

# CRITICAL DISABILITY: POWER, IDENTITY, AND SYSTEMS CHANGE



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# Critical Disability: Power, Identity, and Systems Change

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This text was compiled on 06/13/2026

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## Licensing

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*A detailed breakdown of this resource's licensing can be found in [Back Matter/Detailed Licensing](#).*

## Introduction

### Learning Objectives

#### Learning Objectives for this Book

- Articulate multiple frames for understanding disability in the United States
- Explain how power relations and discourses shape disability experiences
- Articulate points of intersection between disability and other identity categories; and
- Identify how disability discourses structure and affect the lives of people in the U.S. through multiple systems (e.g., education, policy, employment)

## Why Critical Disability Matters

### Why Critical Disability Matters: Summary

- Disability is common
- People with disabilities experience discrimination
- This leads to worse outcomes in health, education, employment, community engagement, and quality of life
- Critical disability gives tools to perceive and improve this

Disability is common. Most, if not all of us, will experience disability at some point in our lives. Maybe you already do.

Yet, we live in a world where disability is often considered a shameful or taboo topic. We are often taught not to talk about it, which can leave us unsure how to talk about it when we need to (and some people hope they don't need to).

People with disabilities experience inequities in all areas of life. Disabled people have worse access to healthcare, worse health, and worse life outcomes than non-disabled people. They are more likely to be denied an education, or to be unemployed—even when highly trained. People with disabilities are underrepresented or excluded from policy decisions, even when the policy is about disability. In arts and culture, both disability and disabled creators remain scarce. Despite how common disability is, people with disabilities remain both systemically and systematically disempowered, devalued, and marginalized.

Critical disability offers tools to perceive the mechanisms behind these inequities. Once exposed, it is possible to understand them. Once understood, it is possible to change them.

## How This Book Is Set Up

The next three chapters are foundations. The first chapter gives staring definitions for disability, accessibility, and community. It also gives an introduction to the language of disability and how it will be used in this book. Chapter 2 presents the [theoretical foundations](#) of this book. The theoretical foundations—paradigms, models, frameworks, and narratives—are high-level structures that can help make sense of the complexity of the real world. Chapter 3 very briefly provides some historical context about disability history in the United States from World War I to present. Chapter 4 puts everything together to introduce critical disability studies, both in theory and in relation to the types of real-world issues it is currently concerned with examining.



*How this Book is Organized*

The middle four chapters use a critical disability lens to unpack how disability interacts with major life areas. Chapter 5 focuses on health and wellbeing, including health and healthcare systems. Chapter 6 examines disability in education and employment. Chapter 7 shifts to community engagement in policy and other social systems such as the legal system and technology. Chapter 8 focuses on disability in arts and culture, including within disability cultures themselves.

The last two chapters are about systems change. They ask the question: How might we use a critical understanding of disability to improve things for disabled people now and in the future? Chapter 9 discusses the tenants of disability justice and then uses a systems thinking approach to illustrate how we might find leverage for change. Chapter 10 takes a futures thinking approach to explore possible futures for people with disabilities, and encourages you to imagine futures of your own.

The chapters interlink and build on each other. However, they are also designed to be read in any order or individually, and each can be read alone.

## Style, Commitment, Positionality, and Scope

This book uses a narrative and own-voices approach, where possible. As the voices of people with disabilities are frequently left out of academic curricula (one of the many ways in which disability is systemically marginalized), it is particularly important to center disabled voices. Whenever possible, this text uses the stories, quotes, creations, and works of disabled people themselves. It includes references and resources the reader can use to interact directly with the source material. Disability studies and critical disability studies, as a field, has been led by disabled people; the summaries of the field in this text have the imprint of our communities on them. Any place where primary information (e.g., quotes, articles, resources) is coming from a non-disabled source is explicitly noted as such.

My positionally as author is as a queer, genderqueer, neurodivergent person. I have light skin and a PhD in systems science. I am both a transdisciplinary academic researcher and a disability and neurodiversity activist. Most of my science is in conducting community-engaged research with neurodivergent, developmental disabilities, and mental health communities, with the aim to improve health services, employment, wellbeing, and to reduce stigma. Most of my activism centers a critical approach to systems change; particularly in how we can change narratives and shift the dominant ways in which society views disability. Throughout I present stories and examples from within both my academic expertise and my lived experience.

Disability culture and community is vast and diverse. We are not a monolithic group that can be easily reduced to a single textbook, course, or discourse. Out of necessity to put some boundaries on that vastness, this book is limited to disability in the United States, and may represent some disability communities more thoroughly than others. Further, I will often draw stories from my own work within the neurodiversity community as both a scientist and as an activist to illustrate points or as case examples. I encourage you to go beyond the borders of this text and my stories to explore other disability histories, cultures, and communities.