation. One such bill, the Family Violence Prevention and Services Improvement Act of 2021 (H.R. 2119), was passed by the House on October 26, 2021, but was never passed by the Senate. The Senate companion bill S. 1275 also stalled. H.R. 2119 explicitly acknowledged the disproportionate rates of domestic, dating, and family violence among d/Deaf individuals and individuals with disabilities and, as such, would have allowed subgrant funds to be used for “making improvements in the accessibility of physical structures, transportation, communication, or digital

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5. According to “section 40002(a) of the Violence Against Women Act of 1994 (42 U.S.C. 13925(a)). The term “underserved populations” means populations who face barriers in accessing and using victim services, and includes populations underserved because of geographic location, religion, sexual orientation, gender identity, underserved racial and ethnic populations, populations underserved because of special needs (such as language barriers, disabilities, alienage status, or age), and any other population determined to be underserved by the Attorney General or by the Secretary of Health and Human Services, as appropriate.

services” (p. 29). Subgrants are grants by which funds from one organization are awarded to another agency or sub-recipient to help further the work.

Further, the bill outlined an expectation that funded National Resource Centers and Technical Assistance providers would help increase the “capacity of community-based organizations serving individuals who are Deaf and individuals with disabilities to respond to and prevent, domestic violence, dating violence, and family violence.” That training and advocacy around prevention would consider “community-based programs serving Deaf individuals and individuals with disabilities” (H.R. 2119, 2021, pp. 42, 82). If enacted, H.R. 2119 would have ensured that the barriers and needs of d/Deaf and disabled people might be acknowledged, lending funding, structure, and accountability to the law. Further, it would lead service providers to seek competence in reaching and serving PWDs. The FVPSA has not been reauthorized since 2010, leaving funded programming open to federal budget cuts and limiting expansion efforts like those proposed by H.R. 2119.

## Victims of Crime Act (VOCA)

In 1984, the Victims of Crime Act (VOCA, P.L. 98-473) was passed, and through its enactment, the Crime Victims Fund (CVF) was established to provide financial support for state victim compensation and assistance programs. In 1988, the Office for Victims of Crime (OVC) was formally established within the Department of Justice (DOJ) to administer VOCA programs. Unlike other federal streams, VOCA programs are specifically funded through federal criminal fines and fees deposited in the Crime Victims Fund (Sacco, 2021). Within the last several years, CVF deposits have been declining, leading to the July 2021 passage of the VOCA Fix to Sustain the Crime Victims Fund Act of 2021 (P.L. 117-27). Although VOCA applies to victims of any violent crime, it is the largest source of federal funding for domestic and sexual assault services in the country (Buchbinder, 2021).

Each year, Congress establishes a cap on the distribution of VOCA funds. For FY22, \$2.6 billion was made available for VOCA-authorized programs (United States Senate, Committee on Appropriations, 2022). This appropriation supported the Children’s Justice Act program, U.S. Attorney General Victim Witness and FBI Victim Witness Specialist staff, and the Federal Victim Witness Notification System. The remainder supported discretionary programs and formula grants. Victim Compensation and Victim Assistance formula grants are distributed to states and territories annually. Victim assistance funds may be used to provide grants to support direct services to victims of crime, including information and referral services, crisis counseling, temporary housing, criminal justice advocacy support, and other assistance needs. Compensation funds may be used to reimburse victims of crime for out-of-pocket expenses such as medical and mental health counseling expenses, lost wages, funeral and burial costs, and other costs authorized at the state level. Discretionary funds have been used for various programs and initiatives over the years. VOCA funds have also been used to authorize programs under the Violence Against Women Act (Sacco, 2021).

Although the Victims of Crime Act does not explicitly mention d/Deaf or disabled survivors, the Office of Victims of Crime (OVC) has shown great dedication to increasing awareness and access for survivors with

disabilities. In the late 1990s, OVC funded one of the first national scope initiatives focused exclusively on the issues associated with crime victims with disabilities. Then in January 1998, the National Organization for Victim Assistance (NOVA) used OVC funds to coordinate *Working with Crime Victims with Disabilities*, a symposium that brought together experts from disability rights, protection and advocacy, crime victim assistance, law, and research. Later that year, OVC published *Working with Victims of Crime with Disabilities* (NCJ 172838), a bulletin addressing the issues that have created and perpetuated obstacles to safety, services, and justice for disabled survivors, including recommendations on how to improve access (Tyskia, 1998).

OVC has continued to use discretionary funds to support d/Deaf and disabled survivors and improve services by funding initiatives to create fact sheets, training and technical assistance programs, awareness campaigns, videos, and toolkits aimed at increasing capacity for agencies, especially law enforcement, to serve survivors with disabilities. In 2017 the National Resource Center for Reaching Victims was developed with OVC funding and led by the Vera Institute of Justice ([www.reachingvictims.org](http://www.reachingvictims.org), n.d.). This collaboration is meant to update and expand the field's resources on crimes against PWDs and seeks to build community capacity by facilitating an online resource library. The library gives the public access to videos and online training, including a toolkit to increase law enforcement's capacity to work with survivors with disabilities. In the Fall of 2021, OVC recently funded the Vera Institute of Justice to develop a "National Sign Language Interpreter Bank for Victim Services," which will provide free sign language interpretation services through virtual technology to survivors across the country (Department of Justice, n.d.). Having been recently funded, this program is still in the stages of development ((Vera Institute of Justice [DeafHope Team], 2022)). OVC has also continued to support ongoing awareness-raising about violence against d/Deaf and disabled individuals, particularly during Crime Victims Awareness Week, which takes place each April.

## Violence Against Women Act (VAWA)

Initially passed in 1994, the Violence Against Women Act (VAWA, Title IV of P.L. 103-322) is considered landmark legislation as it offers a federal legal intervention into what had been previously considered a private issue. While the Family Violence Protection and Service Act (FVPSA) is focused primarily on service provision, VAWA broadens federal response to gender-based violence by including investigation and prosecution of crimes, providing additional services to victims and those who cause harm, and educating the criminal justice system and other stakeholders about the issue. VAWA covers four primary focus areas: domestic violence, sexual assault, stalking, and dating violence. Provisions for survivors of human trafficking are also covered within the law.

Similar to the Family Violence Prevention and Service Act, the passage of VAWA came from decades of grassroots advocacy, research, and a growing interest in understanding the prevalence of domestic and other types of violence against women. Although the FVPSA allocated funds for shelter and direct services, field research and testimony made it clear that there needed to be a more comprehensive response to violence against women, including harsher penalties for perpetrators. As a matter of context, marital rape was not

illegal in all 50 states until 1993, validating the long-held notion that what happens behind closed doors stays behind closed doors (Bergen, 2006; Gover & Moore, 2021) or that women are under the ward of their husbands. Gender-based violence festers in silence and within the patriarchal notion that men and masculine identities hold more power than individuals of other identities. For many, the passage of VAWA meant a greater opportunity to increase safety for survivors, hold offenders accountable, and work toward preventing gender-based violence. The act also authorized the creation of the Office of Violence Against Women (OVW) in 1995 to administer VAWA programs (Sacco & Hanson, 2019).

The Violence Against Women Act requires reauthorization every five years. The act was reauthorized in 2000, 2005, 2013, and most recently in 2022, after it lapsed in 2018. VAWA has primarily been seen as a criminal justice approach to violence, encouraging compliance through legal intervention or punishment. However, this approach does little to address the intersectional needs of survivors, particularly survivors who are black, indigenous, or people of color (BIPOC) who face multiple levels of oppression or risk factors for victimization that may not be addressed by the laws that were mainly created by white men or based on the elevated experiences of white women. From the original drafting of VAWA in 1990 to the present day, the stories of people holding privilege are often highlighted by the media or deemed worthy of public attention. The stories of indigenous women, individuals with disabilities, immigrants, and undocumented individuals, often those most impacted or at risk, go unheard. Policies like VAWA are drafted by privileged people who may have biased perspectives. With each reauthorization of federal legislation like VAWA, there is an opportunity to reconsider whose story is not being heard or who is being left out. The Violence Against Women Act Reauthorization Act of 2022, signed on March 16, 2022, will be in effect from FY2023 through FY2027. Each reauthorization has offered an opportunity to expand access for survivors and increase prevention efforts. This seems especially true for the 2022 reauthorization, which expands tribal authority to prosecute non-native perpetrators<sup>6</sup>, increases services and support for underserved communities, brings a greater focus on and penalties for cybercrime, and seeks to improve medical, legal, and forensic systems response for survivors (Violence Against Women Act Reauthorization Act of 2022, 2022).

According to the Office on Violence Against Women's website, OVW currently administers 4 formula-based and 15 discretionary grant programs, established under VAWA and subsequent legislation ([www.justice.gov/ovw](http://www.justice.gov/ovw), n.d.). Funding is awarded to local, state, and Tribal governments, courts, non-profit organizations, community-based organizations, secondary schools, institutions of higher education, and state and tribal coalitions. Grants are used to develop effective responses to interpersonal violence through activities that include direct services, crisis intervention, transitional housing, legal assistance to victims, court improvement, and training for law enforcement and courts. Rape Prevention and Education (RPE) funding

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6. American Indian and Alaska Natives experience high rates of interpersonal violence across their lifetime, often perpetrated by non-native harm-doers and also experience disability at high rates (DOJ, 2016; CDC, 2008).

is administered through the Centers for Disease Control and Prevention. One of the 15 discretionary grant programs authorized by VAWA is the Disability Grant Program.

When VAWA was originally enacted in 1994, it did not provide specific funding for survivors with disabilities. It wasn't until the 2000 reauthorization that the Disability Grant Program was included to fund education and technical assistance to better meet the needs of disabled victims of violence. OVW began making grants under the Disability program in 2002. When VAWA was later reauthorized in 2005, the act expanded coverage for disabled victims by including funding for education, training, and services, as well as grants to cover construction and personnel costs for shelters. During this time, the Disability Grant Program shifted to a focus on sustainable change by funding the development of collaborative relationships between victim service providers and disability organizations and also provided funding for the development of model programs. The Vera Institute for Justice was also brought on as a technical assistance provider to increase success and sustainability during this time. Since 2006, the grant program has remained structurally the same with a focus on collaboration, organizational change, resource sharing, and education. In celebration of the 25th Anniversary of the Americans with Disabilities Act (ADA), the Vera Institute for Justice used OVW funding to launch *End Abuse of People with Disabilities*, a web-based clearinghouse of resources and information for those working at the intersection of survivor advocacy and disability.

While the grant program itself has been structurally similar since 2006, there were a few changes in the text of the law when VAWA was reauthorized in 2022 aimed at increasing inclusion and access. Specific to section 203, also called *Grants for Training and Services to End Violence Against Individuals with Disabilities and Deaf People*, the text has been amended to state “individuals with disabilities” without specifying gender (VAWA, 2022, p. 809). Several other sections of the reauthorization have also been amended to be inclusive of all individuals rather than a distinct focus on ‘women.’ Similarly, both the section title and text have been amended to ensure “Deaf people” are included as a distinct group of individuals impacted. Throughout the act, in general, when disabled individuals are referenced, the text has been amended to ‘person-first’ language. Specifically, ‘disabled individuals’ has been stricken in each place it appears and replaced with “individuals with disabilities and Deaf people.” Language has also been amended to ensure that “abuse by caregivers” is included as a covered focus by the grant showing a recognition of the unique experiences of some disabled survivors. Cross-training reach has been amended to include ‘first responders’, and there is a focus on enhancing the capacity of agencies to support individuals with disabilities, reflecting a move toward sustainable systems change. There has also been a substantial increase in funding from \$9 million to \$15 million over the next 5 years, beginning in FY23. Other notable changes throughout the act include the insertion of ‘underserved populations’ in multiple areas, which by federal definition includes those with disabilities. This VAWA reauthorization, with the inclusion of the “Supporting Access to Nurse Exams Act,” will also fund research seeking to understand barriers to access for survivors, particularly in Tribal, rural, and other underserved communities (VAWA, 2022).

Despite some increased inclusion when it comes to the law, there continues to be a disconnect between the fiscal needs raised by OVW and final federal appropriations. The Federal FY22 budget authorized \$575

million in total for VAWA programs which is the highest funding level ever; however, this funding amount is still significantly less than what was requested by OVW or included in the President's budget. Specific to funding for disabled survivors, there is a large gap between OVW requests and the finalized budget. Most notable is that although OVW continues to request the creation of a dedicated National Deaf Services line, it was not appropriated for in FY22 (National Network to End Domestic Violence, 2022). For FY23, OVW has again requested \$4 million for the creation of a Deaf Services Line. In their justification, OVW notes that there are only 21 'for Deaf, by Deaf' victim service programs nationwide and that "deaf survivors frequently seek services from mainstream victim service providers, which often are not well-positioned to meet the needs of these survivors. A national Deaf services line will expand the reach of Deaf-specific victim services by providing these services virtually" (p. 56). A deaf services line was last authorized in 2017 when OVW funded the Vera Institute of Justice's Center on Victimization and Safety to create a plan for establishing a National Deaf Service Line that will enable Deaf victims of domestic violence, sexual violence, dating violence, and stalking to speak directly with a Deaf advocate or an individual who is fluent in their preferred mode of communication via video phone 24 hours per day, seven days per week (US Department of Justice, 2017).

## Executive Order 13985

Unlike the other federal policies noted within this section, Executive Order 13985: *Advancing Racial Equity and Support for Underserved Communities Through the Federal Government* is not a public law, nor does it have funding directly attached. However, this executive order can increase access and inclusion for disabled individuals who have been historically underserved by addressing barriers to inclusion at the federal level. Specifically, the order seeks to promote:

...the consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality( Executive Order 13985, 2021).

Since the release of Executive 13985 in January 2021, federal agencies have begun referencing the order on their grant solicitations and specifically considering equity and access in their priority funding areas. For example, a solicitation put out by the Office for Victims of Crime in April 2022 specifically notes that in support of Executive Order 13985, the funder will:

...give priority consideration to applications that include project(s) that will promote racial equity and the removal of barriers to access and opportunity for communities that have been historically underserved, marginalized, and adversely affected by inequality, when making award decisions (OVC, 2022).



Putting in place an order that seeks explicitly to elevate underserved populations, including those with disabilities, in providing violence against women services appears to be a step toward embracing disability justice as a model for change.

## Covid-era Policy

In acknowledgment of the increase in domestic and sexual violence during the pandemic, specific funding was made available through federal legislation to support survivors of gender-based violence. Through the Coronavirus Aid, Relief, and Economic Security Act, 2020 (CARES Act; P.L. 116-136), Coronavirus Preparedness and Response Supplemental Appropriations Act, 2020 (P.L. 116-123), and the American Rescue Plan Act of 2021 (P.L. 117-2) funding was made available to increase service access through the virtual provision of services and the reallocation of funds to support survivors seeking direct services due to increased need brought on by the pandemic. Specifically, the CARES Act provided additional FY2020 funding of \$2 million for the national domestic violence hotline, including hotline services provided remotely, and \$45 million for FVPSA formula grants. The Coronavirus Preparedness and Response Supplemental Appropriations Act of 2020 provided funding to the CDC, which used \$1.6 million to support domestic violence prevention grants. The American Rescue Plan Act of 2021 authorized \$1 billion in supplemental funding for domestic violence and sexual assault services, including \$49.5 million for “organizations that help survivors from historically marginalized communities” (Fernandes-Alcantara, & Billings, 2021; The White House, 2022). Each of these allocations was temporary to help mitigate the increased risk of violence and impact faced by survivors during the pandemic. This funding also allowed expanded service access by increasing the availability of virtual services and support. This virtual support even extended into the courtroom, where survivors could obtain a restraining order through virtual means in many states, while under mandatory stay-at-home orders.

Across-the-board funding for virtual access is a great example of how universal design and access can benefit everyone. Disabled individuals often struggle with transportation and communication-based access, and suddenly due to increased funding for virtual services, survivors were able to connect with a counselor or judge online. To ensure support for those isolating at home, the Department of Justice (DOJ) Office on Violence Against Women (OVW) developed virtual technical assistance and guidance about virtual services and supported courts across the country in providing virtual access for emergency requests, time-sensitive hearings, and victim services (White House, 2021). Some of these funding streams also increased the amount of money being allocated to individuals with disabilities through Medicaid coverage and expanded access to virtual services, transportation resources, and physical modifications to increase access. This is not to say the Covid crisis did not compound the impact on disabled survivors, including increased risk of violence and barriers to help-seeking. However, these policies do highlight how the federal system can adapt and consider creative ways to limit barriers to access all the time, not only during a pandemic. Those with disabilities are not just impacted by disability-targeted programs, they are impacted by all policies.



## Americans with Disabilities Act (ADA)

While the intention of Section 504 of the 1973 Rehabilitation Act and the Americans with Disabilities Act (ADA, 1990) are to ensure access and inclusion for individuals with disabilities, both fall short in closing the gaps experienced by disabled survivors of gender-based violence. Often, the barriers to access faced by many survivors go beyond the public understanding of what the ADA covers, such as cognitive, psychological, or intellectual access barriers. Further, programs are not necessarily funded to support the access needs of survivors, or the capacity building required to ensure that those working with Deaf and disabled survivors are prepared to do so.

Although the ADA has changed the field for many disabled survivors, the act has limitations. According to Section 36.105 of the Americans with Disabilities Act, disability “with respect to an individual” is defined as “(A) a physical or mental impairment that substantially limits one or more major life activities of such individual (B) a record of such an impairment; or (C) being regarded as having such an impairment” (1990). This ambiguity can help some survivors; however, it can also leave agencies and businesses free to decide about access needs based on their biases; these biases mean who decides whose needs fall under the ADA. For example, individuals with certain physical or mental health conditions seeking accommodations through the ADA may find that the ambiguity helps them gain the support they need. However, this same ambiguity means those meant to adhere to the ADA may not have clear guidelines to follow and could therefore decline accommodations for someone whose needs do not fit within their interpretation of the guidelines. This is especially true when individuals with disabilities are not included in decision-making processes.

Federal grant programs also rely on the ADA to set a standard for service provision. The ADA is referenced in most federal solicitations, reminding applicants and recipients that programming must be accessible to individuals with disabilities. This is an example of where bias can impact application. Often agencies consider physical accessibility but neglect to apply accessible design to education, materials, web design, environments, policies, and procedures (Mullen, 2018). This level of critique and application is best achieved by including individuals with disabilities. Often agencies may not even realize how exclusionary their services and policies are. Agencies might collect information about disability status when they provide services; however, if disabled individuals do not know the program exists because their outreach is inaccessible, they are not meeting the requirement of the ADA. This bias in data collection also causes an underreporting of the prevalence and impact of violence on disabled survivors.

One of the limitations of the ADA is that it is a voluntary compliance law, so nothing holds agencies accountable (ADA, 1990). There are no benchmarks or reporting requirements as with other civil rights laws. Suppose someone were to report an agency or business. In that case, agencies often note that the cost of fines for being out of compliance is cheaper than the construction or modification costs of being compliant. To help close this gap and support programs in serving disabled survivors, the Vera Institute for Justice developed tools to help both disability agencies and victim service providers evaluate their commitment to and capacity for serving survivors with disabilities. Agencies can also use this tool online. However, much like the ADA, there

is no financial incentive or support for embarking on this process outside of applying for and being awarded a grant through the OVW Disability Program.

## Interpersonal Violence and Disability in America: Deafness as a Key Example

According to the National Child Traumatic Stress Network (2006), “severe hearing loss or deafness affects approximately 22 out of every 1,000 people” (p. 4). About two million Americans with hearing loss meet the criteria for profound deafness—the inability to hear anything but the loudest of sounds (National Child Traumatic Stress Network, 2006). Most of these two million Americans comprise the American d/Deaf community.

Though many Americans have hearing loss, the d/Deaf community is mainly unknown to the broader hearing public. A common term to describe d/Deaf people is ‘hearing impaired,’ which focuses on what d/Deaf people cannot do—hear<sup>7</sup>. Doing so establishes hearing as the societal norm and infers that d/Deaf people are abnormal because they cannot hear (National Association of the Deaf, 2019). In contrast, members of the Deaf community focus on what they can do and converse in a visually arresting form of manual communication. Often, d/Deaf people live a life of Deaf Gain<sup>8</sup>, enjoying fellowship with other d/Deaf people, and taking pride in their sensory difference (Bauman et al., 2014).

Members of the Deaf community typically ascribe to the social model of disability theory, as well as the cultural model, which posits that Deaf people are a cultural minority (Berger, 2013). These models serve as a stark contrast to the pervasive medical model of disability, which defines a ‘disability’ as a deficiency requiring medical intervention to remedy (Berger, 2013). Proponents of the cultural model of disability posit that a group of individuals with a shared disability, like the Deaf community, are not disabled but rather a cultural minority (Berger, 2013). Furthermore, advocates of the social model of disability state that what we recognize as a disability is a socially constructed state in which the world is the disabling factor versus the impaired body part (Berger, 2013). Often, d/Deaf people straddle the divide between these opposing models; d/Deaf people reside in a world that emphasizes the medical model and devalues our experience. The stark reality of being

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7. People with hearing loss who know ASL and adhere to the values and norms of the Deaf community identify themselves as “big D Deaf” or culturally Deaf (National Association of the Deaf, 2019). Another common term is ‘Hard of Hearing’ (HH), which denotes someone who has mild to moderate hearing loss. People who identify as HH may or may not use amplification technology like hearing aids and cochlear implants that allow them to hear to some degree. Like d/Deaf people, HH people know and use ASL, adhere to Deaf culture, and identify as a member of the d/Deaf community (National Association of the Deaf, 2019). This chapter uses d/Deaf to denote people with hearing loss, as anyone with a hearing loss can join the Deaf community at any time, as well as promote solidarity among people with hearing loss.

8. Deaf Gain redefines hearing differences as positive; Deaf Gain highlights the ways in which humanity has benefited from the existence of deaf people and sign language throughout recorded human history.

Deaf in a hearing world increases our vulnerability to traumatic exposure (Anderson, Wolf Craig, & Ziedonis, 2016; Anderson, Wolf Craig, & Ziedonis, 2017a; Anderson, Wolf Craig, & Ziedonis, 2017b; Hall et al., 2017; Hall, 2018).

Customarily, the hearing world considers hearing loss a pathological state that requires amelioration, but the Deaf community views deafness as an entry into the Deaf-World. The world of the Deaf is a world rich in the visual of American Sign Language (ASL) and the fellowship of other Deaf people (Bauman, Murray, & Solomon, 2014). The Deaf community is a small, tightly-knit group, and the shared experience of Deafness is often a refuge within the larger hearing world. Although the sense of belonging enriches members, being deaf predisposes d/Deaf people to traumatic exposure. While this sense of belonging enriches members, d/Deaf people are at a heightened risk for every variety of abuse (Anderson, Wolf Craig, Hall, & Ziedonis, 2016).

Additionally, the unique composition of the d/Deaf community as a linguistic and cultural minority group complicates access to treatment. Mental health professionals fluent in ASL and/or culturally aware of the d/Deaf community are rare, and access to mental health and trauma treatment remains a significant barrier for the Deaf community (Anderson, Wolf Craig, & Ziedonis, 2017a). Though members of the Deaf community experience trauma at a higher prevalence than hearing people, interventions that treat trauma are few.

## Trauma and Disabilities

Mental health professionals often overlook the increased incidence of trauma within the Deaf community, perhaps since the Deaf community is largely unnoticed in the broader hearing world. Anderson, Wolf Craig, and Ziedonis (2017a) note, “The Deaf community is one of the most underserved and understudied populations in behavioral healthcare, even though the frequency of behavioral health disorders is believed to be higher in the Deaf community than in the general population” (p. 118). Additionally, due to their status as a linguistic minority, members of the Deaf community may be at even higher risk due to the perceived notion that they cannot tell others what is happening to them. Though there are some specialized programs for members of the Deaf community who are experiencing IPV and amazing mental health clinicians who are d/Deaf themselves and provide assistance in ASL on the frontlines, the need for linguistically and culturally accessible services for d/Deaf people greatly outstrips availability.

Recent studies reveal that d/Deaf people are twice as likely to experience trauma as hearing people (Johnson et al., 2018; Schenkel et al., 2014). These types of trauma include physical abuse, unexpected death of family and friends, and natural disasters (Anderson et al., 2016a). ‘Rhonda’ a survivor who shared her story as part of a series produced by the organization, DeafHope, illustrates the weight and experience of compound trauma by sharing:

I want to share my experience with different kinds of abuse. When I see other people experience abuse and share it, it touches my heart. I felt afraid to share because I was scared of gossip and my reputation, and I am a very private person. I stayed silent and wouldn’t share my story for many years. I experience different abuse,

and now there is a suitcase full of experiences of abuse I have carried with me for many years. It gets heavier and heavier, and now I can't carry it anymore.

Many traumas may stem from the fact that d/Deaf people often miss out on incidental learning opportunities, such as hearing that there is impending dangerous weather from a radio announcement or overhearing family members discuss illness and death among loved ones. This lack of access can complicate or trigger a traumatic experience. Johnson et al. (2018) report that d/Deaf individuals are more likely to develop Post-traumatic Stress Disorder (PTSD) than hearing people due to these complex traumas.

Additionally, d/Deaf people may experience developmental trauma triggered by the phenomenological experience of being raised in a hearing-dominant world (Anderson et al., 2016a). Anderson, Wolf Craig, Hall, and Ziedonis (2016a) identify a lack of early language development as a significant factor that increases the vulnerability of d/Deaf people to experience trauma. Other factors include family conflict over education and schools, a preference to have children speak orally rather than use ASL, poor or insecure attachment to parents, and social isolation (Anderson et al., 2016a, p. 353). These stressors predispose a d/Deaf person to a lifeworld filled with trauma and heartache.

## Language Deprivation: A Uniquely d/Deaf Trauma

Recent studies show that up to 70% of all d/Deaf people show signs of language deprivation (Hall et al., 2017). Language deprivation occurs when young children do not have access to language (Hall et al., 2017; Hall, 2018). Despite universal neonatal hearing screening, many d/Deaf children are not diagnosed with hearing loss until they are toddlers (Hall et al., 2017). As a result, these children struggle with communication since spoken language and lipreading are difficult without an existing linguistic foundation. To compound these difficulties, only about 40% of spoken English is visible on the lips in ideal conditions with a skilled lip reader (CDC, 2020). Therefore, hearing-abled families' preference that their d/Deaf family members communicate using spoken language results in an environment where communication is not accessible to their d/Deaf family members.

Recent research indicates that the time window for optimal language acquisition is during the first year of life (Friedmann & Rusou, 2015). If d/Deaf children do not have access to a fully accessible language during that time, they miss crucial opportunities to develop a solid primary language foundation; if people do not have fluency in a language from childhood, problems compound into poor academic performance, frustration with communication that can lead to behavioral problems, interpersonal and inter-relational difficulties, and overall deficits in everyday functioning. Language deprivation also impacts d/Deaf people's understanding of English, which makes the standard intervention of writing back and forth challenging at times and further complicates their ability to effectively answer written screening questions and tools (Hall et. al, 2019).

Researchers identify prelingual<sup>9</sup> deafness and a lack of exposure to ASL during early childhood as often robbing the d/Deaf of a linguistic foundation (Glickman, 2009; Glickman & Gulati, 2003; Freeman, 2003; Hall, et al., 2017; Hall, 2017). Glickman (2009) states, “Some deaf children may be nearly the only examples of human beings . . . who grow up without native language skills” (p. 375). Lack of developmentally appropriate language acquisition means that some d/Deaf people have minimal language skills at best. Freeman (2003) reports that most of her deaf clients grew up prelingually deaf and lacked ASL exposure during childhood. Freeman (2003) states, “Growing up in this linguistically impoverished environment, these deaf children grow up with emotional, social, educational and psychological delays” (p. 36). Additionally, Freeman (2003) notes, “for the deaf or hearing-impaired client whose trauma may have occurred prior to full linguistic acquisition, the trauma remains unconscious and nonverbal” (p. 36). As a result, people with low language fluency struggle to think abstractly (Glickman & Gulati, 2003), which results in extreme difficulties in accessing health treatment because mental health concepts are largely abstract (Hall et. al, 2017).

Because d/Deaf people with language deprivation have varying grasps of formalized language, additional support is often needed to access services (Anderson et al, 2016; Glickman, 2009; Glickman & Gulati, 2003; Hall, 2017). When utilized, Deaf interpreters for the Deaf serve as communication brokers between the hearing ASL interpreter and their d/Deaf client since a simple English-to-ASL translation will leave someone with language deprivation unable to understand fully what is being said (RID, 2022). However, many hearing providers are unaware of the importance of an additional interpreter to interpret the ASL into visual-gestural communication so a d/Deaf client with language deprivation can fully understand.

Additional complications include a lack of culturally and linguistically trained clinicians to help d/Deaf victims of IPV heal. Anderson, Wolf Craig, and Ziedonis (2017a) note, “The Deaf community is one of the most underserved and understudied populations in behavioral healthcare, even though the frequency of behavioral health disorders is believed to be higher in the Deaf community than in the general population” (p. 118). Most social workers are hearing-abled and may be unaware of the importance of ASL and Deaf Culture to members of the Deaf community. Though the Americans with Disabilities Act of 1990 mandates that healthcare organizations provide ASL interpreters for people with hearing disabilities, many doctor’s offices are unaware of this mandate or reluctant to pay out-of-pocket for interpreters (Boness, 2016). A survivor of domestic violence through the DeafHope Survivor Stories series expressed the feeling of isolation created by the lack of linguistic access, saying:

During my time in the shelter, I was always alone. The televisions were not closed captioned. The interpreters were not provided. There were no communications and no television access. Also, no TTYs. No interpreters during support groups. None. I just sat there alone, feeling left out with information going over my head. I gained nothing from it.

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9. Prelingual deafness means being born with hearing loss or becoming deaf before learning spoken language.

This same survivor went on to express the importance of the availability of culturally specific services when saying:

We need a place of our own, not a hearing shelter, for the Deaf women survivors. We need it. It is also for our hearing children. With this shelter, I would still have my children with me. But right now, we don't have one...I want for Deaf women to wake up and realize that they don't need domestic violence, nor deserve it. The children do not deserve it either. It is hard for them to see their mothers go through domestic violence. They want violence-free and healthy homes where they can grow up together with their Deaf mothers.

In his chapter, *The Isolation of Being Deaf in Prison*, published in *Disability Visibility* edited by Alice Wong, Jeremy Wood shares his experience with language deprivation and isolation in prison:

While I was in prison they had no American Sign Language (ASL) interpreters. None of the staff knew sign language, not the doctors, the nurses, the mental health department, the administration, the chaplain, or the mailroom workers. Nobody. In the barbershop, in the chow hall, I couldn't communicate with other inmates. When I was assaulted, I couldn't use the phone to call the hotline set up by the Prison Rape Elimination Act (a federal law meant to prevent sexual assault in prison) to report what happened. And when they finally sent an interviewer, there was no interpreter. Pretty much everywhere I went, there was no access to ASL. Really, it was deprivation.

## Intimate Partner Violence in the Deaf Community

Intimate Partner Violence<sup>10</sup> is endemic in the Deaf community, as it is with others who identify as disabled (Mailhot Amborski et al., 2021). Due to the Deaf community's status as a minority culture, there are not many studies about intimate partner violence in the Deaf community, but the ones that exist tell a consistently negative tale. A national sample found lifetime prevalence rates of 27.1% for emotional abuse, 22.2% for physical abuse, and 16.9% for sexual abuse for d/Deaf women (Pollard et al., 2014).

Due to language barriers, abusers have additional tools at their disposal. They may deny their victims access to communication with others by taking away or limiting access to cell phones, tablets, computers, and Videophones for texting, email, and video chatting. Since signed languages are minority languages, and most d/Deaf people show signs of language deprivation, an abuser can control a person's access to communication. A hearing-abled abuser may use their partner's status as a d/Deaf person to denigrate and marginalize them (Anderson et al., 2017a; Anderson et al., 2017b). In public interactions, a hearing abuser often serves as a communication intermediary between their d/Deaf partner and the hearing world; when an abuser is a conduit

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10. Intimate Partner Violence is abuse or aggression that occurs in a romantic relationship by a former or current partner or spouse (CDC, n.d.). Intimate Partner Violence falls under the interpersonal violence umbrella.



through which a d/Deaf person can communicate with a hearing person, the abuser can manipulate what is being said to disempower the abused.

As part of a survivor story series produced by DeafHope, a survivor of domestic violence shared:

I went through “Nine Lives”. I had many close calls with death during my domestic violence experience. However, I am lucky to be alive today. I am a survivor from trying to stay alive. I have tried calling the police several times. My husband blocked me from the phone. He took away the phone. Many times he prevented me from calling because he wanted to keep it a secret. One day the neighbor heard us and called the police. The police came but my husband (hearing) talked to them. They didn’t talk to me much. The police thought that everything was okay and left. They did nothing to help. As soon as the police left, my husband started to beat me up again. This time the neighbors did not want to call the police again.

Additional complicating factors include language deprivation, which limits the abused and the abusers’ ability to express what they have experienced, as well as to explain what is bothering them. Professionals who work with people who have experienced trauma understand that trauma is cyclical, and abusers are often abused themselves (van der Kolk, 2015). Without the ability to express and process previous trauma, d/Deaf people struggle with accessing appropriate treatment and behavioral change (Anderson et al., 2017a; Glickman, 2009).

Language deprivation affects more than someone’s ability to express themselves. If a d/Deaf person does not have a strong language foundation, they may not know that it is inappropriate to hit others or force themselves on others sexually. It is important that those working with d/Deaf clients be aware of possible language deficits and the lack of general knowledge that many d/Deaf people face (Hall, 2017).

Another important consideration is a client’s membership in the capital D-Deaf community. As mentioned before, the Deaf community is small, insular, and tightly knit. Members of the Deaf community tend to be more collectivist in their perception of the world, valuing their membership in the group over their individuality (Bauman et al, 2014). While the Deaf community is often a source of support and fellowship for Deaf people, intimate partner violence can complicate Deaf community membership, especially if both the abuser and the abused are members of the Deaf community. Friends may be compelled to take sides, and due to the collective nature of the community, gossip will abound. Therefore, it may be easier for a victim of IPV to stay quiet about the violence than risk being “outed” by the whole community and potentially losing friends and supporters.



# Macro-Policy and Practice Implications for Working with PWDs Who Experience Abuse

## Application of Theoretical Perspectives

### Types of Disability and Violence

A disability can have a physical, intellectual, sensory, cognitive, emotional, and/or psychiatric basis, and their impairments can be singular or occur in combination, including learning disabilities. We have chosen to use d/Deaf as an example of disability, yet we want to emphasize that disability is complicated and multidimensional (Altman, 2011) and individual. d/Deaf as an example of a disability is illuminating, as it highlights the fact that some disabilities are not visible. Kattari et al. (2018) note that those with invisible disabilities “are still exposed to forms of rejection, ableism, and discrimination; in fact, they may even have more trouble accessing support services than their visibly disabled counterparts due to being expected to prove their disability” (478). For example, those with learning disabilities are more likely to experience hate crimes, harassment, bullying, and name-calling than those with other disabilities (Wiseman & Watson, 2021). Also, those with sensory disabilities are at greater risk for sexual victimization (Amborski, Bussieres, Vaillancourt-Morel, & Joyal, 2021). Moreover, we see those with disabilities, particularly those who fall victim to violence, being part of a disability justice movement focusing empowerment on the individual and the collective rights of all those with disabilities and other marginalized communities.

### Abuse and Myths for Those with Disabilities

Pertinent to social work practice is awareness and understanding that society still holds some misunderstandings and myths about how IPV happens for PWDs. PWDs experience multiple forms of abuse, including physical, emotional, psychological, financial, sexual, and disability-related. The approach of the worker with PWDs should include the examination of the workers’ understanding and feelings regarding disability, including ableism and able-bodied privilege, then address their perspectives that do not support a strengths-based practice (Plummer & Findley, 2012). This examination should also look externally at the social forces that allowed the violence to occur, including oppression and other forms of structural inequalities (i.e., poverty) that allow for higher tolerance of maltreatment of PWDs (Hollomotz, 2012).

### Critical Cultural Competence

For social workers who work with PWDs, it has become increasingly salient to work with a framework that brings not only recognition of the disability the individual has but, more so, all that comprises the individual.

Regardless of disability, this chapter has emphasized that these individuals must be treated with inclusion and respect and be recognized as members of the greater community. This is paramount as violence itself is complex and intersectional. Working with individuals requires understanding the complete biopsychosocial foundation of the individual as well as what having a disability means for that specific individual.

Working in a frame of critical cultural competence requires that social workers develop critical cultural competency by understanding themselves, their clients, and their clients within their communities. Workers need to develop an understanding and awareness of the intersectionalities that their clients bring (NASW, 2015). For example, social workers need to see a client as a parent, a student, a person of color, and an individual with a disability. As social workers, we need to reflect on all that individual brings and how it shapes the client's social identity while at the same time having an awareness of our attitudes and beliefs about all of those intersecting identities.

Critical cultural competence is an ongoing practice rather than a box to check. This means that social workers are expected to participate in continuing education, training, and consultation that helps them to identify their own biases and minimize the imposition of those assumptions on the individuals they serve. It is also essential to ensure that those with lived experience inform practice. Research and policies, whether agency or federal, practice interventions need to include the perspective of those who will be most impacted.

## Self-Determination

Supporting this stance allows one to make choices for themselves and is an integral part of strengths-based social work. This concept has even more relevance when we are working with PWD. We want to support and empower PWDs across the life course. In particular, related to IPV, social workers need to consider our thoughts and beliefs to ensure we are working with PWDs as partners, and we are not disrespecting or infantilizing these individuals. For example, empowering clients to make decisions or choose resources for themselves helps them gain a sense of self-determination.

## Nothing About Us Without Us

This phrase provides a solid underpinning that policy about PWDs should only be decided with the full and active participation of PWDs. The consideration of who is involved should include an intersectional and inclusive perspective. Furthermore, social workers must remember that not all with disabilities are similar. Pushing this conversation further, some disability justice advocates have recently modified this call to action to be “Nothing without us!” reflecting the notion that PWDs need to be included everywhere, not only the places someone has deemed to be about disabilities (National Democratic Institute, 2022).

## Limitations of Federal Policy: Implications for Practice

There have been strides in the last 30 years to ensure that PWDs are remembered within federal policy administration. However, there is still much more to do; those who are d/Deaf need to be considered and included in advocacy and policy development at the very foundation. Federal policies need a more robust benchmark than a reliance on the ADA for compliance measures as well as programming and services based on non-discretionary funding.

### Promote IPV Inclusion in Policy

Federal appropriations for gender-based violence intervention and prevention services are based on a conglomeration of legislation. Community-based agencies rely heavily on federal funding for service provision, which can change frequently based on organizational priorities. Funding priority areas may also change year to year and limit the types of services covered by specific funding streams. The needs of survivors, especially those with disabilities, do not go away because funding does. Further, disabled survivors and their needs should be codified within the law rather than having the ADA, or an Executive Order applied as an overlay to encourage inclusion. Promoting inclusion without financial or other resources means that sustainability will remain impossible.

### Primary Prevention is Needed

While there is ample research on the prevalence of violence in underserved communities, there is a dearth of research and money looking at primary violence prevention in the disabled community. Although VAWA and FVPSA money supports primary prevention, there seems to be an expectation that agencies will either modify prevention strategies to meet the needs of individuals with disabilities or focus their education on risk reduction. Things you can do to lessen your risk of becoming a victim.<sup>[/footnote]</sup>, which can prompt victim-blaming and does not stop the perpetration of violence before it happens. Even the OVW Disability Grant does not fund primary prevention programming since that is covered under Rape Prevention and Education grants distributed through the Centers for Disease Control and Prevention (CDC) (CDC.gov, 2022). This is another example of how excluding individuals with disabilities can impact programmatic priorities and outcomes. While the CDC has developed toolkits for communities to address domestic and sexual violence prevention, it neither mentions the unique needs of PWDs nor shares primary prevention strategies that have been vetted for use with disabled populations.

## Include PWDs in Research, Evaluation of Programming, and Policy Efforts on IPV

Federal policy is based on research, data collection, program evaluation, and feedback from constituents. When you exclude PWDs at the very root of research and data collection, the policies seeking to reach these individuals will fall short. Further, if the expectation is to stop the perpetration of violence against PWD, then federal policy and funding allocations need to meet that expectation. Policymakers must ensure that communication channels are open for individuals with disabilities to share their concerns and feedback. Programs and agencies need benchmarks to follow and should be evaluated based on their ability to reach survivors with disabilities.

The abuse of people with disabilities is a historically under-examined and under-researched topic. However, there is an awareness that the overall rates of abuse against PWDs are higher than those without disabilities. Moreover, the debate over what constitutes abuse is rooted in the systemic silence of the provider agencies and organizations in which the abuse occurs. Attempts to intervene for those with disabilities who have been abused or assaulted have been reactive rather than preventative and culturally aware. While there has been progress in policies related to PWDs and IPV, work is left to be done to advance the rights and protections of PWDs under the law and in practice. This knowledge should serve as a call to action for social workers and clinicians who need to develop the critical cultural competence necessary to work with individuals with PWDs in this area and to promote policy change.

## Case Study

Now it is time for you to take all of this knowledge and apply it to a fictionalized situation. Here are the details of the hypothetical case, based on experiences from the authors' decades of work in the d/Deaf community.

**Scenario:** Imagine you are a hearing social worker at a local domestic and sexual violence program serving individuals who have experienced IPV. The program provides crisis intervention services and short-term counseling for all community members but does not explicitly offer specialized services for the d/Deaf. As a result, your knowledge of the d/Deaf is relatively sparse.

Your supervisor tells you there is a new referral for you and mentions that the woman is Deaf. Your supervisor hands you the information packet, which is all of the information you have going into your upcoming meeting with “Maria.”

Maria is a bisexual Latinx woman in her early 30s who lost her hearing due to illness when she was about two years old. Maria communicates in American Sign Language (ASL), but significant general knowledge and language gaps complicate comprehension. Maria reports significant trauma, from sexual molestation at the hands of her brother, sexual abuse while at the residential school for the Deaf, and severe emotional and sexual abuse in her last romantic relationship, which led to the current sexual assault referral.

Like most d/Deaf adults, Maria is the only d/Deaf member in her family. No one else in her family uses ASL to communicate, and Maria says she does not feel a deep connection to her family because she cannot communicate with them. Maria has created her own support system of people in the Deaf community. One of Maria's support system members is "Kevin," with whom she has had a sporadic and sometimes abusive relationship. Kevin is a fixture in the local d/Deaf community, and Maria is worried that talking about her problems with Kevin will cause her to be ostracized.

Like many PWDs, Maria lives at or near the poverty line. She relies on Social Security Disability Insurance for her primary source of income, does not have a car or reliable transportation, and relies on numerous government and local agencies for day-to-day support. After an emergency room visit where she stated that she felt unsafe in her romantic relationship, a referral was made to your domestic and sexual violence program for Maria to get counseling and support. Although your agency's brochure mentions that you provide domestic violence services to all community members regardless of disability status, Maria has never heard of your organization before. Maria lined up medical transportation, but her ride arrived 30 minutes late, which made Maria 45 minutes late for her scheduled appointment.

Unbeknownst to you, upon arrival, Maria realizes that she must push a button and communicate with someone via speakerphone to gain access to the building. Maria enlists the help of a hearing passerby to gain access to the facility. Once inside, Maria is confused about where she must go as there are no signs. Maria starts to wonder if coming here to discuss her recent sexual assault is worth it. She's also 45 minutes late, and doctors usually get mad at her if she is late to appointments.

Luckily, she spots a woman all in black sitting in the hallway, and taking a chance, she approaches her and realizes that the woman is there to provide ASL interpretation for her. Maria and the woman greet each other, and during the conversation, the interpreter realizes that Maria is suffering from language deprivation. To an outside viewer, Maria's signing is fluent and mesmerizing. However, fluent knowledge of ASL lets the interpreter realize that Maria's signing style obscures the fact that she does not understand what is being said most of the time. Maria's communication is very basic, and she tries to cover up for her lack of understanding by smiling and being agreeable.

Once you have time to meet with Maria, who missed her scheduled appointment slot, you go and get Maria and the interpreter. You're still a little annoyed about the transportation problems, but that's nothing compared to the fact that you are very nervous about this meeting. You are not sure you have ever met a person who uses ASL to communicate, and that's anxiety provoking.

The three of you walk down the hallway silently because you are unsure how to proceed. After what feels like a very long walk, you all arrive at your office. Everyone sits down, and you turn to the interpreter to ask why Maria is here. The interpreter informs you that you should speak directly to Maria and not the interpreter. You cannot help but get flustered—there is a lot to remember! You take a deep breath, apologize to the interpreter and Maria, and begin the session.

You start by asking Maria the questions on the standard intake form, but her answers could be clearer, and despite asking her in different ways to provide the information, you need help getting your point across. You

quickly remember that Maria became deaf when she was very young, and it seems she has significant language and communication gaps. Maria talks a little about her relationship with Kevin and states that while she is scared of him, she does not want anyone to know about what happened since she doesn't want people to talk about her in the tightly-knit Deaf community.

After a while, Maria goes to the bathroom, and the interpreter suggests to you that Maria may benefit from a certified deaf interpreter (CDI). These are Deaf interpreters for the d/Deaf, who can interpret from ASL using “gesture, mime, props, drawings and other tools to enhance communication” (RID, 2022). The interpreter explains that CDIs are vital in ensuring full access to communication for d/Deaf people who have language deprivation, yet you, like most people, know nothing about CDIs. Armed with this new information, you check with your supervisor, who mentions that your agency does not have a contract with any CDIs, noting that they can only hire from a previously approved list of interpreters and says you will need to make do with the one interpreter you have.

## Discussion Questions:

1. The ADA requires accessibility for individuals with disabilities. There are five types of barriers to access. Attitudinal: including assumptions or bias; Organizational: including policies or practices that discriminate; Physical: including architectural design like narrow doorways, low lighting, small bathrooms; Communication: including improperly formatted documents, inaccessible language, poor design, lack of captioning; and Technology: including inaccessible websites, documents without alternative text.
2. What barriers to access are you able to identify in Maria's story?
3. Thinking specifically about attitudinal barriers, what assumptions were made about Maria in this scenario? Consider applications at the macro, mezzo, and micro levels of practice.
4. Collaboration between victim service providers and PWD can be a key component in ensuring safety and access for survivors with disabilities. Who might you want to collaborate with to help address some of the safety and access barriers experienced by Maria?
5. Universal design means designing systems, services, and environments so that they are accessible to everyone. How do you think Universal Design could be applied within this agency?
6. Empowerment theory is often applied when working with survivors of IPV and aligns well with social workers' responsibility to promote self-determination. How do you think that you could promote self-determination and help empower Maria?
7. What local and state policies might impede your ability to maintain the client's self-determination and cause an ethical dilemma?
8. Who might be members of Maria's circle of support? How do those members support her? How might Maria's intersectional identity impact her experience?
9. How do you think Maria's experience may have been different if you were familiar with the Deaf

Community and d/Deaf people in general? What about if you were a Deaf social worker yourself?

10. What power dynamics and imbalances might occur among you, Maria, and the employment and housing institutions surrounding her? How would you address them?
11. Do you, as the social worker, follow the NASW ethical standard of cultural competence when providing for d/Deaf clients? What about the agency?

### To Learn More:

- **Sexual Violence and Intimate Partner Violence Among People with Disabilities**, an overview by the Centers for Disease Control and Prevention. <https://www.cdc.gov/violenceprevention/sexualviolence/svandipv.htm>
- **Abused and Betrayed**, an NPR series about violence against people with intellectual disabilities. <https://www.npr.org/2018/01/08/570224090/the-sexual-assault-epidemic-no-one-talks-about>
- **Many Deaf Women Aren't Safer at Home**, an article addressing the intersection of Covid stay-at-home orders and the experience of Deaf survivors. <https://www.bitchmedia.org/article/deaf-women-domestic-violence-pandemic>
- **DeafHope – Deaf Survivor's Story: Enduring Domestic Violence**, a filmed interview with a survivor of domestic violence sharing their experience. This video is presented in ASL with closed captioning. <https://www.youtube.com/watch?v=W8sNlbO4JI4&t=124s>

## Direct Services and Crisis Intervention

- **Abused Deaf Women's Advocacy Services (ADWAS)** is the first agency in the United States to focus on empowering d/Deaf survivors of interpersonal violence. ADWAS is a model deaf-by-deaf program and also keeps a list of partnering agencies where d/Deaf survivors can find support nationally <https://www.adwas.org/information/links/>
- **The Deaf Hotline** provides 24/7 crisis intervention and support for d/Deaf individuals who have experienced domestic or sexual violence: <https://thedeafhotline.org/>
- **RAINN, The National Sexual Assault Hotline**, provides 24/7 support by chat or phone to survivors of sexual violence: <https://www.rainn.org/>

## Tools and Toolkits

- **Disability Justice Audit Tool**, this interactive online tool provides an overview of disability justice and helps individuals consider its application in their agencies and practice. <https://www.northwesthealth.org/djaudittool>
- **Partnering to Promote Safety, Access, and Inclusion for Every Survivor** is a toolkit developed by



the Center for Research on Ending Violence at Rutgers School of Social Work, which aims to foster ongoing collaborative relationships to promote inclusive and equitable services for all survivors.

[Collaboration Toolkit 2021](#)

- **Power and Control Wheel People with Disabilities and their Caregivers**, this tool adapted by the National Center on Domestic and Sexual Violence highlights common power and control tactics a person might use to abuse their family member or someone in their care.  
<https://www.communitysolutionsva.org/files/DisabledCaregiverPCwheel.pdf>
- **Power and Control Wheel adapted for the d/Deaf community**, this tool adapted by ADWAS highlights specific power and control tactics that may be experienced by d/Deaf survivors.  
<https://www.adwas.org/wp-content/uploads/2013/04/unhealthywheelsignatue.jpg>
- **Serving Deaf Survivors of Domestic and Sexual Violence**, this guide produced by the Vera Institute of Justice seeks to increase individual/agency capacity for working with d/Deaf survivors.  
<https://www.vera.org/downloads/publications/serving-deaf-survivors-domestic-sexual-violence.pdf>
- **Working with a Deaf Survivor: A Resource Guide**, this resource guide produced by Deaf Vermonters Against Violence offers best-practice tips for working with d/Deaf survivors.  
<http://www.deafta.org/blog/resourceguideforhearingprograms>

## Training and Technical Assistance

**The Vera Institute for Justice** manages several initiatives at the intersection of violence and disability and other underserved communities. The following may be of interest:

- **End Abuse of People with Disabilities** focuses specifically on building movements and cultivating leaders. Supporting organizations, leveraging resources, and advocating for change to end violence against PWD. <https://www.endabusepwd.org/about-the-movement/our-work/>
- **National Resource Center for Reaching Victims** The Resource Center is a one-stop-shop to get information and expert guidance to enhance the capacity to identify, reach, and serve all victims, especially those from communities that too often have less access to healing services and avenues to justice. <https://www.reachingvictims.org/>
- **Deaf Action** The Deaf Action Initiative is an OVW-funded training and technical assistance project designed to increase the capacity of Deaf organizations to address domestic violence, dating violence, sexual assault, and/or stalking in Deaf communities in the United States. <http://www.deafta.org/about>

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14.

# AN INTERSECTIONAL ANALYSIS OF DISABILITY RESISTANCE MOVEMENTS: LOOKING BACK TO LOOK FORWARD

Valerie Borum and Elspeth Slayter

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## Learning Objectives:

- To explain the intersectional nature of the disability civil rights and disability justice movements
- To analyze the involvement of intersectional communities in disability advocacy
- To assess the progression of disability rights movement
- To contrast the disability civil rights and disability justice movements

## Introduction

As this textbook comes to a close, it becomes clear that in many of the sectors in which the disability community is involved, their experiences are not always optimal. While much progress has been made in some of these sectors, such as employment, healthcare, and education, other sectors, such as mental health care and addiction treatment, are in need of much work to make empowerment-oriented disability social work a reality (see Chapter 2). With respect to the former, while there have been successes for the disability community through the path of litigation, lawyer David Ferleger (2022) noted in a recent lecture, “Litigation cannot be the primary tool for social reform [related to disability]. Social reform should grow from social movements and transformations of consciousness” (n.p.).

As we begin this review, it is helpful to provide a definition of what we mean by resistance movements. Here addressed are social movements that people engage in to resist oppression. As sociologist Diani (1992, p. 1) states, “social movements are defined as networks of informal interactions between a plurality of individuals, groups and/or organizations, engaged in political or cultural conflicts, on the basis of shared collective identities.”

In the case of this chapter, we are talking about movements that benefit the disability community in some way, shape, or form, whether they are disability-identified or are considered in partnership with or accomplices to the disability community. For example, the continued Black struggle for civil rights has had an intersectional impact on equity-seeking movements (e.g., Deaf President Now!). As Hearth (2020) states, “the push for Black freedom and equality began America’s journey towards becoming a true democracy. They fought for rights for Black people initially, and then that had an impact on the women’s rights movement, and eventually on disability rights efforts as well” (p. 1).

In order to lead the way forward, we thought it best to conclude this textbook with an intersectional review of the disability resistance movements in our society’s past and present, with a focus on race, ethnicity, gender, sexual orientation, and disability status. This is especially important given that many of the books highlighting the disability civil rights movement seem to highlight White activists, for example, without much attention to the many people of color who were very involved in these movements (Bryan; Reid, 2017; Zames Fleischer & Zames, 2011; Vaughn Switzer, 2003; Zames Fleischer & Zames, 2001; Charlton, 1998). We see the same erasure of queer and transgender people, and to a lesser extent, the women’s community. For these reasons, we draw on many non-traditional resources in our citations, including many internet-based resources that report on these topics in a way that we don’t see in the literature. Questions that guide this chapter include: How has the disability community resisted ableism, sanism, and oppression? See definitions of these terms in Chapter 1. How have these efforts manifested across the spectrum of the disability community, intersectionally? How have disability activists partnered with activists from other communities to fight for social justice? How have the resistance movements of other non-disability-identified communities engaged in benefited the disability community as well as themselves?

## An Intersectional Approach

Building on the work of Black scholars W.E.B. Dubois and Anna Julia Cooper, Intersectionality was further conceptualized by Crenshaw (1989; 1991). This work entails viewing and understanding diverse and intersecting identities as pathways to coalition building while challenging disability movements to contest exclusionary and oppressive practices that marginalize some community members (e.g., BIPOC, LGBTQIA+ people). It also entails interrogating the history of the disability rights movements as constructing whiteness as the norm (as well as straight, cisgender, and both White men and women with disabilities) In other words, For example, throughout history, disabled people and queer people have shared powerful solidarity, although this

intersection is often overlooked (Brownsword, 2020; Fowler & Wallach, 2022). An analysis of this type is also especially important given the documented challenges the disability rights movement has privileged the voices and experiences of White people (Erkulwater, 2018; Lukin, 2013; Wright & Leung, 1993).

A critical and deeper interrogation of solidarity illustrates the complexities and the convergence of real-life power systems, the application of intersectionality principles, and the implications of White-focused solidarity (Crenshaw, 1989; 1991). For example, while the LGBTQIA+ community has made societal gains and acceptance, it continues to engage in historic and contemporary exclusionary practices. For instance, Toronto, Canada's 2016 Pride parade received a lot of news coverage and social media attention for providing the world evidence of how the absence of an intersectional approach to pride and community can further generate exclusion and marginalization.

During the Pride parade, Black Lives Matter (BLM) staged a 25-minute sit-in and presented the Toronto Pride's Executive Director with a generated list of demands. The demands consisted of centralizing Black, Indigenous, people of color, trans, and disabled people in key positions in future organizing efforts. BLM members received death threats from both White queer and White non-queer people in response to their BLM activism. What was lost was the fact that the BLM movement was founded by three radical Black queer women organizers in Los Angeles, California, in 2013—Alicia Garza, Patrisse Cullors, and Opal Tometi. The BLM movement began after the shooting of Trayvon Martin (Thomas et al., 2017). This movement, along with others, originated in the African American community.

We take an intersectional approach in this chapter because, as historian Douglas Baynton remarks, “not only has it been considered justifiable to treat disabled people unequally, but the concept of disability has also been used to justify discrimination against other groups by attributing disability to them” (James, 2022). For example, both prejudice and discrimination related to disability have been used in arguments promoting slavery, women's oppression, and for the limitation of immigration.

The paradoxical nature of disability and Blackness stems from the historical divide related to the embodiment and experience of disability and Blackness in the United States. For instance, for the majority of African Americans, their experiences are “shaped by an understanding of Black bodies as a productive labor force” (Gavieta, 2020, p.4). Gavieta (2020, p. 5) also states:

This dehumanizing characterization of Black Americans has caused them to be viewed as subjects... barred from weakness—and disability. Since non-normative bodies were conflated with “unsuitability, Black people [couldn't] afford to be disabled. Overall, Black Americans never had the luxury of being perceived as weak; those with disabilities were tossed aside. This stigma remains horrifyingly salient in today's society, and it acts as a significant barrier to Black Americans attempting to acknowledge their disability. It places their “already precarious self at further risk of marginalization and vulnerability to state and medical violence, incarceration, and economic exploitation. These considerations must be kept in mind, and readers ought to be wary of how they approach “Black people's reluctance to identify as disabled, for their reluctance is rooted in an anxiety of racial oppression and a hyper-awareness of precarity.”

## The Challenge of Building Common Disability Identities

Henceforth, activists in both the civil rights movement and the disability rights movement could not determine how to build a common disability identity that honored differences in how oppression is experienced intersectionally (Erkulwater, 2018). Erkulwater (2018, p. 367) notes, “though [disabled activists] yearned for racial solidarity, in practice, activists could not overcome institutions that separated antipoverty and racial politics from disability policy, nor could they figure out how to incorporate minority voices in an identity-based movement forged around disability rather than color.”

The whiteness of the movement has been exacerbated by disability studies research (Dunham, Harris, Jarrett, Moore, Nishida, Price, Robinson, & Schalk, 2015; Bell, 2006). Commenting on this, Erkulwater (2018, p. 367) states, “despite the fact that racial minorities report higher rates of disabilities than whites, Chris Bell and Josh Lukin argue that disability studies scholarship largely chronicles the achievements and experiences of white Americans.”

## Chronology of Disability Resistance Movements

James (2022, p. 1) identifies three main ‘waves’ of disability activism: “single-issue disability activism (mid-1800s to mid-1900s), cross-disability activism based on accessibility (1960s-1980s), and critical, cultural disability activism (1990s-present).”

### Early Disability Organizing Efforts

One of the earliest group efforts to raise awareness of ableism – in this instance, in connection to sexism, was led by Agatha Tiegel Hanson (1873-1959) (James, 2022). She was deaf and was the first woman to graduate with a degree from Gallaudet College. A women’s rights advocate, Tiegel’s activism began at Gallaudet, where she created the group O.W.L.S. (now Phi Kappa Zeta) in 1893, which was known as a secret society for women advocating for voice and representation in the deaf community (James, 2022).

One of the best-known early examples of disability resistance to ableism occurred in the 1930s (Pelka, 1997). However, it was the long and shameful history of discrimination and oppression in Black and African American communities that created a foundation for the disability rights movement (Orange Grove Center, 2019). Disabled people in New York City formed a group named the League for the Physically Handicapped in 1935 during the Great Depression era (Longmore and Goldberger, 2000). Comprised of over 300 members, this group included people with cerebral palsy and the after-effects of polio, among other disabilities (Fleischer and Zames, 2001). They were drawn together by the fact that they had been refused work by the Works Progress Administration (WPA), which was a government project designed to provide economic relief to the many jobless people in the country at the time (Fleischer and Zames, 2001).



According to The Disability History Project, and other scholars such as Paul Longmore, “the Home Relief Bureau of New York City was supposed to forward their job requests to the WPA, but was stamping all their applications ‘PH’ for physically handicapped, as a signal to the WPA not to give these people jobs” (Disability History Project, 2021, p. 1). After a director refused to meet with members of the League, members staged a sit-in – some advertised it as a “death watch” – which went on for nine days (Fleischer and Zames, 2001). These actions received much popular support and attention from newspapers and other press. A weekend-long sit-in happened at WPA headquarters as well.

In addition to these actions, picket lines and demonstrations in which League members spoke about disability oppression to labor unions also took place (Fleischer and Zames, 2001). These actions led to the creation of several thousand jobs for members of the disability community (Fleischer and Zames, 2001). While the League was only in existence for a few years, it was effective in this effort. And perhaps this effectiveness stuck in the societal consciousness, as starting in 1945, there was a national week entitled “Employ the Physically Handicapped Week” in Washington DC (Acheson, 1945). Sponsored by a Presidential committee, this campaign spread out in state and local areas to highlight the idea that disabled people were competent workers and that hiring them was good for business (Acheson, 1945).

The National Federation of the Blind (NFB) was founded on November 16, 1940, in Wilkes-Barre, Pennsylvania. The NFB is an organization by and for Blind people that seeks to “promote the economic and social welfare of the blind” and change public policy for disability rights (Fowler & Wallach, 2022, p. 1)

## The Start of the Independent Living Movement

Not long after the NFB’s work, a young man named Ed Roberts came down with the disease polio in 1953, causing him to be paralyzed from his neck to his toes and landing him in a countryside polio hospital (Danforth, 2020). This was a happenstance that would change his life, leading him to later become known by some as the father of the independent living movement (Disability Rights Timeline, 2022). A review of how Roberts got from point A to point B is instructive in understanding the development of his part in this resistance movement. Scot Danforth reflects on this in the following narrative of Roberts’ life:

At age 14, after languishing for nine months in a county hospital polio ward, Roberts attempted suicide. Killing yourself takes great creativity when you are paralyzed from neck to toes. The iron lung’s baffle chambers whooshed a 24-hour rhythm of inhalation and exhalation. Only his head peeped out of the end of the colossal steel hull. Chronic indigestion and a lack of appetite came with the poliomyelitis infection. A nurse cajoled and coerced Roberts into eating enough food to sustain his frail frame. Roberts clamped his teeth shut in existential defiance, and his body withered down to 50 pounds.

Describing Roberts’ refusal to eat as a suicide attempt is both accurate and misleading. The poliovirus had stolen a vibrant body from a young athlete, leaving him able to command only his head, one finger, and two toes. One thing he could control fully, however, was what entered his mouth. His feeding battle with a demanding nurse represented the boy’s complete rejection of the scant existence polio had left him. He

wouldn't exist in a mechanized tomb staring up at the ceiling of a hospital ward. He refused to inhabit an empty biography.

But the boy's hunger strike meant more than the oft-stereotyped wish of a disabled person to die. It was his first step in taking control of his life. His fun-loving youth had been traded overnight for a personage seemingly defined by tragedy and pity. In the 1950s, America had zero imagination for a fulfilling life for a person like this, and Roberts had not yet started to reject the diminished life story that society offered him. So his desperate, vaguely conscious demand was that his life gain significance through his own decisions and actions. Whatever body and life remained in the aftermath of polio must devolve fully to his ownership and control. It might not be much, but it had to be his. (Danforth, 2020, 1)

This formative experience led to Roberts' later activism in the early 1960s while studying at the University of California, Berkeley (where he was initially rejected for admission due to his disability). He is famous for founding a group known as the 'Rolling Quads,' short for quadriplegics, who lived at the UC Berkeley Health Center and created the Disabled Students' Program (Charlton, 2000). This small group is known as the hub of the independent living movement that spread worldwide. They were based in the Center for Independent Living (CIL), which was for the larger community, founded in 1971 (Charlton, 2000). In writing about Roberts' organizing, Erkulwater (2018, p. 380) notes

"Because independent living first took root on college campuses, its founders were mostly white and much more educated than the typical person with a disability. From the earliest days of the Berkeley center, its leaders were determined to diversify the independent living movement and spread the philosophy of self-help and collective action to minorities. During board meetings between 1971 and 1972, they suggested recruiting more "third world people" and committed themselves to an affirmative action policy for hiring, even as debates over racial preferences roiled college campuses.

Schweik's (1979) research documents the fact that in 1975, the Berkeley CIL wanted to foster a presence in majority-Black Oakland, CA. This resulted in a partnership with the Black Panthers with a goal of offering independent living services through the community-based health clinic that they ran. Draper (1979, p. 1) also notes that between 1977-1980, cross-disability organizing and counseling offered in Spanish, Mandarin, Cantonese, and Tagalog were primary goals of the CIL, "in an effort to hammer home the imperative of a disability identity that transcended traditional social cleavages."

Reflecting more broadly, Erkulwater (2018, p. 370) notes that this movement emerged at a time when America's racial order was in turmoil. In the 1960s, blatant white supremacy gave way to a formal commitment to egalitarianism, not just with respect to race but also gender. By the 1970s, however, efforts to transform social and economic institutions so as to achieve egalitarianism in fact, rather than just in name, had stalled...Though they aspired to an inclusive movement, in practice, activists could not overcome institutions that separated antipoverty and racial politics from disability policy.

Ed Roberts is said to have noted of this challenge that "African Americans are reluctant to embrace disability rights because Blackness in the United States has so often been equated with physical and mental deficits.

Disability becomes just another hardship that Blacks must deal with (Brune, 2015, p. 122). How accurate this is, or what the Black community felt about this at the time, is unknown.

White activist Kitty Cone was also a part of this work at the time (James, 2022). Often seen as a White effort only, recent historical research has uncovered the fact that Black disabled activists such as [Donald Galloway](#) were “fierce advocates for the rights of people with disabilities and for the inclusion of people of color in the disability rights movement” while working at the Berkeley, CA CIL (Center for Learner Equity, 2022, p. 1). Later, Galloway obtained a master’s degree in social work, worked as the executive director for the Colorado Governor’s Council on Disability in Denver, directed Peace Corps operations in Jamaica, and ran the Center for Independent Living’s Washington, D.C (Center for Learner Equity, 2022). After that, he was employed as a disability affairs specialist by the D.C. Department of Housing and Community Development and the D.C. Department of Consumer and Regulatory Affairs (Center for Learner Equity, 2022).

Key to the founding of one of the other early CILs (Hayward, CA) was Black disabled womanist advocate [Johnnie Lacy](#) (Center for Learner Equity, 2022). She was instrumental in helping to found the CIL at Berkeley and was the Director of Community Resources for Independent Living (CRIL) in Hayward, California. She earned grants, funding, acquired a building, and oversaw the plans for the construction of its independent office. Lacy’s leadership also entailed integrating the “mostly-white and oblivious disability rights activist movement of her time and heightened intraracial understandings about Blackness and Disability...” (Mwatuangi, 2020). It is important to remember that the history of the independent living movement is inextricably connected to the Black civil rights movement of the late 1960s and 1970s (HASL Center for Independent Living, 2022). As an activist, Johnnie Lacy “brought to light the intersectionality of race and disability and worked to tackle ableism in the Black community and racism in the largely white-dominated disability community” (Center for Learner Equity, 2022, p. 1).

During this period in the mid-1960s, the racial justice-focused civil rights movement was well underway in the United States. One well-known leader of this movement and member of the Student Nonviolent Coordinating Committee (SNCC), Fannie Lou Hamer, was a disabled Black woman (American Association of People with Disabilities, AAPD, 2022; Center for Learner Equity, 2022). SNCC was an interracial civil rights group known for playing a vital role in organizing Black residents in the Southern states to register to vote (Blain, 2022). Hamer became a well-known advocate for voting rights. Notably, Hamer lived with the long-term effects of polio and became further impaired, losing most of her sight, among other impairments, due to a four-day series of beatings she received when in police custody due to her activism in this movement (Blain, 2020; Center for Learner Equity, 2022). Among her many accomplishments as an activist, she advocated for more federal funding for Head Start programs benefiting disabled children, lobbied for public housing programs, and was instrumental in founding the National Women’s Political Caucus to foster women’s political participation (Center for Learner Equity, 2022). Her legacy marks her as crucial to the Civil Rights movement and the women’s rights movement, as well as the foundations of the disability rights movement (Center for Learner Equity, 2022).

Concurrent with the work of the independent living movement on the west coast, disabled educator and

activist Judy Heumann was living on the east coast in New York City. Her actions also spurred the independent living movement. An early act of disability-related resistance in her career involved suing the New York City Board of Education in 1971 when her application for a teaching license was denied due to her disability – specifically, the idea that her wheelchair was a fire hazard. The principles of the independent living movement that activists such as Kitty Cone, Judy Heumann, and others created were that disabled people should be based in the community wherever possible, that services should be delivered in a cohesive versus fragmented manner, and that disabled people should be honored as the experts on their own lives (James, 2022). These principles are core to empowerment-oriented social work practice still today.

## The Disability Civil Rights Movement Takes Hold

In 1970, another one of the first organizations led by members of the disability community was founded in Philadelphia, PA, ‘Disabled in Action’ (DIA) (Fleischer and Zames, 2001). While Judy Heumann is often noted as the founder of DIA, other disabled activists involved at its inception were Denise McQuade (White), Bobbi Linn (White), Frieda Tankas (unknown race and ethnicity), Fred Francis (unknown race and ethnicity), and Pat Figueroa (unknown race and ethnicity). DIA is famous for adopting the slogan “Nothing about us without us” from the anti-Apartheid movement in South Africa (Fleischer and Zames, 2001). Their mission statement is:

We are a civil rights organization committed to ending discrimination against people with disabilities—all disabilities. We fight to eliminate the barriers that prevent us from enjoying full equality in American society. Founded in 1970, DIA is a democratic, not-for-profit, tax-exempt, membership organization. DIA consists primarily of and is directed by people with disabilities. We believe in the motto, “Nothing about us without us!” (Disabled in Action, 2022, p. 1).

Building on the foundation of this mission, DIA sought to raise consciousness about ableism, paternalism, and stigma in addition to policies creating disability oppression (DIA, 2022). This also meant advocating for effective legislative and budget initiatives centered around independent living (DIA, 2022). All of this translated into creating an organization for disabled activists to work in community towards these efforts (DIA, 2022). In reflecting on the DIA’s work and the reasons for the savviness and political involvement of its members, Denise Figueroa states, as noted in Bonney, 2000, p. 1:

“I do think it really had so much to do with the fact that the women’s movement and the civil rights movement were—I mean, we were just right on the edge of all of that stuff. You had the ’64 Civil Rights Acts, you had the seventies women’s rights—you know the seventies was the women’s rights actions and movement, and here we were, it was ’72. You had the antiwar movement in there. The college campuses were really active. Everybody was very political at the time. We were just all fired up.

Later led in part by Patricio “Pat” Figueroa (Latino activist), the DIA is also famous for its action in 1976, where they conducted a picketing of the [United Cerebral Palsy’s annual](#) telethon, naming telethons as

“demeaning and paternalistic shows which celebrate and encourage pity” (New York State Independent Living Council, 2022; Disability History Timeline, 2022, p. 1).

Meanwhile, also in 1970, Latina transgender activist Sylvia Rivera and Black disabled transgender activist Marsha P. Johnson co-founded Street Transvestite Action Revolutionaries (STAR), which focused on trans and disability rights from an intersectional perspective. Johnson’s efforts to stop forced psychiatric incarceration of queer people and to end conversion therapy are well known, although her disability identity is not (Fowler & Wallach, 2022). Of her commitment to noticing and acting on intersecting social identities, Johnson said, “How many years has it taken people to realize that we are all brothers and sisters and human beings in the human race? I mean, how many years does it take people to see that? We’re all in this rat race together!” (Cheung, 2020).

In the early 1970s, the Willowbrook scandal broke in Staten Island, New York. The terrible conditions in which disabled people lived were broadcast on television for all to see. Approximately one-third of the people living in Willowbrook at the time were Black or Latinx, specifically Puerto Rican. Approximately 200 of the non-ambulatory disabled residents were transferred to a facility in Manhattan but, due to budget cuts, were later threatened with being moved back to the large institutional setting on Staten Island. What has received little coverage is the fact that the Gouverneur Parents Association (GPA), named for the facility to which these residents were moved, engaged in actions which combined racial justice work with disability civil rights work. The GPA protested the transfer of these residents spurred on by the leadership of Willie Mae Goodman, a Black school cafeteria worker whose rallying cry was “only over our dead bodies.” (The Staten Island Advance, 1971). The GPA conducted street protests and engaged in court battles to temporarily stop the transfer of the residents. Another leader in this movement was Maria Caceres, who was advocating for her disabled son, and who is also known for organizing other Spanish-speaking parents (Valldejuli, 2019).

Around the time of the founding of the DIA and STAR, we also saw the Disabled Women’s Coalition emerge at the University of California, Berkeley in 1974, led by Susan Sygall (White), Deborah Kaplan (White, immigrant), Kitty Cone (White), Corbett O’Toole (White), and Susan Schapiro (White). This organization ran support groups, organized retreats specifically for disabled women, provided writing for feminist journals, and provided speakers on issues related to the intersections of disability and women’s issues. Reflecting on her involvement in the Coalition, Corbett O’Toole says:

[In] March of ’74, I went to International Women’s Day. UC Berkeley had a big event and Sue Sygall was sitting there, staffing a table because she and Debby Kaplan had decided to start having meetings for disabled women—it was called the Disabled Women’s Coalition. They had a booth there. Susie was in her chair, and I was on my cane and I walked past her booth, looking at different things, and then turned around and walked past her booth again. This went on for about twenty minutes and finally, I walked up and said, “I don’t know if I’m disabled enough for your group, but [laughter] could I get information?” Susie laughed and said, “Fine, just show up. There’s all this stuff happening”...“I really wanted to do something...personal, and so I started a disabled women’s rap group that used to meet at the old disabled students’ program at UC Berkeley on like Sunday afternoons. So that got my foot in the door about women in disability issues. (Sherer Jacobson, 1998)

Also in 1974, the National Association of the Deaf (NAD), founded largely by George Veditz, adopted a mission to “promote, protect and preserve the civil, human, and linguistic rights of the deaf and hard of hearing individuals in the United States” (NAD, 2013, p. 1). Soon after its founding, NAD saw the need for a data-driven approach to disability advocacy and conducted a census of D/deaf Americans (Garretson, 1996). They determined that there were 13.4 million hearing Americans and 1.8 million D/deaf Americans.

The timing of the NAD census coincided with the Inaugural Convention of People First in Portland, Oregon. This nationwide group was founded by people with intellectual and developmental disabilities who promoted the idea of self-advocacy and self-determination. This effort was focused on people supporting one another in learning to speak up for themselves; the self-advocacy movement led by this community continues to this day.

## Implementation of the Rehabilitation Act of 1973

A landmark year in the history of disability resistance movements was 1977, when on April 5th, a group of disabled people staged a sit-in at the Health, Education, and Welfare Department in San Francisco. This was done to protest Secretary Joseph Califano’s refusal to complete and implement the regulations for Section 504 of the Rehabilitation Act of 1973. This law would have made it illegal for federal agencies, public universities, and public institutions that received federal monies to discriminate due to disability. Representing a coalition of movements, the Section 504 sit-in brought together a racially diverse group of disabled people who were bolstered by the Black Panther Party and the gay rights Butterfly Brigade (Erkulwater, 2018). This disability resistance action lasted for just shy of one month and is the longest occupation of a federal office by protestors in U.S. history.

The efforts of the group were successful in forcing the regulations to be signed and concurrently allowed for raising awareness of the need for disability civil rights along the way. This sit-in was led by Judy Heumann, although Black activist and Black Panther member Brad Lomax was also heavily involved in leading the organization of the action (Connelly, 2020; Scweik, 2013; Hall, 2005). Brad Lomax became engaged with the disability civil rights movement as a result of his personal experiences as a wheelchair user. Connelly (2020, p. 1) notes, “in Oakland, Lomax struggled to navigate its transit system. To board a bus, his brother, Glenn, would have to lift him out of his wheelchair, carry him up the steps and place him in a seat, then go back to retrieve the wheelchair.”

[With respect to Lomax’s involvement in the 504 sit-in, his participation was crucial to the success of the action.](#) In reflection on the connection between the Black Panther’s organizational mission and the disability rights movement, Judy Heumann notes that “Brad was able to get the Black Panther Party to see that this was critical to the work that they were doing...he was the linchpin for that” (Connelly, 2020). Lomax, and his personal care attendant, Chuck Jackson, were central to obtaining the solidarity and support of the Black Panthers, who brought hot meals and other necessities to the sit-in every day (Connelly, 2020). White, lesbian activist [Corbett O’Toole](#), now considered an elder in the disability communities, notes, “without the presence



of Brad Lomax and Chuck Jackson, the Black Panthers would not have fed the 504 participants occupying the H.E.W. (United States Department of Health, Education & Welfare) building...without that food, the sit-in would have collapsed” (Connelly, 2020, p. 1).

## An Increase in Recognizing Different Identities in Disability Advocacy

We also began to see more intersectional collaboration in 1977, when the Rainbow Alliance of the Deaf (RAD) was founded in Florida. This is an organization focused on promoting D/deaf rights and offering community for D/deaf and hard-of-hearing queer people (Fowler & Wallach, 2022). 1977 further proved it was an active year in the history of disability resistance movements as in May of that year, Corbett O’Toole, mentioned above, founded the National Disabled Women’s Educational Equity Project (which was based at the Disability Rights Education & Defense Fund (DREDF) co-founded by Mary Lou Breslin and Patrisha Wright in 1976) in Berkeley, CA (Temple University Disability Timeline, 2020; James, 1992). This group’s founding is a demonstration of disabled women’s awareness of the oppression they faced as well as their community organizing efforts during the ‘second wave’ of feminism (Price, 2011).

This group also saw the need for data-driven work and conducted the first national survey on disability and gender, likely due to intersections with the women’s movement at the time (Temple University Disability Timeline, 2020) Other activities the Project engaged in included publishing *No More Stares* for young disabled women, organizing regional training programs targeting younger disabled women’s empowerment and putting together the first national Conference on Disabled Women’s Educational Equity, held in Bethesda, Maryland (Locsin and Purnell, (2009).

A related project spearheaded by Harilyn Rousso based at the YWCA in New York City focused on putting together the Networking Project on Disabled Women and Girls and writing a book (later a film) titled, “Loud, Proud and Female.” Building on the momentum of these projects, in 1980, Womyn’s Braille Press (WBP) was founded to make lesbian and feminist literature accessible to blind people (Folwer & Wallach, 2022). Producing and distributing 800+ books on tape as well as 40 in Braille, the WBP also provided a quarterly newsletter in multiple formats. Wallach & Folwer (2022) note that these projects created a sense of community for disabled lesbians and other queer women. Barbara Faye Waxman’s work around disability and sexuality is tied into this work.

As the women’s movement continued, Black scholar and activist Audre Lorde became known for commenting on how gender, sexuality, race, and disability, among other social identities, intersect and as well are foundational to many social movements. While Lorde did not identify as disabled, she explored the topics of disability and illness in her book *The Cancer Journals* (1980) and *A Burst of Light* (1988) about her experience with breast cancer. Lorde is known for lifting up the importance of accepting difference as a resource versus perceiving it as a threat (Wallach & Fowler, 2022).

In 1981 we saw the first Disabled Lesbian Conference, honoring the intersection of those two social



identities, spearheaded by Connie Panzarino (Wallach & Fowler, 2022). Building on this momentum, a group of disabled lesbians in Wisconsin founded a grassroots newsletter entitled *Dykes, Disability & Stuff (DD&S)*, which began with the goal of promoting access to lesbian culture and community (Wallach & Fowler, 2022). Jumping ahead to 1982, the United Nations General Assembly took a stance on disability rights due to disability advocacy and adopted “The World Program of Action Concerning the Disabled.” The goal of this document was to promote full participation and equality for disabled people worldwide. Commentary on the effect of this document? Back in the United States, A Pennsylvania group known as *Speaking for Ourselves* emerged with a focus on self-advocacy.

## Intensified Advocacy and Activism for Disability Rights

In 1983, a group that would become central to the next phase of disability resistance was founded, *Americans with Disabilities for Accessible Transportation (ADAPT)* in Colorado (Vaughn Switzer, 2003). Chanting, “We will ride!,” disabled activists staged seven years’ worth of protests in Denver, Colorado over the fact that public transportation was not accessible to wheelchair users (ADAPT, 2022). Key leaders in this organization were Bob Kafka, Stephanie Thomas, and Mike Auberger (Fleischer and Zames, 2001). These leaders were known for blocking, among other companies, Greyhound buses, in a range of U.S. cities in order to engage in radical tactics to show that there was a need for accessibility for all as part of the “Wheels of Justice” effort (ADAPT, 2022).

At the end of the decade, in 1988, Gallaudet University in Washington, D.C., was the location of a major protest in the D/deaf community. The rallying cry of these protests was “Deaf President Now!” at the world’s only university dedicated to D/deaf and Hard of Hearing students. This protest emerged when a faction from the National Association of the Deaf, known as the ‘ducks’ stepped forward. The University’s Board of Trustees put in place a hearing president yet again after many others, instead of honoring the community through being representative of that community in their choice of a president. Led by four Gallaudet students, Bridgetta Bourne, Jerry Covell, Greg Hlibok, and Tim Rarus. The protest became world-famous in the D/deaf community and resulted in the appointment of I. King Jordan, Ph.D., as the first D/deaf president at Gallaudet University. As Tim Rarus notes, “It represented Deaf People Now and their freedom. Freedom from ignorance. Freedom from being oppressed. It made me very proud to be a Deaf American (Gallaudet University, 2022).

While Deaf members of the dominant culture (read: White) were feeling empowered as a result of this historic protest, many BIPOC D/deaf people felt marginalized and excluded from the Deaf President Now! Movement (Stuart & Gilchrist, 1991). For example, many compare this protest to the 1960s civil rights movement. There were calls by Deaf protestors to “end the plantation mentality” at Gallaudet University. In mirroring one powerful image, protestors directly borrowed from the “I Have a Dream” speech from Dr. Martin Luther King Jr. However, BIPOC D/deaf people experienced marginalization and exclusion from this historic protest. Twenty D/deaf leaders were chosen from various organizations throughout the United States

to lead the protest. Twenty white D/deaf people were chosen. Angel Ramos, a deaf Hispanic/Latino math teacher, stated (Stuart & Gilchrist, 1991 p. 3), “There are no black leaders up there; there are no Hispanic leaders up there.’ I am not saying this was intentional, but it was the same kind of oversight we minority deaf experience again and again in the deaf world.”

Dr. Steven Chough, an Asian D/deaf Coordinator of International Student Services during this time, stated the following (Stuart & Gilchrist, 1991, pp. 3-4):

Prejudice still exists within the deaf community as well as in society as a whole. Deafness does not erase racism...The issue of racism in the deaf community is not different from the issue of racism in the hearing community. While it is true that deaf people are bound by the commonality of hearing loss, we still come from diverse backgrounds that are influenced by the larger society. The deaf community needs to learn to respect cultural differences within its own community and realize that we are not all the same just because we are all deaf.

The isolation experienced by Black D/deaf members was apparent, as they were only admitted into the National Association of the Deaf (NAD) as late as 1965 (Stuart & Gilchrist, 1991). However, their issues pertaining to the Black D/deaf community did not make it to NAD’s agenda. Two Black D/deaf members, Linwood Smith and Carolyn Mccaskill-Emerson, assessed the Black D/deaf community in terms of holding a national conference. Overwhelming support for this idea was gathered by June of 1980. By August of 1980, “the movement had a name: Black Deaf Advocates (BDA)” (p. 11).

Challenges continue with the Deaf community. For example, Deaf culture and American Sign Language (ASL) are based primarily on White Deaf members (Whitmer, M.A., 2021, Fernandes & Myers, 2009). The normative and all-encompassing Deaf culture and the accompanying ASL have been synonymous with White. As a result, there is a demand for BIPOC D/deaf people to conform to the “core White Deaf community’s” standards (p. 19). This assumption and demand for conformity have been so central to identity that BIPOC cultures of D/deaf people are marginalized and labeled as “deviations from the norm of Deaf culture, as non-Deaf, or even as unhealthy manifestations of deaf people with unrealized Deafhood” (p. 19) In 1988, we saw the founding of Disability Awareness Month, an effort to bring attention to the community en masse – this event has, more recently, shifted to a focus on disability employment (Department of Labor, 2021).

## Advocacy for and Passage of the Americans with Disabilities Act of 1990 and Beyond

1990 was a watershed year in the history of disability resistance movements. Of particular note is the “Capitol Crawl protest,” which took place on March 12, 1990, when disability activists came to the U.S. Capitol in support of the Americans with Disabilities Act (ADA). Over a thousand protesters convened to decry the delay in passing the act. Approximately sixty activists collectively abandoned their wheelchairs and other mobility aids to crawl up the 83 steps to the U.S. Capitol Building, in what has become an iconic action. Chants used by these protesters included “What do we want?” ADA! When do we want it? NOW!” One protester was

interviewed about her reasons for participating in what became known as the ‘Capital Crawl.’ This protester stated, “I want my civil rights,” Paulette Patterson said, an activist from Chicago stated as she inched her way to the top (Disability Rights Timeline, 2022). Another stated, “I want to be treated like a human being.” The “Capitol Crawl” has become an iconic moment instrumental in the passage of the ADA (Disability Rights Timeline, 2022). To mark the passing of the law, disabled people based in Boston created the inaugural Disability Pride Day, which included speakers and a parade. The notion of disability pride celebrates disability as a part of human diversity, similar to how the queer pride movement provides a space to celebrate queerness (Fowler & Wallach, 2022).

What received much less attention in 1990 was the founding of the National Black Disability Coalition in response to the need for Black disabled people to organize around their unique concerns. Focusing on poverty, the organization’s purpose was to take an intersectional approach to what being Black and disabled in the United States was like. The organization supports the idea that Black disabled people must coalesce to secure the rights and privileges of full community participation. Drawing on approaches from the racial justice civil rights movement, the organization’s focus is on achieving collective power and inclusion for Black disabled people in the family and faith contexts as well as in the disability community (Lead On Network, 2016).

In 1991, Roland Johnson was a Black activist with an intellectual disability who is known for his work in the fight to shut down the Pennhurst State School and Hospital, where he had endured unspeakable abuses for thirteen years. He founded Self Advocates Becoming Empowered and is also known for his involvement in the Philadelphia chapter of Speaking for Ourselves (Rifkin, 2020). Also in 1991, Black disabled activist Donald Galloway (mentioned above) was involved in a key court case related to the rights of visually impaired people (Center for Learner Equity, 2022). When he was called for jury duty in Washington, DC, he brought his guide dog but was dismissed by the judge “on the grounds that being unable to see the proceedings meant he could not fulfill the duties of a juror” (Center for Learner Equity, 2022, p. 1). Galloway sued in 1992, stating that the automatic disqualification of blind people from jury duty violated the Constitution and won. In the finding, it was noted that jury membership should represent a cross-section of the peers of the defendants in question, including disabled people.

## After the Olmstead Decision

In 1999, the disability community celebrated the *Olmstead v. L.C.* case, which determined that unjustified segregation of disabled people with disabilities was a violation of the ADA. This meant that it was unconstitutional for people to be forced to remain institutionalized when they had the capacity to live in community settings. One of two plaintiffs in this case was Black disability activist Lois Curtis, a person with cognitive disabilities, who had lived in a Georgia institution from age 11 to 29 despite being capable of achieving community inclusion (Elaine Wilson, a white woman, was the other plaintiff). The state had refused to pay for this type of placement. The *Olmstead* case paved the way for thousands of disabled people to live in the community (Center for Learner Equity, 2022).

Starting in the early 2000s, we began to see the autistic self-advocacy movement, sometimes called the autism rights movement or the autistic acceptance movement. Building on work by autistic activists in the 1980s and 1990s who emphasized that a cure for autism was not needed, this movement focuses on neurodiversity and the idea that autism is a result of natural variations in brain function as opposed to an impairment that should be fixed (Solomon, 2008). The goals of this movement are for society to evidence better acceptance of autistic behaviors; autism services that address how to improve quality of life as opposed to fitting into neurotypical societal expectations, and on recognizing the autistic community as a minority group. The Autism Self Advocacy Network (ASAN) is a prominent organization in this movement and is well-known for its role in the Autism Speaks Boycott, which protested the lack of representation of autistic people in the organization and for engaging in exploitative practices (ASAN, 2019). More recently, a central figure in this movement is Autistic attorney Lydia X.Z. Brown (who created the blog, Autistic Hoya). They partnered with Autistic Women and Non-Binary Network to edit and publish a book entitled *All the Weight of Our Dreams: On Living Racialized Autism* in 2017. Modeling reflectivity and reflexivity, the editors of this groundbreaking book reconsidered their work after identifying unintentionally racist and otherwise oppressive commentary was reflected upon ([Brown, Ashkenazy, Giwa Onaiwu & daVanport 2021](#)).

In 2002, hundreds of disabled queer activists took part in the first-ever Queer Disability Conference in San Francisco, CA. At the conference, sessions focused on medical discrimination, coming out in the workplace, queer crip performance, work with partners and allies, queer crip sexualities, and other topics. Fowler & Wallach (2022) report that the conference created room for discussions, community, networking, and mutual learning across identities. A central focus was the use of medically unnecessary surgeries for people identifying as intersex.

Founded in 2003 with a solid focus on the social model of disability in which the environment is seen as disabling, The Icarus Project focused on creating a space that acknowledged the flawed world we live in, and how this can create mental health struggles for people. After a series of internal conflicts related to racism, transphobia, heterosexism, and sexism, this group re-emerged as the [Fireweed Collective](#), now centering the voices and leadership of people of color, members of the Queer communities and women/femmes, among other oppressed populations (Fireweed Collective, 2022).

## The Birth of the Disability Justice Movement

In 2005, disabled Asian American activists Mia Mingus, Patty Berne, Stacy Milbern, and other disabled activists of color and from the Queer communities such as Leah Lakshmi-Piepzna-Samharasinha (author of *Beyond Survival: Strategies and Stories from the Transformative Justice Movement*) gathered as part of *Sins Invalids* (Berne & Sins Invalid, 2015) to discuss the ways in which the disability civil rights movement often took a single social identity frame (i.e. disabled), erasing the other aspects of social identity in the community (Kafai, 2021). Explaining this phenomenon, Berne notes:

Its leadership has historically centered white experiences; its framework leaves out other forms of oppression

and the ways in which privilege is leveraged at differing times and for various purposes; it centers people with mobility impairments, marginalizing other forms of impairment; and centers people who can achieve rights and access through a legal or rights-based framework. The political strategy of the disability rights movement relied on litigation and the establishment of a disability bureaucratic sector at the expense of developing a broad-based popular movement. While a concrete and radical move forward toward justice, the disability rights movement simultaneously invisibilized the lives of people who lived at intersecting junctures of oppression – disabled people of color, immigrants with disabilities, queers with disabilities, trans and gender non-conforming people with disabilities, people with disabilities who are houseless, people with disabilities who are incarcerated, people with disabilities who have had their ancestral lands stolen, amongst others (Berne, 2022, p. 2).

Responding to this reality, this group of activists promoted the development of a progressive and radical movement conceptualized as a ‘second wave’ of disability rights, now known as the Disability Justice movement. In describing this movement, Berne (2022) notes:

A Disability Justice framework understands that all bodies are unique and essential and that all bodies have strengths and needs that must be met. We know that we are powerful not despite the complexities of our bodies, but because of them. We understand that all bodies are caught in these bindings of ability, race, gender, sexuality, class, nation-state, and imperialism and that we cannot separate them (Berne, 2022, p. 4).

In 2007, Leroy F. Moore founded Krip-Hop Nation, a collective for artists with disabilities. Moore is a Black/African American writer, poet, and community activist who was diagnosed with cerebral palsy (Gavieta, 2022). In the disability justice tradition, Moore relied on the use of the hip-hop medium for political activism that would connect the Black/African American and disabled communities, noting the oppression that both groups face in hip-hop culture. Krip-Hop was conceptualized as a form of intersectional advocacy that stands up to racism and ableism in society as well as specifically calling out police brutality, racial profiling, and ever-present access barriers (Gavieta, 2022). KripHop Nation embraces as a series of tenets: use politically correct lyrics; do not put down other minorities; use our music to advocate and teach not only about ourselves, but also about the system we live under; challenge mainstream & all media on the ways they frame disability; increase the inclusion of voices that are missing from within the popular culture; recognize our disabled ancestors, knowing that we are built on what they left us, and nothing is new, just borrowed and know that sometimes we fail to meet the above standards but we are trying (Gavieta, 2022).

Also following in the disability justice tradition, in 2014, after the killing of Michael Brown in Ferguson, Missouri by law enforcement, Black, transgender, disabled activist Ki’tay Davidson created the #DisabilitySolidarity hashtag as well as the @dissolidarity Twitter account. Ki’tay’s work was vital in creating a societal conversation about the intersection between disability, race, and ethnicity (Yo! Disabled and Proud, 2019). The social media platform Twitter has become a central space for disability civil rights and disability justice organizing (Sarkar, Forber-Pratt, Hanebutt, & Cohen, 2021). Ki’tay pointed out that disabled people of color and/or with LGBTQIA identities, along with other multiply-marginalized communities, are more

likely to face violence, especially from law enforcement. He championed the idea that these are disability rights issues (Yo! Disabled and Proud, 2019).

While primarily considered an achievement of the LGBTQIA+ movement, in 2015, the Supreme Court decision on *Obergefell v. Hodges*, stated that couples of any gender could get married in all 50 states as well as be granted the right to full, equal recognition under the law (Wallach). Little known is that Jim Obergefell's husband, John Arthur, had ALS, a chronic health condition covered under the ADA. After John Arthur's death, James Obergefell became a plaintiff in the fight for federal recognition of their marriage (Fowler & Wallach, 2022).

## Onset of the #CripTheVote

Asian American activist Alice Wong and White activist Andrew Pulrang founded the #CripTheVote movement in 2016 (Beratran, Pulrang, and Wong, 2016). Describing the movement, Beratran, Pulrang and Wong (2016) note:

#CripTheVote is a nonpartisan online movement activating and engaging disabled people on policies and practices important to the disability community. Our movement is grounded in online conversations encouraging individual and collective action in the face of inequality, ableism, and oppression in all forms. Our movement is intersectional, local, global, and focused on the political participation of disabled people. (p. 1)

The architects of this movement have pledged to continue to be an intersectional movement by and for the entire disability community that remains online and as decentralized as possible in their effort to promote political participation (Beratran, Pulrang & Wong, 2016). In doing this work, #CripTheVote intends to ask questions of and demand accountability from elected and public officials regarding disability concerns (Beratran, Pulrang, and Wong, 2016). This translates to engagement with disability concerns in local, state, national, and international domains (Beratran, Pulrang, and Wong, 2016). The movement seeks to support direct actions and their disabled organizers by sharing and amplifying information about them (Beratran, Pulrang, and Wong, 2016). This requires partnership with disabled people to broaden the movement's perspectives and garner more expertise (Beratran, Pulrang, and Wong, 2016). Further, the movement pledges to oppose any policy or practice that could harm the members of the disability community. This includes exploring and/or promoting ideas for improved disability policies and programs (Beratran, Pulrang, and Wong, 2016).

Moving ahead to 2020, Rebecca Cokely (2022) notes that we began to see the fruit of the #CripTheVote movement and the disability justice movement in general in the 2020 presidential election. At this time, 15 candidates issued disability policy platforms, from Kamala Harris' concise approach focusing on, for example, disability marriage equality, sub-minimum wage payment, and increased funding for home and community-based services, to Bernie Sanders' 35-page platform. Cokely notes that this reality speaks to the power of the disability civil rights and disability justice movements, such as the action in support of Obamacare in 2017



discussed above. Those protests highlighted the connections between disability rights and the rights of all people. In addition to these movements, Cokely notes, equally important is the case law coming from disability rights organizations as well as allies in and out of government. During the 2020 election, we began to see leadership in the House and Senate begin to identify as disabled, such as Katie Porter, Tina Smith, Ayanna Pressley, and Tammy Duckworth. Moving beyond the “all but disability” (ABD) tradition, these leaders have seen disability as a lens for policy work in all sectors, such as when working on an education bill, thinking about how it impacts disabled children or considering access for disabled workers in bills about small business (Cokely, 2022).

## More Attention to Intersectionality

2016 also saw the founding of The National Coalition for Latinxs with Disabilities (CNLD) volunteer organization comprised of Disabled Latinx leaders and allies in the United States. Of their purpose, the group states, “We came together in 2016 to form CNLD because we shared the experience of living fractured identities (in Disabled and Latinx worlds, respectively).” The organization was inspired to develop connectedness in the community because approximately 12 million Latinx-disabled people reside in the United States. Conchita Hernández Legorreta is a primary leader in this group seeking a national scope (CNLD, 2022).

2017 saw the development of the virtual Disability March movement – perhaps building on the community building emanating from #CripTheVote. This ‘march’ was created in response to the 2016 election, which was followed by the large protest known as the Women’s March, in Washington in January 2017. Focused on lifting up “disabled activists who could not take part in the physical Women’s March but needed to have their voices heard,” event organizer Sonya Huber and team featured 3,104 photos with accompanying text for individual ‘marchers.’ The group’s mission statement indicates:

While we did not come together to adopt a formal mission statement, the effort was launched through a desire to have disabled people visible during a time in which far-right policies will fall hard on the disabled community. The disabled community is endangered because much able activism is difficult to access, and that needs to change. We need to be visible, to be leading and forming alliances, to be counted as activists and as members of our communities (Disability March 2022, p. 1).

For example, individual ‘marchers’ cited the ways in which requiring accessibility aids, including service dogs, as well as facing physical and/or mental limitations as reasons for not being able to participate in the in-person march (James, 2022). This group challenged both the assumptions as well as the disability definitions of the non-disabled community as well as the dominant disability rights community (James, 2022).

As the disability justice movement overall continued to take effect in the disability community, activists such as Asian American organizer Sandy Ho and colleagues saw the need for more of a focus on intersectional identities in that community. Putting together the Disability Intersectionality Summit (DIS), first organized in 2016, members of the disability community gathered to elucidate themes related to intersecting social



identities in their community. One of the campaigns coming out of DIS is framed by the [#AccessIsLove](#) hashtag and website. This campaign seeks to get out the message that accessibility is understood as an act of love versus being seen as a burden or even an afterthought. Focused on raising accessibility awareness, this campaign encourages the incorporation of access into everyday patterns.

In 2019, [The National Alliance of Multicultural Disabled Advocates \(NAMD\)](#) was founded. This is a group led by disabled Black Indigenous People of Color (B.I.P.O.C.) who worked collectively to conduct a demonstration during the National Centers for Independent Living conference. At the time, their stated purpose was “to address the ongoing issues of racism, xenophobia, sexism, homophobia, transphobia, colonialism, and ableism in the broader disability rights movement” (Gray, 2022). In their position statement at the time, the group noted:

Disabled B.I.P.O.C., particularly black and brown disabled people, are disproportionately locked up in detention camps, jails, prisons, institutions, and nursing homes. Additionally, disabled B.I.P.O.C. are more economically disadvantaged by hiring practices in our own community and are rarely elevated into management and executive roles. The reasons for this are not for lack of people or talent but rather discrimination, tokenism, and systemic oppression. We can no longer ignore the pain and suffering of our people just to satisfy those who call for “unity.” We, the NAMD, must resist comfort and speak out about the discrimination and violence that remains rampant in disability organizations (Lead On Network, 2022, p. 1). Their current mission statement indicates that they are:

a network that supports the leadership of disabled Black and Brown change agents, advocates, entrepreneurs, and communicators. We convene leaders who have a collective commitment to racial & disability justice, and we share fundamental strategies with individuals that work to enhance the social, political, and economic standards of their communities.

Later, in 2019, Keri Gray and Justice Shorter, Black disabled activists, coined the hashtag campaign [#BlackDisabledLivesMatter](#). Reflecting on why they coined the hashtag, Shorter and Gray state that they “knew that they weren’t the only ones who felt limited by the inaccessibility of protests but still wanted to be seen and heard in this global movement” (Kim, 2020, p. 1). This built on the fact that the original Black Lives Matter creators were attentive to recognizing the disability community in their mission statement, although simultaneously critiqued at times by disabled people of color for the lack of disability awareness in many of their organizing spaces nationally (Doucette, 2017). Regardless of this, NAMD felt it was important to amplify the intersections of ableism and racism through the use of the hashtag (Kim, 2020, p. 1). One of the primary reasons for this given by the women was that they feel that disability narratives are erased in the Black community, a practice going back over two hundred years (such as the fact that Harriet Tubman was disabled).

Although controversial for some proponents of the [#BlackLivesMatter](#) movement who argue against the need for ‘disabled’ in the traditional [#BlackLivesMatter](#) hashtag in favor of lifting up harm to the Black and brown communities, a number of disabled people of color embrace this campaign, such as the Movement for Black Lives (Harriet Tubman Collective, 2016). Of the campaign, Shorter notes:

I hope that we continue to have those types of conversations, but if nothing else, it has helped people feel seen, it has helped people feel heard...It has helped people just feel a sense of community, which is so important during a time where so many of us have felt isolated” (Kim, 2020, p. 1). Related to this work is the hashtag campaign #DisabilityRightsInBlack, where activists such as Kayla Smith and Morénike Giwa Onaiwu promote an intersectional approach. Kayla is known as a young self-advocate who created another hashtag campaign, [#AutisticBlackPride](#) (National Disability Rights Network, 2020).

Perhaps the first large-scale exposure the disability civil rights and disability justice movements received was in the release of the documentary “Crip Camp” in 2020. What is not well publicized is the role of Black disabled activist Andraéa LaVant. LaVant, the ‘impact producer’ of this film, led the film’s efforts to promote an understanding of disability as a social justice issue and to build coalitions around this idea (LaVant, 2022). Moving forward, it is important that the study of disability resistance movements entails more attention to how colonial (pre-and-post) violence intersects with present-day oppression, disability, and, for example, Black Lives Matter via direct, cultural, and structural processes of violence against Black bodies (Galtung & Fischer 2013). Such a focus and intentional inclusion can assist activists, educators, and social workers with an overall intersectional, anti-oppressive, critical coalition building across diverse peoples and communities, including the National Black Disability Coalition, National Coalition of Latinxs with Disabilities, and Asian Americans with Disabilities, etc. (AADI, 2022).

## Conclusion

This chapter has discussed the need to take an intersectional approach to the history of disability resistance movements in the United States. We reviewed the chronology of major aspects of disability resistance movements since the late 1890s. As advocacy for disability rights has evolved from a single issue focus to a more multifaceted one, social workers can learn from this evolution. It will be important for social workers to see all of the social identities their disabled clients have, and how, together, all of those social identities impact their intervention experience. This review of disability activism should serve as inspiration for how we can listen to the diverse members of the disability community as we move forward to make the social work profession as disability-affirming and disability aware as it should be.

For social workers involved with policy formulation and implementation, taking an intersectional approach to thinking about policy will also be important. With an understanding of the history of disability activism and resistance movements, social workers can see where we have come from, and where we still need to go – such as the resolution of the disability marriage penalty and the use of sub-minimum wage for disabled people. As you consider what you have learned in this chapter, please consider the following discussion questions:

1. Given the challenges that disability resistance movements face concerning an intersectional framework and the resulting building of bridges across social justice movements, how does your practice participate

in this regard, and what could you be doing better?

2. Consider a policy that impacts your professional practice working with persons with disabilities/ disabled persons. Does it take a single-issue focus on disability or more of an intersectional one that honors the complexities of social identities, locations, and positionalities?
3. As an implementer of disability policy in your practice with individuals at a micro level, do you take a single-issue focus on disability or more of an intersectional one that honors social identities and their connection with systems of power, privilege, and oppression?
4. Which of the current disability activism organizing groups discussed (or not discussed) are you curious to learn more about so as to apply this knowledge to your practice?
5. How does the #CripTheVote help the disability community and exclude members of the disability community (e.g., access to online resources/computers/internet services, etc.)? And how can you connect clients and colleagues to #CripTheVote and make it more accessible to all disabled persons?

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# CHAPTER AUTHOR BIOGRAPHIES

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## **Elsbeth Slayter, MSW, MA, PhD, Co-editor and chapter author**

Dr. Slayter is a Professor in the School of Social Work who does disability services research related to addictions and child welfare. She teaches social welfare policy, research, evaluation, field, disability practice and forensic social work courses at Salem State since 2005. Dr. Slayter coordinates the School of Social Work's [Certificate on Equity-Minded Practice](#), a partnership with the Massachusetts Department of Children and Families. Dr. Slayter is the co-founder of [#SWEducActs](#), a national group focused on anti-racist practice in social work education. Dr. Slayter also co-facilitates the [NASW-MA Disability Justice Shared Interest Group](#).

## **Lisa Johnson, MSW, PhD, Co-editor and chapter author**

Dr. Johnson has practiced in both the child welfare and healthcare fields and has worked with complex systems for non-profit development and community organizing. Her research and scholarship interests encompass child welfare; diversity, equity, and social justice; workforce development; disability studies, and social work education.

## **Rose C. B. Singh, MSW, Chapter author**

Rose is a registered social worker with the Ontario College of Social Workers and Social Service Workers (OCSWSSW), an Ontario Association of Social Workers (OASW) member, and an Ontario Association of Child and Youth Care (OACYC) member. Rose has a multidisciplinary educational foundation including a Social Service Worker Diploma and Human Resources Management Post-Graduate Certificate from Conestoga College; an Honours Bachelor of Arts, Diploma of General Studies in Social Work, and Certificate in Studies of Child Abuse from the University of Waterloo; a Bachelor of Social Work from the University of Victoria; and a Master of Social Work from Dalhousie University. Rose is committed to life-long learning and is currently working towards a PhD in Social Work.

## **Nikki Fordey, MSW, MA, Chapter author**

Nikki Fordey is a social worker and substance use disorder clinician. She is dedicated to furthering progressive values and policies that recognize and champion the inherent dignity and worth of all people. Nicole utilizes her personal and professional experiences to connect those in positions of power and authority to the truth of the issues people who use drugs and/or have mental health conditions face. In addition, Nicole has used her experiences with the health care system as a person with a disability (a chronic and incurable illness affecting mobility and causing continuous pain) to highlight the need for reform and regulation, including single-payer health care.

## **Esther Son, MSW, MA, PhD, Chapter author**

Esther Son is an Associate Professor in the Department of Social Work at the College of Staten Island. Her primary research interest is the enhancement of the physical and mental health and emotional well-being

of children and young adults with disabilities and their families. She has been investigating the health care disparities among people with disabilities, in particular, disparities in health care access, service utilization, and quality of care among minority children with autism and developmental disabilities and women with intellectual and developmental disabilities, and violence against people with disabilities. Her work has been supported by the Deborah Munroe Noonan Memorial Research Fund, Health Resources and Services Administration (HRSA), US Department of Health & Human Services, and the City University of New York among others. She received her Ph.D. in social work from Rutgers University and completed a two-year postdoctoral fellowship at the Lurie Institute for Disability Policy at The Heller School for Social Policy and Management at Brandeis University. Her work has appeared in *Children and Youth Services Review*, *Exceptional Children*, *American Journal on Intellectual and Developmental Disabilities*, *Journal of Intellectual Disability Research*, *Disability and Health Journal*, *Families in Society-the Journal of Contemporary Social Services*, *Journal of Community Practice*, and *Public Health Reports*.

**Sharyn DeZelar, PhD, MSW, LICSW, Chapter author**

Sharyn DeZelar joined the St. Catherine University faculty in fall 2019 as a full-time Assistant Professor. Dr. DeZelar earned a PhD in Social Work in 2018 from the University of MN (Twin Cities) along with a certificate in Disability Policy and Services. She earned her MSW in 2006 from St. Catherine University/University of St. Thomas School of Social Work, and her BSW from the University of Wisconsin-Eau Claire in 1998. Dr. DeZelar's research focus is largely related to disabilities, and its intersection with family support, parenting, poverty and child welfare. Dr. DeZelar also has been working on several projects related to diversifying the social work profession via inclusion and equity for students with disabilities. She has significant practice experience in housing services, disabilities and mental health.

**Olivia Elick, MSW, LGSW, Chapter author**

Olivia Elick was raised and continues to reside on Dakota and Annishinabe land, currently known as Minneapolis, MN. Olivia is a lifelong learner in the study of abolition, which embodies transformative activism that is evident in the past, present and future of liberation within our collective selves. She received her Bachelor of Science degree from The University of Minnesota – Twin Cities in Youth Studies and Social Justice (2018) and Master's of Social Work from St. Catherine University – St. Paul (2022). Olivia has a passion for working with the young people in her community spanning across parks, libraries, community programming, and school settings through long term relationships and community building. She has a wealth of experience in fierce advocacy for herself, family, friends, and community in educational, therapeutic, governmental, and medical settings. Olivia hopes to continue learning, growing, and being in communion with those who also seek and embody collective liberation.

**Robyn Powell, JD, MA, PhD, Chapter author**

Robyn M. Powell joined the OU Law faculty in 2022, where she teaches courses on Family Law, Disability Law, and Professional Responsibility, among others. Previously, she was the Bruce R. Jacob Visiting Assistant Professor at the Stetson University College of Law, where she taught Torts, Disability Law, and Public Health Law. For three years, Dr. Powell was an Instructor at Boston University School of Law, where she taught

Disability Law. As a disabled woman, Dr. Powell has dedicated her career to advancing the rights of people with disabilities. For nearly five years, Dr. Powell served as an Attorney-Advisor at the National Council on Disability (NCD), an independent federal agency that advises the President and Congress on matters concerning people with disabilities. Previously, she served as a Research Associate at the Lurie Institute for Disability Policy at Brandeis University, Disability Rights Program Manager at the Equal Rights Center, Assistant Director for Policy and Advocacy at the Disability Policy Consortium, and Staff Attorney at Greater Boston Legal Services. While in law school, Dr. Powell interned for NCD and the Disability Law Center, the Massachusetts Protection & Advocacy agency. Dr. Powell is one of the country's foremost authorities on the rights of parents with disabilities. She is the principal author of NCD's report, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children*. As a leading expert, Dr. Powell has been interviewed by various news outlets, including the Washington Post, N.Y. Times, NPR, BBC, ABC News, the Daily Beast, and the Associated Press. In May 2016, she was an invited speaker at the White House Forum on Civil Rights of Parents with Disabilities.

**Katie Sweet, LICSW, Chapter author**

Katie Sweet is an experienced and committed clinical social worker with experience as a case manager, skills instructor, program director, supervisor, and direct care professional with a 15+ year successful track record of providing social and health care services to people with differing abilities. She is an effective communicator and skilled in organizing and providing personalized and group programs to children, adolescents, and adults with trauma, chronic illnesses, physical disabilities, developmental disabilities, dementia, Alzheimer's, and other concerns which increase their care needs.

**Ami Goulden, PhD(c), MSW, MA, BSW, BA, Chapter author**

Ami Goulden is an Assistant Professor at the School of Social Work at Memorial University and a doctoral candidate at the Factor-Inwentash Faculty of Social Work, University of Toronto. She has earned a Master of Social Work (University of Toronto), a Master of Arts in Child and Youth Studies (Mount Saint Vincent University), a Bachelor of Social Work (Dalhousie), and a Bachelor of Arts (Mount Saint Vincent University). Ami has over ten years of social work practice experience in various settings, including inpatient and ambulatory pediatric and adult healthcare settings and child welfare. She received clinical training on one of the largest pediatric brain injury rehabilitation programs worldwide at the Holland Bloorview Kids Rehabilitation Hospital in Toronto. Ami has practiced in both urban and rural settings in Nova Scotia and Ontario. Her most recent experience includes working in multidisciplinary healthcare clinics serving clients with chronic health conditions and their families during the coronavirus pandemic.

**Shanna K. Kattari, PhD, MEd, CSE, ACS, Chapter author**

Shanna K. Kattari (they/them/theirs) is an associate professor at the School of Social Work, in the Women's and Gender Studies Department (by courtesy), and is the director of the [Sexuality|Relationships|Gender] Research Collective. A white, Jewish, nonbinary, disabled, chronically ill, neurodivergent, polyamorous, queer fat Femme, their practice and community background is as a board-certified sexologist, certified sexuality educator and social justice activist. Kattari's research focuses on three areas that often overlap: disability and

ableism, sexuality and sexual health, and queer and trans affirming practice. Their work aims to understand how power, privilege and oppression systematically marginalize, exclude and discriminate against people regarding their identities, while also uplifting the brilliance and resistance demonstrated by these communities in the face of stigma and harm. Recently, Kattari's work has focused on the health disparities among trans/nonbinary communities, across physical, behavioral and sexual health, using community-based participatory research and arts-based methods. Their work has also included several studies on disability and ableism, particularly regarding the academy, and social work education. They are committed to engaging, innovative education and critical pedagogy, multi-level omnidirectional mentorship models and supporting individuals from a variety of identities in entering, navigating and succeeding in the academy.

**Andrea J. Murray-Lichtman, MSW, PhD, Chapter author**

Andrea Murray-Lichtman is a clinical associate professor at the University of North Carolina at Chapel Hill School of Social Work. She completed the NABSW Academy of African Centered Social Work and is currently a doctoral student. Andrea's research interests include racial equity in access and outcomes across social systems, and her theoretical expertise includes Critical Race Theory, Critical Whiteness Studies, and methodologies centering counter-narratives. She has a combined 17 years of physical health, mental health, and substance misuse treatment experience within integrated healthcare and criminal justice settings serving people living with co-morbid mental health, substance misuse, and chronic physical health diagnoses. She currently manages a substance use prevention, education, and research grant and is a co-investigator with the Specialty Mental Health Probation research team. Since joining the UNC-Chapel Hill faculty in 2013, Andrea has taught in the full-time and part-time programs. Her educational philosophy encompasses providing social work education through the lens of racial and social justice. She facilitates students' insight into the lived realities and agency of marginalized groups, and the impact decisions and interactions with the social work profession have on the lives of the under-resourced. Andrea received the Dean's Excellence in MSW Advising Award in 2018 and the Dean's Recognition of Teaching Excellence Award in 2015. Andrea served on the 2020 Anti-racism Task Force for the Council on Social Work Education. She also consults on several international projects for racial and social equity in social work education and practice.

**Michael L. Clarkson-Hendrix, MSW, PhD, Chapter author**

Michael Clarkson-Hendrix is an Associate Professor of Social Work in the Department of Sociocultural and Justice Sciences at the State University of New York at Fredonia. Dr. Clarkson-Hendrix's research targets the intersection of behavioral health, disability, and social welfare, particularly in employment and workforce development. Dr. Clarkson-Hendrix has extensive practice experience in the areas of behavioral health and child welfare. His research targets the intersection of behavioral health, psychiatric disability, and social welfare, particularly social welfare as it relates to employment and workforce development.

**Mallory Cyr, MPH, Equity & Inclusion Consultant, LLC, Chapter author**

Mallory Cyr is the Program Manager of Children & Youth with Special Health Care Needs (CYSHCN) at the Association of Maternal and Child Health Programs (AMCHP). Mallory earned her Master of Public Health with a concentration in Maternal & Child Health from Boston University and a Bachelor in Fine Arts



in Creative Writing from the University of Maine at Farmington. Mallory brings an extensive background of 14+ years of experience and a strong understanding of the CYSHCN population. Mallory has consistently attended the AMCHP conference and served on the former AMCHP Family and Youth Leadership Committee (now the Family LEAD Committee). Mallory is incredibly passionate about improving opportunities for meaningful youth engagement, leveraging social media for stakeholder engagement, and applying personal lessons learned to her work from her lived experience navigating systems for CYSHCN in multiple states. At AMCHP, Mallory supports SPHARC, leading the Autism Community of Learners and other SPHARC activities, in addition to supporting the needs of the CYSHCN workforce through the Public Health Emergency Preparedness project, the Leadership Institute for CYSHCN Directors, and expansion of the National Standards.

**Gabrielle L. Gault, MSW, LSW, Chapter author**

Gabrielle L. Gault, is the Senior Program Coordinator at the Center for Research on Ending Violence at Rutgers the State University of New Jersey, School of Social Work. Gabrielle's work is rooted in the belief that by working together, in community, we can dismantle systems of oppression that perpetuate violence and cause further harm.

**Alison B. Wetmur, DSW, LCSW, Chapter author**

Alison Wetmur is a clinical social worker by training, Alison specializes in working with people who have experienced trauma. Alison owns a private practice in CT, where she specializes in treating trauma and working with d/Deaf people. She is also on the faculty of Connecticut College. Alison is also Deaf, and provides mental health counseling to adults and teenagers who are hearing, d/Deaf, and hard of hearing. Alison approaches her work with clients with compassion, relying on the formation of a successful therapeutic alliance that has proven results.

**Sara-Beth Plummer, PhD, MSW, Chapter author**

Sara-Beth Plummer is the Assistant Director of the Baccalaureate Social Work (BASW) Program at Rutgers University. Her practice experience includes being both a social worker and an Assistant Director at Barrier Free Living, Inc., an agency that provided services to individuals with disabilities who were survivors of abuse. Her academic interests include curriculum development, assessment, and online education. Dr. Plummer's area of practice include individuals, families and groups with a focus on interpersonal violence and people with disabilities. Her interests include curriculum development, assessment, and online education.

**Patricia A Findley, DrPH, MSW, Chapter author**

Patricia A. Findley is an Associate Professor of Social Work, Director of the MSW program, and Special Assistant to the Dean for Interprofessional Health Initiatives. Her research interests include chronic illness, physical disability, interprofessional health education, disaster preparedness and response, and cancer survivorship. She holds a research scholar position within the Veterans Administration where she explores both physical and mental health issues, as well as trauma issues within the veteran population. Past projects included examining a Medicaid Traumatic Brain Injury Waiver through a NIH K-Award grant and validation of the Medical Listings and program reform of the Social Security Disability Determination Process through

a collaborative agreement with the Social Security Administration. Dr. Findley has a long clinical history in working with those with disabilities in medical rehabilitation settings, and co-authored a book, *The Cancer Survivor Handbook: The Essential Guide to Cancer Survivorship*. With funding from USAID, she has collaborated with American, Israeli, and Palestinian colleagues on educating students and mental health professionals on disaster preparedness and response. More recent work has her exploring the impact of Hurricane Sandy on both individuals in New Jersey as well as the state behavioral health system response to the storm. Her research appears in peer-reviewed rehabilitation, public health and medical journals including *Archives of Physical Medicine and Rehabilitation*, *Women's Health Issues*, *Preventive Medicine*, and *Journal of General Internal Medicine*. She serves a senior associate and managing editor for the *Journal of Occupational Rehabilitation*.

**Sandra M. Leotti, MSW, PhD, Chapter author**

Sandra Leotti received her MSW from the University of Montana and her Ph.D. from Portland State University. She has over a decade of direct practice experience in the areas of mental health, disability, and youth development. Her research pursues two overlapping areas of inquiry: examining social work's role in upholding systems of injustice and the study of contemporary issues pertaining to the carceral state. A primary goal of her scholarship is to advance community-based, non-punitive approaches to addressing harm and need. Sandra's teaching and scholarship are driven by an emphasis on social justice and aim to strengthen the relationship between critical and feminist theories and social work education, research, and practice.

**Alexandria Lewis, Ed.S., MSW, LCSW, Chapter author**

Ms. Lewis' focus area is educational technology and online learning as it relates to Social Work curriculum. This interest led her to seek graduate level education in online education through the MU School of Information Science & Learning Technologies (SISLT). In 2014, she earned a Graduate Certificate in Online Education. To further enhance her knowledge and skills in this area, she earned an Educational Specialist degree (EdS) with an emphasis in Educational Technology. In particular, Ms. Lewis is interested in ways to enhance student learning in the online environment. She is fascinated with the research on this topic and finds ways to integrate the research into her teaching. She received an award from the Mizzou ET@MO Teaching with Technology Innovative Fund (TTIF) to incorporate a digital lesson creator program into her course lessons. She utilizes this program with media, written content, and self-check activities including "quiz poppers" for her classes. Ms. Lewis is also interested in ways to incorporate active learning into the online classroom. By incorporating activities within the course lesson, her hope is that students will feel more active and engaged in their learning. Through self-check activities, students have the opportunity to evaluate their own learning for course lesson content.

**Valerie Borum, MSW, LMSW, PhD, Chapter author**

Dr. Borum has experience as both a BSSW Program Director and an MSW Program Director. As a social work practitioner, she directed two programs, supervising social work and human services professionals serving persons with disabilities and intersecting identities. Her research and scholarship focus on the role of ethnoculture as a protective and promotive factor in health, mental health, and disability, with attention

to Black/African Americans. She also studies the intersection of disability, deafness, and ethnoculture, with attention to Black/African Americans and Afro-Latinx/Black Hispanics families with deaf and hard of hearing children. Dr. Borum completed her post-doctoral studies (e.g., focus on suicide and ethnoculture) at the University of Rochester, School of Medicine, Rochester, NY. Dr. Borum received her Ph.D. in Social Work from Howard University, School of Social Work and her MSW from Gallaudet University. She received the Ester Ottley Fellowship, a one-year internship for one female student who most exemplifies qualities of leadership and humanity while at Howard University. While studying at Gallaudet University for her Master's in Social Work, all of her instruction was in American Sign Language (ASL). She received her B.A. in Psychology with minors in Biology and Philosophy from Mundelein Women's College at Loyola University, Chicago, IL. Dr. Borum is currently conducting research with a focus on advocacy and families of color (visible racialized minoritized groups) as a research collaborator/consultant with Laurent Clerc National Deaf Educational Research Center at Gallaudet University in Washington, D.C.

# GRANT INFORMATION

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For more information about the ROTEL Project, please visit our project website at <https://sites.google.com/view/rotelgrant/home>.