Praise for

THE ANTI-ABLEIST MANIFESTO

"Tiffany Yu guides readers through a cross-disability exploration of ableism in a warm, easy-to-read style. Her book is a precious gift for new allies and experienced advocates alike."

—Haben Girma, bestselling author of
Haben: The Deafblind Woman Who Conquered Harvard Law

"Tiffany Yu's *The Anti-Ableist Manifesto* offers a timely, practical, and generous field guide. It's a clear, comprehensive, and accessible instruction manual for anyone who cares about disability (and, even more crucially, for those who don't)."

—Andrew Leland, author of the Pulitzer Prize-finalist
The Country of the Blind

"Tiffany Yu's *The Anti-Ableist Manifesto* is brilliantly written and very well researched! It provides a much-needed framework for any discussion of ableism and methods for defeating this deeply harmful practice of supremacism. Credibility comes from Yu's lived experience with disability and her powerful way of expressing its harm and how to stop it."

—John D. Kemp, cofounder of the American Association
of People with Disabilities and author of *Disability Friendly:*
How to Move from Clueless to Inclusive

"*The Anti-Ableist Manifesto* does more than just challenge the status quo; it offers a blueprint for genuine allyship. Yu's work is a clarion call to broaden our understanding and embrace the full potential of all individuals. This book is a must-read for anyone committed to building more equitable workplaces and a more just world."

—Jennifer Brown, bestselling author of *How to Be an*
***Inclusive Leader* and host of the *Will to Change* podcast**

"Tiffany Yu just made my life a lot easier with this thorough, yet approachable, guide to disability and ableism. From now on, when someone asks me how to become a better disability ally, I'm simply going to hand them this book. Our world has needed a book like this for a long time."

—Shane Burcaw, author of *Laughing at My Nightmare*

"For the first time, we have a comprehensive guide outlining the steps to transform a world entrenched in ableism. Tiffany Yu has given us that gift."

—Sasha Hamdani, MD, board-certified psychiatrist and
author of *Self-Care for People with ADHD*

"*The Anti-Ableist Manifesto* is a vital resource that will shape how we understand and confront ableism. This book is essential reading for anyone committed to equity, inclusion, and meaningful allyship. I'll be using it as a reference for years to come."

—Liz Plank, international bestselling author of
For the Love of Men

"Tiffany Yu has created an essential field guide to help people learn about ableism, how to navigate the ways it permeates everyday life, and what to do about it. *The Anti-Ableist Manifesto* will help those unfamiliar with ableism—and those outraged by it—learn how to combat it. *The Anti-Ableist Manifesto* will be required reading for decades to come."

—Eric Garcia, author of *We're Not Broken:*
Changing the Autism Conversation

"*The Anti-Ableist Manifesto* is a guide for everyone. Tiffany Yu has a way of mapping out ableism and bias that is digestible and eye-opening. This book will help the disabled community create extraordinary progress!"

—Ali Stroker, Tony Award-winning actress
and coauthor of *The Chance to Fly*

"An insightful guide… Readers will find this to be a sensitive and helpful resource."

—Publishers Weekly

THE ANTI-ABLEIST MANIFESTO

How to Build a Disability-Inclusive World

TIFFANY YU

SOUVENIR
PRESS

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To nine-year-old Tiffany:
I can't wait for you to see who you become.

To my dad, Stanley (1948–1997):
May your memory live on in these pages and beyond.

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FOREWORD

Forget everything you think you know about disability. It's not a charity case or a feel-good story. We're segregated, ignored, and denied basic access. This isn't some distant problem. It's happening on your street, in your workplace, to your neighbor and maybe to you.

Confined to designated parking spaces, charity telethons, and the occasional tear-jerking documentary, disability often feels like a different world altogether. In the UK, this marginalisation continues despite a long and proud history of fighting for disability rights.

The US and UK might be separated by an ocean, but they share a common enemy: ableism. It's the pervasive belief that being non-disabled is the default, the "normal" state of being. This insidious ideology fuels discrimination and creates a world with constant hurdles for disabled people.

Isn't it time we challenged the very idea of "normal" as a standard that excludes millions? Disability is an inherent part of the human experience, a spectrum of variations that enriches society rather than diminishes it. Yet systemic barriers – from inaccessible public transport to a shortage of suitable housing – create a daily struggle for disabled people.

Tiffany Yu's *The Anti-Ableist Manifesto* is a much-needed intervention in this narrative of separation. It's a call to arms, not just for the disabled community, but for every single one of us. Dismantling ableism, the pervasive system of assumptions and prejudices that undervalues and marginalizes disabled people, requires a collective effort. This powerful, accessible manifesto equips us all with the tools to be active allies and recognize and challenge the ableist structures woven into our daily lives.

While the core principles of anti-ableism transcend borders, specific aspects of the disability landscape differ between the US and the UK.

The National Health Service (NHS) has shaped the fight for inclusion in the UK. The NHS provides a social safety net for healthcare that doesn't exist in the same way across the pond. Yet, access to vital services and specialist care is still a postcode lottery, with vast disparities in provision depending on location and socioeconomic background. In recent years, these have been exacerbated by the well-documented crisis facing the NHS, with record waiting times and staff shortages creating further barriers to access.

Staggering inequality in healthcare access and outcomes for disabled people are evident: over 30% faced NHS treatment delays in 2023[1] and avoidable deaths among people with learning disabilities doubled in 2022.[2] During the pandemic, 60% of COVID-19 deaths were of disabled people[3], and those with learning disabilities were six times more likely to die.[4]

The statistics paint a clear picture of the profound impact that inequalities have on disabled people, extending far beyond just their disabilities. They are a direct consequence of ableism – a system that throws up additional obstacles for disabled people, exacerbating vulnerabilities and diminishing their opportunities for a fulfilling life. It goes beyond simply living with a health condition or impairment; it's about being systematically excluded and ignored.

Inaccessible public transport: broken lifts, limited step-free access, and a lack of real-time information restricts mobility, hindering work, social life, and independence. The housing crisis is even more acute. A shortage of accessible homes, expensive modifications, and rental market discrimination creates a constant battle for secure housing, impacting employment, social interaction, and overall wellbeing.

The legislative landscape also tells a different story. In the UK, the Equality Act 2010 serves as a cornerstone for disability rights, similar to the Americans with Disabilities Act (ADA) in the US. However, the fight for its consistent application is ongoing. Unlike the US, where legal action seems to drive compliance more readily, achieving accessibility in the UK often involves navigating a complex legal system with a focus on reaching a mutually agreeable solution, rather than resorting to a court case. This can be a lengthy process and may not always result in the desired level of accessibility.

Yet, amidst these disparities, there's a shared spirit of solidarity and activism. The UK and Ireland boast a vibrant disabled rights movement, with tireless advocates pushing for change. From grassroots campaigns to high-profile legal battles, disabled people here are demanding their rightful place at the table, refusing to be relegated to the sidelines.

This is where *The Anti-Ableist Manifesto* becomes a powerful tool for both the disabled and non-disabled communities. It delves into the complexities of ableism, unpacking unconscious bias and challenging the dominant narratives that perpetuate the "otherness" of disability. Are you ready to be an ally and dismantle these barriers? *The Anti-Ableist Manifesto* equips you with the tools to start today.

For Non-Disabled Readers: Unmasking Your Ableism

Are you ready to confront your assumptions? This manifesto will force you to examine your language, your navigation of the world, and how you might unwittingly contribute to a system of exclusion.

For Disabled Readers: Strength in Numbers

This book reminds you that you are not alone. It validates your experiences and ignites a fire within – a fire that fuels the fight for a world where your opinion matters, your dreams are attainable, and your existence is celebrated, not ostracized.

The Anti-Ableist Manifesto is a beacon of hope, a blueprint for a future where disability isn't a barrier but a facet of human diversity. It's a future where every single one of us is free from barriers that hinder our goals and aspirations, whatever they may be.

This fight isn't about handouts or pity. It's about dismantling a system that marginalizes millions. It's about creating a world where access and opportunity are not privileges but fundamental rights. The US and UK might have different landscapes, but the fight for disability rights is a global one.

Ready to ditch the myth of "normal" and build a better future? Let's get started.

Dr Shani Dhanda
UK's Most Influential Disabled Person, Shaw Trust
Inclusion and Accessibility Specialist, Broadcaster and Author

INTRODUCTION

Let's start from the beginning.

I'm the youngest daughter of a Taiwanese immigrant and a refugee from the Vietnam War. I was born in Washington, DC, and grew up nearby in Maryland, with short stints in Barbados and Taiwan, both when I was too young to remember.

On November 29, 1997, I was in fourth grade. It was a Sunday, and I was getting ready to go back to school after the Thanksgiving break. I had not only celebrated Thanksgiving with my mom, dad, and three siblings, but my dad's forty-ninth birthday had been the day before, on November 28.

My mom had a business trip to Taiwan planned the next day, so my dad, one of my brothers, my sister, and I piled into our Toyota Camry to see her off to the airport.

When we were on our way home, my dad lost control of the car, which flew across the empty lanes of the highway. The last thing I remember was some greenery on the side of the road. Luckily, no other cars were involved.

When I regained consciousness, I was in a helicopter on my way to Children's National Hospital in Washington, DC. I had broken my femur and tibia in my left leg and had acquired a severe nerve injury in my right arm, known as a traumatic brachial plexus injury (TBPI), a type of paralysis.

My dad passed away as a result of the accident. At nine years old, I was mostly in shock and didn't know how to process everything. No one really offered me guidance, either. I lived at the hospital for three weeks, with a cast that covered almost the entirety of my left leg, and moved about in a manual wheelchair, my right arm limp in a sling.

I spent a long time after his death feeling angry. No one else I knew at the time had lost a parent. My mom also didn't really want me to talk about him, perhaps influenced by her own cultural upbringing and views around death. It would take me almost twenty-five years, on a 2020 trip to climb Mount Kilimanjaro, to remember the gifts that my dad had given me and forgive him. In many ways, I still miss him, and part of the reason why I've dedicated this book to him is so that he's remembered.

On that November day, my body, my family, and my life changed. I describe the events surrounding the car accident now as multiple layers of grief: loss of a loved one, loss of the way my right arm used to be, and loss of childhood innocence.

I call this sort of scenario a disability origin story. It's the story of when our disability happened, whether it was congenital (from birth), an accident, cancer, or something that emerged over the course of our lives.

I'm reminded of a quotation from Brené Brown: "Our stories are not meant for everyone. Hearing them is a privilege, and we should always ask ourselves this before we share: 'Who has earned the right to hear my story?'"[1]

Thing is, we don't owe anyone our disability stories. Some of our disabilities may be a result of traumatic events that we don't want to revisit or relive. As the daughter of Asian immigrants, I internalized that I should not share anything that might seem shameful for fear that it might make my family look bad. Through the lens of this East Asian culture, death in the family, disability, and the car accident were all examples of such things. For twelve years after the accident, it became my shameful secret. I wore long sleeves year-round to "hide" my arm and told everyone my dad was away on a trip.

A lot of the people I grew up with didn't know what had happened to my dad. It sucked to not be able to talk about him. They also assumed that my arm injury was from birth. Two decades later, I was diagnosed with post-traumatic stress disorder (PTSD), a mental health–related disability. I suspect that not talking about the car accident exacerbated my mental health in a way that became PTSD.

So, then, why am I sharing my story when I don't owe it to anyone?

We all have varying levels of comfort around how much we share. Part of why I'm so open about my disability story is that I remember what it felt like not to honor my truth. For twelve years, I felt like I was operating as a shell of myself, keeping track of all of the lies. Now, I want to take control of and reclaim my narrative rather than let others make assumptions. As Emily Ladau says so eloquently, “If we want the world to be accessible to the disability community, then let’s make the ideas and the experiences surrounding disability more accessible to the world.”[2] But just because I’m open about my disability story doesn’t mean that every disabled person is—or that they have to be.

When I was a senior in high school in 2005, I wrote a letter to my guidance counselor titled “It’s Time.” We were beginning the college application process, and I had begun reflecting on what life after high school might look like. I shared my hopes, dreams, and aspirations for the future. I also wrote about how maybe one day I’d write a book.

That dream stayed in the letter for many years afterward.

There was not only a massive amount of imposter syndrome—me, a writer?—but also the logistics of it all. At the age of nine, I had to learn how to write with my non-dominant hand—not because I wanted to but because I had to. Becoming disabled impacted the way I wrote and the way I typed. And while I initially thought it would diminish my voice on the page, I would later find out that that wasn’t the case.

Now, I’m reflecting on my unconventional journey: from the way my literary agent reached out rather than me pitching him to using speech-to-text technology in drafting my proposal. It was all similar to how I’ve navigated daily life with a paralyzed arm in a two-armed world—different but creative and, most importantly, presented in a way that works for me.

So how did I get here, from twelve years of silence to telling my story on global stages at TED and the World Economic Forum in Davos, across social media, and within the pages of this book?

Accidentally.

I didn’t set out to be a disability advocate.

More than a decade after the car accident, I was invited to speak on a student panel about disability as part of a half-day event at Georgetown University called Accessing Difference: New Politics and Pedagogies of Disability. It was October 22, 2009.

I took a seat at the front of a conference room along with two of my fellow classmates. I had never spoken about this topic before, and I felt like my heart was beating out of my chest. I was so nervous. When it came time to introduce myself, through tears, I shared the story of the car accident publicly for the first time.

A few things also happened before October 22, 2009, that led to what felt like a watershed moment for me and my advocacy journey.

When I was a freshman at Georgetown, in 2007, I cocreated a Taiwanese American club with a few classmates. When we first decided to start the club, we were told by another organization, the Chinese Student Alliance, that there wasn't a need for a Taiwanese club. We persevered, and until my junior year, I was part of the leadership team. Cofounding the Taiwanese American club introduced me to pride, culture, and community in a part of my identity that I had thought I had to erase in order to assimilate. As I write, the club is still active. From this experience, I learned what it was like to start a community group. Starting a Taiwanese American club gave me the confidence that it was possible to start a disability club.

I had a summer internship in investment banking at Goldman Sachs after my junior year. Each week, we received performance feedback from a recruiter. A few weeks in, I remember leaving my session feeling a little low because I was having a tough summer and making a lot of small mistakes in tasks. Sending calendar invitations was the bane of my existence, and I couldn't seem to get them right. Those small mistakes were reflected in my feedback. As a perfectionist at the time (though I feel that I am currently in recovery), I was being extra hard on myself. The Goldman recruiter, Jenny, had known me for a few years, since one of the schools she covered was Georgetown. She said, "Tiffany, you deserved your place here. You don't need to have a chip on your shoulder."

I call this a gentle callout. Jenny's comment pushed me to start thinking critically about the ways in which I thought I wasn't operating at my full potential. Because I had internalized society's views and the media portrayal of disabled people that said we could not measure up, I had set the bar too high for myself, wanting to prove them wrong.

In August 2009, at the start of my senior year, now with a full-time offer to return to Goldman, I decided to apply for a Fulbright research fellowship in China, where I had studied abroad. In my research on China, I came across a statement that students there needed to be physically, mentally, and emotionally healthy in order to pursue their education.[3] I was curious about how this requirement would impact the educational outcomes of the students who had become physically disabled during the Sichuan earthquake in 2008. Putting together the proposal for the fellowship was strenuous and required several letters of recommendation. Prior to asking for these letters, to help guide my professors, I shared my personal statement, which included my personal story and connection to disability. One told me that while he knew my topic might be controversial, he thought I was the best person to pursue it, given my personal experience with disability.

Spoiler: I didn't get the fellowship, but the process made me realize that there was value in my experience as a disabled person.

Also in August 2009, I was a resident assistant, and we went through a diversity training exercise called The Big 8, where we were asked to cut slices of a pie based on how important different aspects of our identity were to us. The slices represented race, ethnicity, sexual orientation, gender identity, ability, religion/spirituality, nationality, and socioeconomic status.

Being a woman was a big part of my pie. My Taiwanese identity had become prominent since creating the Taiwanese American club. Being disabled made up almost half of my pie.

I looked over at my neighbor and saw that being non-disabled was the thinnest sliver of his pie. I realized that if you're not disabled or not affected by disability, you don't really think about it. However, I thought about not being able to use my disabled arm on an almost daily basis.

An idea of creating a disability club sparked in me. Today, some of you might recognize me from Diversability, the disability-centered community business with more than eighty thousand members that we've built over the years to elevate disability pride, build disability power, and advance disability leadership. Back in 2009, Diversability started as the first student-run disability club at Georgetown University. Diversability continued as an active club until 2014, and in 2019, a new student club called the Georgetown Disability Alliance would continue this work.

After I graduated, I went on to work at Goldman Sachs, where I was actively involved in the firm's disability employee resource group (ERG). In my final year at the firm, I joined the investment banking campus recruiting team, which helped me understand what companies were thinking about when they recruited talent from underrepresented backgrounds.

After I left Goldman, I joined Bloomberg Television. During my off hours, I cofounded its disability ERG, pitching its creation to Bloomberg's chief diversity officer. At the time, Bloomberg was in the nascent stages of forming its ERGs, and having met the leaders of the Asian American, Native Hawaiian, and Pacific Islander (AANHPI) ERG, I knew there was an opportunity to bring my knowledge of disability communities to the company.

I left after a year to join the media network REVOLT and put my finance hat back on, working directly with REVOLT's chief financial officer as its director of business development. At a Black-owned company, I witnessed that it was possible to build a company that was racially and gender diverse. In 2018, the company was 67 percent Black, Indigenous, People of Color (BIPOC) with over 60 percent women in senior leadership.

While I was at REVOLT, itching to find a way to connect to the disability community, I relaunched and incorporated Diversability. Our earliest supporters were my colleagues at REVOLT. We started by hosting panel events and fireside chats in New York City. Our first event happened in a packed room of over seventy attendees, making me realize that there was a desire to create spaces for disabled people to gather and to build a stage for our voices. We then started hosting events in seven other cities, including Los Angeles, San Francisco, and Chicago. At the start of the pandemic in 2020, with support from Meta's Community Accelerator Program, we made all of our programming virtual and increased our digital footprint and community fourfold. Today, we see ourselves as the mostly virtual disability ERG for the world—one that exists outside a company.

At the same time, I started noticing that friends and people I'd meet in real life or on social media kept asking the same questions.

"How can I be a better ally to disabled people?"

"How can we get disabled employees to self-identify?"

"How can we get disabled employees to join our disability ERG?"

I have never been the biggest fan of disability etiquette trainings. I say this a lot throughout the book: the disability community is not a monolith. But I started having more conversations with friends, doing podcasts, and engaging with corporate partners about where we could begin to talk about disability inclusion and allyship. And I started thinking more about what it would look like to move from a disability-negative culture to a disability-positive one, phrases I have adapted from the sex-positive movement.

In 2020, in the wake of George Floyd's murder, many of us who were non-Black were trying to figure out how to support our Black peers. I was confronted with the ways in which I had upheld white supremacy in my own life. I read *How to Be an Antiracist* by Ibram X. Kendi. My friend Nicole Cardoza started *The Anti-Racism Daily* newsletter, which grew to over 300,000 subscribers in three years. In the years that followed, anti-Asian racism rose due to misinformation about the origins of the COVID-19 pandemic. All of this elevated my consciousness that I needed to do more than *not* be racist. I needed to be *anti*-racist.

As companies made statements about racial equity, I tried to better understand intersectionality in the context of anti-racism. *Intersectionality* is a term coined by Kimberlé Crenshaw to highlight the ways in which different aspects of our identity create a compounded experience of oppression.[4] As a disabled Asian woman, I sit at the intersection of ableism, racism, and misogyny.

In December 2020, I started *The Anti-Ableism Series* on TikTok, a video series highlighting the different ways we can be better allies to disabled people. There are so many ways that ableism shows up in our society, from not including captions in videos and building entrances that don't have step-free access to asking disabled people intrusive questions about our bodies and medical history. I wanted to create a digestible tool that people could use to start their own journey to becoming anti-ableist. The series currently has over two hundred videos with more than five million views.

The Anti-Ableist Manifesto was born out of that series and from talks I've given over the years to answer the aforementioned questions.

I came across an Instagram post from the United Nations entity for gender equality and the empowerment of women (UN Women) in 2020 that said, "Ending discrimination starts with self-reflection."[5] This has been the guiding phrase for my work and this book, because in order to know where we're going, we need to know where we're coming from. The work is as much about what you do as about what you value and how you think. To that end, you'll find prompts and reflection questions at the end of every chapter as you embark on this journey from self-reflection toward action. Consider these a version of the "gentle callout" that Jenny did for me, to guide you to a deeper understanding.

The book is divided into three sections organized through a framework called "Me, We, Us." It starts with your individual journey and ends with how we can come together as a collective to create systemic change. I was introduced years ago to this framework, which was influenced by a storytelling framework called public narrative,[6] developed by Harvard professor Marshall Ganz as a way of looking at how we can make impact and change as individuals, in our communities, and in the world.

For the purpose of clarity, I have adapted the framework in the following sections:

1. Anti-Ableism and You: What is disability, ableism, and anti-ableism? What does anti-ableism look like to you as an individual, and what can you do to be anti-ableist? These first couple of chapters will be more historical to create some shared context.
2. Anti-Ableism and Your Community: How can we be anti-ableist in our personal relationships, on our teams, and in our communities?
3. Anti-Ableism and Societal Change: What does anti-ableism look like in public spaces, such as the workplace and online? How can we collectively build anti-ableist systems and structures so that we live in a society that is equitable, inclusive, and accessible for all?

Whether you are a diversity, equity, and inclusion (DEI) professional or part of the disability community, a friend or family member of a disabled person, or just someone who wants to learn more, I hope this book provides you with the guidance to show up with more care and compassion for yourself and each other. The fact is, we live in an ableist society that influences the way we think, behave, live, and treat others. We're all impacted by ableism, whether we realize it or not. If we're fortunate to live the full extent of our lives, we'll all end up disabled. We'll also learn that many of the innovations that benefit disabled people, such as curb cuts, audiobooks, electric toothbrushes, and remote work, also benefit all of us. This book is for all of us.

This book isn't all-encompassing; it can't be. I'm coming at this from the perspective of someone who was born in the United States to immigrant parents, who acquired my disability at a young age, who was raised in a single-parent household, and who had the privilege to attend a private university and work in the corporate world. One thing I've had to learn is that I will not be able to single-handedly dismantle the system of oppression that is ableism. But we can take steps toward doing that together.

Throughout this book, I've made a decision to include a variety of stories from disabled people with unique backgrounds, experiences, and opinions. As many of us say, "Once you've met one disabled person, you've met one disabled person." My goal is to add color and share some of the challenges and triumphs that come with living with a disability in an ableist society. Though these stories may look different for everyone, when taken together, they provide a powerful and compelling picture of the disability community. And no matter how diverse or different these stories are, remember that we're all connected through our common humanity. I hope these stories will help to make our experiences more accessible to you and serve as a call for you to embrace the authenticity of your own. I hope this can be one resource in a choir of other disabled voices and resources that will help shape your perspectives.

Learning is never about shame, so I'm grateful that you showed up so we can all learn together. Thank you for being here and joining me on the journey to becoming anti-ableist.

PART 1

ANTI-ABLEISM AND YOU

CHAPTER 1

What Is Disability?

According to Merriam-Webster, *disability* is "a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions."[1]

However, I don't like using the word *impair* to describe a person's body and/or mind. The term *impair* means to diminish, weaken, or worsen.[2] And when we say that disability *impairs* our life experiences, it suggests two things: First, it imbues disability with a negative connotation. Second, it suggests that our disability is the reason for or cause of any negative life experiences.

This is inaccurate. Disability itself is not the cause of our negative experiences, as we will come to learn in the next few chapters. Instead, it is the way that our society is built to favor non-disabled people and discriminate against disabled people that causes us to be harmed.

If something as basic as a dictionary definition can get it wrong, I knew we had to try to change it.

A few years ago, in partnership with the Link20 initiative of the Ruderman Family Foundation, a few disability advocates and I drafted a note to try to change Merriam-Webster's definition of *disability*. We were inspired in part by Drake University graduate Kennedy Mitchum successfully petitioning Merriam-Webster to change the definition of *racism* to incorporate systemic oppression in 2020.[3]

Unfortunately, we did not receive a response to our letter. But who knows—someone at Merriam-Webster read that letter. Perhaps they learned something new. Much of advocacy work looks like this: planting the seeds for work that others will take on in the future. Even if we do not achieve the original goal, it can bring about wins that we may not know about for years to come. This letter was the first of many I've drafted to my elected officials pushing for change and to corporate leaders urging them to champion disability inclusion, some of which have been very effective. At the very least, discussing definitions with our friends, family, and colleagues helps to widen the circle of awareness.

I define disability as a health condition of the body and/or mind that impacts the way a person participates in daily activities. There is no negative value judgment in this definition.

In my presentations and speaking engagements, I choose to share the definition of disability from the World Health Organization (WHO), which states that "disability results from the interaction between individuals with a health condition, such as cerebral palsy, Down syndrome, and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support."[4]

And yet, even though we have this shared definition of disability, our experiences of disability are diverse.

To highlight this, I want to share a story from my own experience. In June 2022, I attended a camp hosted by the United Brachial Plexus Network (UBPN), which brought together people who live with brachial plexus injuries. I met with doctors who served our community, parents and family members who loved us, and other people with the same diagnosis. One of my most significant moments during the camp was confronting the fact that my injury is most severe in my hand. My hand looks different. There's a significant amount of muscle atrophy, and over time, my knuckles have hyperextended.

I remember telling one of my fellow camp attendees with a brachial plexus injury at breakfast, "I'm surprised that no one else's hands look like mine."

He responded, "Before I saw your hand, I didn't know that our injury could look like that."

While all of us had brachial plexus injuries, they all manifested in different ways. I realized that even if someone has a brachial plexus injury like mine, they might navigate and experience the world in a totally different way. To live with my paralyzed dominant arm, I adapted many daily activities, such as typing, tying my shoes, putting my hair up, and wearing a necklace. I have a steering knob requirement on my driver's license, but I learned that many other drivers with brachial plexus injuries don't. Similarly, life and access might look totally different for someone who can use both hands but has a disability that affects their ability to walk, see, or hear.

Although I've been in disability rights advocacy for years, I left the camp with a renewed understanding and appreciation of the sheer diversity of disability.

Disability doesn't have "a look," or at least not one look. Some of us are full-time wheelchair users. Some of us are ambulatory wheelchair users, which describes people with chronic illnesses or mobility issues who have some capacity to walk but who still use a wheelchair in certain situations. Some of us have speech- or vision-related disabilities. Some of us have disabilities that may not be obvious at all. Some of us have disabilities that are not always apparent but that may become apparent, such as the seizures in epilepsy, known as dynamic disabilities. As diversity, equity, inclusion, and accessibility (DEIA) consultant Catarina Rivera shared in a LinkedIn post on dynamic disabilities, "A person might need a mobility aid one day for their condition, while the next day they don't. People with dynamic disabilities might be able to perform a task one day, and then another day be unable to perform the same task. This doesn't mean they're faking their symptoms.…People with dynamic disabilities want others to know that their conditions are real and that variation is typical."[5]

There are one billion of us globally,[6] and one in four American adults have a disability.[7] As Dr. Amy Kenny, inaugural director of the Georgetown University Disability Cultural Center, sees it, "Disability is a culture and a community, a way of being that invites us to reimagine a new world where all access needs are met without condemnation or critique; where rest is not earned, but relished; where we recognize that we move, think, and communicate in beautifully diverse ways; and where we know that time is a construct. Disability drives innovation and teaches non-disabled people the inherent wisdom of our bodyminds. We, the disability community, are the future."[8]

We are here, we are diverse, and we are more than Merriam-Webster's dictionary definition.

Reflection Questions

1. How have traditional definitions of disability influenced your perception of a disabled person?
2. Prior to reading this chapter, how did you define disability? Does your definition frame disability in a negative, neutral, or positive light?
3. Ask a couple of friends to share their definitions and see where there are similarities and differences.

CHAPTER 2

Not All Disabilities Are Apparent

Imagine this: you're sitting on the subway when the train arrives at a crowded stop. As people get on, a person who seems to be in their twenties eyes your seat meaningfully. You look closer: they aren't in a wheelchair, and they don't have a cane to signify that they might be blind or have low vision. There is no clear marker that would lead you to think they are disabled. *Surely they don't need my seat, because they don't have a disability*, you tell yourself.

Have you ever found yourself in such a scenario? But what if this person has a disability that isn't obvious or can't be perceived externally—a **non-apparent disability**?

Non-apparent disabilities are physical, mental, or neurological conditions that are not immediately apparent but can impact someone's movements, senses, or activities. Note: I use the term *non-apparent disability* instead of *hidden disability* or *invisible disability*. According to Disability:IN, a nonprofit resource for disability inclusion in businesses, *hidden disability* implies that the disabled person is "purposefully withholding this information," but "there is a difference between choosing to not self-disclose a disability versus actively hiding it." Meanwhile, *invisible disability* suggests that "the person is not visible or that you cannot discern that a person has a disability," which is not always true since "non-apparent disabilities may become apparent depending on the type of disability." In addition, "invisible disability" might make those with non-apparent disabilities feel invisible, overlooked, and invalidated in their disability experiences. *Non-apparent disability* simply says it as it is.[1]

It is estimated that 70 to 80 percent of all disabilities are not apparent.[2] Additionally, according to a 2017 Coqual report, 62 percent of disabilities in the workplace are not apparent.[3] The takeaway: the majority of disabilities are not apparent. Examples of non-apparent disabilities are mental health disabilities such as depression, anxiety, and schizophrenia; learning, attention, cognitive, and neurodivergent disabilities such as attention-deficit/hyperactivity disorder (ADHD), dyslexia, and autism; chronic illnesses and autoimmune conditions such as diabetes, asthma, lupus, and multiple sclerosis; substance use disorders such as alcohol addiction; hearing-related disabilities; and long-haul COVID. This list can help us gain a beginner's understanding of the sheer diversity of disability, but it isn't comprehensive. Furthermore, though I tried to categorize a few non-apparent disabilities previously listed, many people experience multiple disabilities—called comorbidities—that don't necessarily fit into a single category.

I have both apparent and non-apparent disabilities. My apparent disability—the brachial plexus injury in my right arm—helps people understand my condition because they can see that my arm looks different. However, my non-apparent disability—living with PTSD—isn't always perceived by others, so people sometimes focus more on my apparent disability without giving due attention to my non-apparent disability, even though PTSD impacts me more than the fact that I can't use one of my arms. While I'm grateful for ongoing mental health support, I'm still learning to better manage my response when I'm triggered and the unpredictability of when it happens.

People with non-apparent disabilities face unique challenges precisely because of this tension. Often, we are stigmatized, doubted, or disbelieved simply because our disabilities are not noticeable or obvious. For example, because mental health disabilities are not always apparent to others, they seem "less real" and are not always at the forefront of people's minds. We are perceived as being lazy or lying about our condition. Plus, the constant judgment, misunderstandings, and rude questions from others implying that we have to justify ourselves leave us exhausted and even ashamed.

Statements like "But you don't *look* sick!" or "You don't look disabled" reveal how others judge us based on what they perceive with their limited capacities, even if we *are* sick or have pre-existing conditions. Angie Collins-Burke, a nurse and coauthor of *Just Pick Up the Peg: A Nurse's Journey Back from Stroke*, explains the complex emotions that come with her non-apparent disabilities, which include brain injury, depression, chronic pain, and epilepsy: "I continually beat myself up because I'm unable to work. I frequently ask for help and am unable to function at the level that others expect. Feeling like a burden or that we're not achieving enough can lead to feelings of guilt."[4] Dealing with frequent questions and suspicions is draining and causes self-doubt. Collins-Burke continues, "Sometimes I let doubt get the better of me, and I wonder, 'Am I an imposter?' When others assume it's all in your head, it can make you question your reality."

The statement "You don't look sick," which you'll later learn is a type of ableist microaggression, invalidates our experiences because it suggests that we should look radically different from non-disabled people. It also perpetuates the belief that we need to put our disabilities on display and "prove" them in order to be accommodated. With such ableist beliefs, it is no surprise that non-apparent disabilities are often underreported, especially within the Asian American and Pacific Islander (AAPI) community. Members of the AAPI community are 50 percent less likely to seek out mental health support than members of other racial groups because the assumption is that if you can't perceive it, then it doesn't exist.[5] However, if a condition like anxiety makes it hard for us to get out of bed in the morning or affects our social interactions, that just shows how real mental health disability is, and it should be treated as such. Pushing through and masking our symptoms should not be the norm.

The stigma and misconceptions of non-apparent disabilities also affect society at large. We are often misdiagnosed or medically gaslit (meaning a medical professional dismisses or downplays a patient's symptoms). For example, when people casually use psychiatric or clinical terms to describe personality quirks, such as "I'm so ADHD" after forgetting to do one thing or "I'm a little OCD" (referring to obsessive-compulsive disorder) when describing their design preferences, they are furthering the stigma, says psychiatrist Sasha Hamdani. This makes it harder for people who actually need help to get it because society invalidates what real ADHD and OCD may look like.[6]

We also face a lack of resources to handle or treat our non-apparent disabilities. According to Nancy Becher, a chronic and autoimmune disease specialist, health care systems do not prioritize long-term management of and research on chronic and autoimmune diseases because people with those diseases are viewed as having a lower quality of life, and health care systems are mostly designed to focus on acute care and emergency services.[7] As former Centers for Disease Control (CDC) director Rochelle Walensky once said, we are "unwell to begin with"[8] and therefore not prioritized in terms of care.

People with non-apparent disabilities face another unique challenge: we sometimes have the privilege to choose whether to disclose our disabilities, which impacts how we are treated, something that people with apparent disabilities can't do. While choice is a good thing, it adds to the potential burden of "outing" ourselves in order to obtain the support we need. For example, whenever I take carry-on luggage onto a plane and ask for assistance to store it in the overhead compartment, a bystander can see my paralyzed arm and understand the situation. While some people with chronic conditions are also unable to lift their luggage, they might experience pushback if they ask for assistance unless they explain their disabilities. If I'm not wearing my wrist splint on my injured arm and someone doesn't notice it, I experience similar pushback. It's like that twenty-something person you encountered on the subway who might be experiencing debilitating pain and who requires a seat. When someone asks, if you are able, give up your seat.

Becca Lory Hector, an autism and neurodiversity advocate, explains the problem she has with this false choice: "Not disclosing…means I am not somewhere or with someone that I feel safe with. It also often means committing to ignoring or suppressing my needs and accommodations, or masking, through the interaction. Yet still, more often than not, that is the easier route."[9] Hector is not alone. According to a 2023 Involve study, 37 percent of people with non-apparent disabilities choose not to disclose at work due to a fear of discrimination and a lack of support.[10]

Eric Garcia, a thirty-three-year-old autistic author and journalist based in Washington, DC, shared an experience he had early in his career when he attended his first Senate hearing—and how his disability made it more challenging to read the social cues his colleagues might tacitly comprehend:

> They had to adjourn for votes. And I remember shouting across the dais to ask a senator a question. An officer said, "If you do that again—you'll

> be thrown out," or, "—you'll be arrested." And I remember just being horribly mortified. And it was because…being autistic, I didn't understand a lot of the social cues. I didn't understand the rules.…It reminded me of how autistic people often have to…do a lot of guesswork with social rules, with social situations. Something that might have just been natural to a lot of my colleagues as reporters wasn't natural to me.[11]

Often, people with non-apparent disabilities choose not to disclose because we feel as if we shouldn't take up advocacy space, but this is a double-edged sword: as a result, people have a poorer understanding of non-apparent disabilities. Fortunately, more and more of us are speaking out, including celebrities who willingly spotlight their conditions. Pop superstar Selena Gomez, who was already living with lupus, canceled her Revival world tour in 2016 to deal with depression and anxiety and was diagnosed with bipolar disorder two years later.[12] In 2022, in addition to sharing her journey with mental illness in a documentary, she cofounded Wondermind, a platform that "destigmatizes and democratizes mental health,"[13] and joined the inaugural White House Conversation on Youth Mental Health led by the US Department of Health and Human Services and MTV Entertainment/Paramount.[14]

When more public figures disclose their disabilities, it makes it easier for the rest of us to do so, too. When I worked at Goldman Sachs, it was public knowledge that the president at the time, Gary Cohn, was dyslexic.[15] When someone so senior at a Fortune 500 company disclosed his disability, it made me feel that I could be more open about mine.

To become comfortable talking about non-apparent disabilities, our larger society has to collectively cultivate an anti-ableist environment that acknowledges and supports the reality of disability. According to the same 2023 Involve study, 50 percent of workers who did disclose their non-apparent disabilities shared that the difficulties they faced in getting support made the process not worth it. Hector adds, "The real conversation isn't about disclosure in the workplace; it's about discrimination in the workplace."[16] I discuss accommodations later in the book, but when the process to even request accommodations is demeaning, stressful, and overly complicated, it makes it more difficult for disabled people to participate.

Disability is diverse, and we must respect and make space for all types of disabilities, whether apparent or non-apparent. Just as the umbrella term *Asian American* came into being in 1968 to consolidate the voice and power of everyone in the diaspora despite the different cultures, languages, and experiences, I believe that the disability community has more power when we come together as a collective and in solidarity. I discuss more strategies on how to support people with non-apparent disabilities in the Anti-Ableism and Your Community section.

Reflection Questions

1. Prior to reading this chapter, what did you think disability looked like? How has this chapter challenged or reinforced your pre-existing perceptions?
2. Do you, or does anyone else you know, live with a non-apparent disability? What are the unique experiences that you/they face? How do you acknowledge or label your own non-apparent disabilities when you talk about them?
3. Can you think of other non-apparent disabilities that this chapter doesn't mention? Check out resources such as the Invisible Disabilities Association (IDA), Understood.org, National Alliance on Mental Illness (NAMI), and the Autistic Self Advocacy Network (ASAN).

CHAPTER 3

Disability Is Not a Bad Word

I often encounter people who are uncomfortable with the word *disability*.

They sometimes say that the root of their discomfort comes from the prefix *dis-* in front of *ability*. The etymology of *disability* dates back to the 1570s "as a combination of the prefix 'dis-' which connotes 'apart,' 'asunder,' 'away,' 'utterly,' or having a privative, negative, or reversing force; and 'ability' which connotes power or capacity to do or act physically, mentally, legally, morally, financially, etc."[1] Through this lens, disability is linked to the *inability* to do or act physically or mentally.

While we can't change the origins of the word, we can challenge the lens through which it was created and reclaim what it means to our community.

Not all words that start with *dis-* have negative connotations, says recording artist and disability advocate Lachi. *Distinguished*, *discovery*, *distinct*, and *discussion* are a few that come to mind.[2] While this exercise is not entirely accurate through a linguistic lens, it still encourages us to start unlearning the automatic association of *dis-* with "without" or "less than."

Therapist Meriah Nichols takes this conversation a step further by highlighting how *dis-* is also related to the Latin prefixes *bis-* and *duo-*, which connote "twice" or "two ways." *Dis-* is then reframed as "another way of doing and being," so that *dis-* plus *ability* becomes "the ability to do or be in another way."[3]

The fact is, *disability* is not a bad word but rather a neutral term. Disability just *is*.

I used to joke that people who are uneasy with the word *disability* should repeat it ten times in a row to become more comfortable saying it. I've now realized that this is actually a psychological phenomenon backed by science. *Semantic satiation*, coined by psychologist Leon James (Jakobovits) in 1962, refers to how the uninterrupted repetition of a word reduces it to meaningless sounds and enables the speaker to separate their thoughts and associations from the word.[4] Repeating the word *disability* again and again in everyday use causes it to lose the negative value judgment we may have assigned to it. The more we use the word, the better we can remove the stigma society associated with it and attribute new meaning as well as neutral or even positive value judgments to it.

For example, to me, the word *disability* now connotes a sense of pride, a source of strength, and empowerment.

There are two main themes I'd like to address when it comes to using language to describe disability. First, there are **identity-first** and **person-first language**, the terms most commonly adopted by the disability community to describe ourselves. Then there are **euphemisms**, words people use in place of *disability* because they think it is a bad word.

When people from the disability community describe themselves or self-identify, we usually pick one of two ways: identity-first language—"I am a disabled person" or "I am disabled"—or person-first language—"I'm a person with a disability." Person-first language was initially introduced in the 1970s among disability advocacy groups[5] by people with disabilities who said, "We are not our disabilities. We are people first. I'm a person first."[6] Non-disabled people needed reminders of disabled people's humanity. However, some people in the movement now believe that person-first language has ableist undertones because it separates the person from the disability, assuming our disability to be bad, negative, or undesirable. In comparison, identity-first language—"I'm a disabled person"—views disability as a core part of our identity, in the same way that I'm an Asian woman. I can't separate my personhood from my disability. And I wouldn't.

Next, we have euphemisms, which include phrases like "differently abled," having "unique abilities," or having "special needs" to describe disabled people. Though popular for a while, they were used during a period when disability was still highly stigmatized, which explains the desire to hide the word *disability* under alternative phrases.

Here is a list of euphemisms for disability in addition to those previously mentioned that are often used:

- Different abilities
- Handicapable
- Challenged
- People of determination (used in the United Arab Emirates)

Overall, terms like *differently abled*, *special needs*, *unique abilities*, and *people with determination* diminish the very real hardships that come with living with a disability in an ableist society or the pride people feel in our experiences. Describing someone as having “special needs” instead of simply “disabled” suggests that our basic human rights are “special” or out of the ordinary as opposed to simply necessary. You’ll also hear people say, “We all have different abilities” or “We all have special needs” as a way to encourage people to see the humanity of the disability experience, but that also suggests that disabled people exist on a level playing field with the rest of society, which undermines the issue. It’s called the Americans with *Disabilities* Act (ADA) for a reason. The ADA prohibits discrimination based on our legal categorization of “disabled,” not any euphemism. “Disability” is what is enshrined in our civil rights. You can check out the #SayTheWord campaign and movement started by disability community activist Lawrence Carter-Long that encourages people to use direct and specific language when referring to disabilities.[7]

It is important to note that when referring to a disabled person as an individual, always check in with us first to see what type of language we prefer. Preferred language varies from person to person and is up to the individual. For example, I often find myself switching between identity-first and person-first language, though I prefer the former (“I’m disabled”) for the many reasons I’ve shared in this chapter. Some time ago, I received a direct message from a stranger on social media who requested that I change my language to person-first language (“I’m a person with disabilities”) because they had been taught this in a university class. An important part of allyship is being nuanced and appreciating the diversity that exists within disability—say it with me: we are not a monolith. So it’s important to respect and defer to individual preferences.[8] In fact, some disabled people still prefer to identify themselves as "differently abled" and having "unique abilities," and you should honor that. However, when talking about the community broadly, the main takeaway is to use the word *disability* when referring to disabilities. Call it like it is.

Now, you might ask, *But Tiffany, why is your organization called Diversability? Isn't that a euphemism?* The short answer is yes. The longer answer is when I started Diversability in 2009, I often got blank stares when I mentioned that I wanted to start a movement around "disability pride." People were confused by how anyone could be proud to be disabled. I chose "Diversability" because disability for me is a natural variation of human diversity. I wanted to highlight that and the fact that disability itself is diverse. I suggest using *Diversability* only as a proper noun when referring to our organization and using *disability* otherwise.[9]

It is also important to know which terms have become outdated and should not be used, like *handicapped* and *crippled*. *Handicapped* in particular has negative connotations, probably due to the common belief that it is derived from the term "hand-in-cap" to describe beggars, though this etymology has proven to be false—*handicap* actually refers to actions that make a game more equitable. You might still see mention of "handicapped parking" in public spaces, but I suggest using "disability parking" or "accessible parking" instead.

As you progress on your anti-ableist journey and rethink the language you use, it's possible that you'll encounter some disabled people who say, "I personally don't have an issue when you use such language. It doesn't bother me." And there are exceptions of people with certain disabilities preferring to use outdated terms like *crip* to refer to themselves or people with mental illness using *mad* as a way to reclaim those terms. As Andrew Pulrang says, "When we 'reclaim' such terms for ourselves, we do so with a great deal of care and discretion. And this is not a privilege open to people outside of our disability communities."[10] Each individual disabled person is entitled to their own opinion on what type of language is used to describe them. However, it would be wrong to imply that it is therefore acceptable to do so for all other disabled people.

Such comments are an example of a type of ableism known as lateral ableism, which you'll learn about later. According to Aubrey Blanche-Sarellano, a designer of equitable processes, products, and operations, disabled people who are personally unbothered by ableist language cannot prevent the harm done to the wider community. "The fact that you are not personally harmed does not mean that others are not. Your focusing on yourself rather than the broader system of white supremacy-enabled ableism is…exactly what these systems of oppression want."[11]

If we are to truly become anti-ableist allies, we must start with language. If something as simple as the words we say and the phrases we use causes discomfort, how much more difficult will it be to change actual thoughts and behaviors? Our current situation exists partly because we have stayed silent, not knowing what to say or how to say it in a way that seems polite or perfectly informed. And when we stay silent, we don't learn, grow, or make progress. Instead, let's learn to sit with our discomfort and then move through it so that we can break down old, harmful associations and attribute new meaning and power to our words.

Reflection Questions

1. What do you think about when you hear the word *disabled*? Write down some of the feelings you've had.
2. If you have used or heard of a disability euphemism, why do you think it was used in that context?
3. What are some other words that you can think of that start with *dis*- that don't have a negative connotation?
4. If you notice yourself feeling uncomfortable with the word *disability*, say the word ten times in a row. *Disability, disability, disability, disability, disability, disability, disability, disability, disability, disability*. How does that make you feel?

CHAPTER 4

Disability Is Not a Bad Thing

In the previous chapter, we learned that *disability* is not a bad word. We talked about the importance of naming disability for what it is and confronting our discomfort. But why? What's the larger motivation behind this?

Disability is not a bad word because we need to realize that *disability is not a bad thing.*

We've been brought up in a disability-negative culture, where most of us view disability as a trait that is less than, broken, and in need of fixing. This produces a damaging social view of disability that continues to contribute to the marginalization of and discrimination against disabled people.

Take, for example, the conversations around whether autistic people and people with ADHD, depression, anxiety, or OCD belong to the disability community. We learned in Chapter 2: Not All Disabilities Are Apparent that autism and ADHD are examples of non-apparent disabilities that fall under developmental and learning disabilities, and depression, anxiety, and OCD are examples of mental health disabilities. However, some people continue to resist this categorization with responses like "Saying that ADHD and autism are disabilities sends the message to children and late-diagnosed people that they are less able and less than." As DEI consultant Julie Harris observes, "These common beliefs and statements show more about one's beliefs about disability than the actual diagnoses."[1] Her point is that people are riled up because of their preconceived notions of the word *disability* rather than because ADHD and autism are considered disabilities. Instead, if they can come to terms with this categorization, it might empower them to better understand the barriers people with neurodivergent disabilities face in a neurotypical world.

A big part of my work is dedicated to moving us toward a disability-positive culture, where society can view disability as simply part of the human experience with a neutral, or even positive, value judgment. If we want to change the culture, we have to first change our attitudes. A simple first step is to change the everyday language we use, not just around our disabled family, friends, and acquaintances but also within non-disabled spaces.

Let's begin with **inclusive language**: using language that avoids excluding particular groups of people or perpetuating harmful stereotypes based on gender, race, sexual orientation, age, or disability status. An example of gender-inclusive language is saying "everyone" instead of "you guys." Inclusive language "acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities."[2] The goal is to make everyone feel valued so that we can create a more welcoming environment for all with the words we use. For example, we should use the inclusive term *non-disabled people* as opposed to *able-bodied people*. *Able-bodied* assumes a binary and stagnant state that does not take into account people with non-apparent or dynamic disabilities. It also wrongly suggests that people with disabilities are not capable of using our bodies well.

We can't talk about inclusive language without bringing up the different types of non-inclusive language, whether they are subtle **microaggressions**, harmful **figurative terms** we use daily, or outright **insults**.

What is implied when someone says, "The only disability in life is a bad attitude"? While the sentiment might be well-intended, this **microaggression** equates disability with someone's bad attitude and conveys that actual disability does not exist or matter. Microaggressions are dangerous because although their subtle language may not be "obviously" or intentionally hurtful or damaging, they still inform the way we think—that disability is a bad thing. We will learn more about microaggressions in a later chapter.

I was on a podcast some time ago, and the press release mentioned that the featured disabled podcasters had "overcome their disabilities." Even if it sounds well-meaning, the phrase *overcoming disability* is another example of a microaggression because it suggests that disability is something negative that needs to be conquered or defeated. Plus, I am still disabled, and I am okay with it! An alternative phrase could be *overcoming adversity in the face of ableism*, which names ableism as the main problem rather than disability. Here are other examples of microaggressions in language and better alternatives:

Ableist Words and Phrases to Avoid	**Alternative Words and Phrases**
suffering from disability	living with disability
they accomplished this despite their disability	they accomplished this with their disability
handicapped parking	accessible parking / disability parking
wheelchair bound	wheelchair user
lost their battle with cancer/depression	died

Let's talk about some of the common **figurative terms** that we use daily, perhaps unthinkingly, that end up weaponizing disability as a negative experience. These phrases may be figurative, but for some disabled people, they are literal. As TV presenter and disability advocate Sophie Morgan says in her memoir *Driving Forwards*, "People often describe themselves as 'paralyzed by fear,' and as a paraplegic, I would agree, there is nothing more paralyzing than fear—other than paralysis itself, that is. But while one is real, fear, on the other hand, is imagined."[3]

Metaphors like "falling on deaf ears" to describe a statement that is ignored or "the blind leading the blind" to describe a directionless effort are harmful because they carry negative connotations. In an Instagram video, speaker and DEI consultant Catarina Rivera demonstrates how she leads her friend, accomplished author and activist Haben Girma, on the dance floor. As both women sway in rhythm, Rivera explains in a voice-over, "Being blind doesn't mean being ignorant. Haben and I think we should all get rid of this ableist phrase because the blind leading the blind can be quite fabulous."[4]

"It's just a metaphor! I don't mean it seriously," someone might say. But what does it mean when someone chooses to make light of terms that describe and make assumptions about the lived realities of disabled people? It demonstrates that they don't take our concerns seriously.

It might seem difficult, even tedious, to make a conscious decision to change the way we've been speaking for years, but this interruption to our personal thought patterns is part of our anti-ableist work. Luckily, language is fluid and ever changing, and there are so many alternatives we can make use of to express ourselves in creative ways.

Ableist Words and Phrases to Avoid	**Alternative Words and Phrases**
paralyzed by fear	terrified / frozen with fear / riveted with fear
blind leading the blind	directionless / clueless / going in circles
falling on deaf ears	not getting through / not resonating
tone-deaf	oblivious / ignorant / out of touch
blind spot	missing piece / gap in knowledge / bias / area of limited awareness
analysis paralysis	state of inaction
that's a real handicap	that's a real challenge

Finally, sometimes people use disability terms (whether current or outdated) as outright and overt **insults** or **jabs**. This contributes to the ongoing stigma and negative attitude surrounding disability.

Examples of Disability Terms Used as Insults

That's so lame.

Are you deaf?

He's a vegetable.

She's crazy/insane/psycho.

You're retarded/stupid.

Instead of using these figurative insults, just say what you actually mean, whether you mean "boring," "nasty," or "uncool" instead of *lame*; "absurd," "wild," or "ridiculous" instead of *crazy*; or "foolish," "immature," or "silly" instead of *retarded*. By making this linguistic switch, you're removing harmful stereotypes about the disability experience.

It's okay to make mistakes along the way. Ableist language and value systems have been ingrained in most of us since we were young, and it'll take years for all of us—whether we're just starting out or have been allies for some time—to unlearn it all. What's important is how we claim our mistakes and own up to them.

The good thing about correcting our mistakes when it comes to inclusive language is that all we need to do is change the words we use. It may feel hard at first, but to paraphrase Glennon Doyle, I know you can do hard things.[5] It is natural to react defensively when you're challenged—just breathe through it, and recognize that someone trusted and respected you enough to tell you the impact of your words on them. These shared understandings of disability provide common language so that we can learn more about the historical roots of disability rights and collective action next.

Reflection Questions

1. Have you used ableist language in the past? How can you be more mindful of your language going forward?
2. What are some other common ableist phrases not mentioned in this chapter? What better alternatives can you replace them with? How might these phrases contribute to ableism?
3. Are there examples you can point to of public figures updating their language? How can you learn from such instances and be open to evolving your language?
4. Find a news article about a disability-related topic and look at the language it uses. Is it written through a neutral lens or with negative value judgment of disability? How would you correct this language, if necessary? If you are unsure about alternatives, you can search disability journalism guidelines for suggestions.

CHAPTER 5

A Brief History of the Disability Rights Movement

The cosmologist Carl Sagan said, "You have to know the past to understand the present."[1] Even though this might be your first time learning about disability history, there is a long legacy of disability activism. None of this work exists in a vacuum, and I'm grateful for the disability activists who paved the way for me and those who will come after.

As a brief history, I encourage you to use the information laid out in this chapter as a catalyst to dive into areas that are of interest to you. Professor Kim E. Nielsen's book *A Disability History of the United States* could be a great place to start.

I first started learning more about disability history in 2015 around the twenty-fifth anniversary of the ADA. I was living in New York City when the mayor proclaimed July Disability Pride Month, and the city was celebrating its first Disability Pride Parade. Even in the process of researching for this chapter, I learned a few things!

So how did it all start?

In the ancient world, disability was viewed through the lens of superstition and religious beliefs. In some religious cultures like Christianity, it was seen as a manifestation of the divine, but it was viewed mostly as a curse or punishment from a god. During the periods of the Greek and Roman empires, which valued human perfection, disability was seen as inferior, undesirable, and disposable. Roman fathers were responsible for deciding whether a disabled child would live or die, and the child was often abandoned in the woods. In Sparta, the child was the property of the state, and abandonment of a disabled child was required by law.[2]

From the Middle Ages through the Renaissance, around 1000 to 1700, disability continued to be shunned as the devil's work or punishment for a parent's, and eventually the grown child's, sins. During this period of social and economic hardship, families couldn't afford to care for disabled family members—or they simply didn't know how to—and disabled people were evicted and often became beggars or were hidden out of public spaces. In 1247, Europe's first mental health hospital, Bethlem Royal, was founded in Britain, later gaining notoriety for its brutal "treatments" of disabled patients, such as bleeding and cold-water therapy,[3] that were a mix of punishment and religious devotion, and for its use of "chains, manacles, locks, and stocks."[4] Owing to the rise of witch hunts during the 1600s, many disabled people were also accused of witchcraft and sorcery.[5]

By the 1700s, the start of the Industrial Revolution, disability was commonplace. Long hours in horrible working conditions and a lack of workplace safety regulations, combined with a rise in population and poor medical facilities—as well as wars—left many disabled.[6] Technological advancement also exacerbated social inequities and increased poverty. Into the 1800s, disabled people continued to be scorned and cast off. As the number of people experiencing homelessness grew in cities, new policies were enacted to address the "problem." Cities began the practice of "warning out" disabled people, which meant telling them that they were no longer welcome. Disabled people were also loaded onto carts and dropped off at the next town.[7] In addition to forced displacement, disabled people were locked away in poorhouses or jails.

The 1800s also saw the first emergence of disability rights in the United States. Formal education for the Deaf community began when oral and manual schools were created in the early 1800s.[8] Oralism and manualism are two methods of teaching Deaf people to communicate, with oralism using speech and lipreading, and manualism using American Sign Language (ASL). Around the mid-1800s, nurse and advocate Dorothea Dix visited jails, poorhouses, and asylums across the United States and observed appalling conditions where disabled people lived.[9] Dix appealed to Congress to set aside land to accommodate disabled people, paving the way for the first publicly funded state institutions in the United States for people with disabilities. This was a turning point in promoting the belief that the US government had a responsibility to care for its disabled citizens.

Unfortunately, history would show that institutionalization was not an ideal solution. Like Bethlem Royal Hospital six hundred years before, these institutions had poor and overcrowded living conditions. Instead of providing care and rehabilitation, they abused and neglected the disabled residents, adopting cruel treatment methods that resembled torture, imposing isolation, and even using the residents as free labor. Additionally, institutionalization took away the choice and agency of disabled people, leaving them in the hands of their family members and doctors. Nevertheless, institutionalization became a widespread practice, keeping hundreds of thousands of disabled people segregated from the rest of the population in a practice known as "warehousing."[10] Meanwhile, outside institutions, "ugly laws" in certain cities banned disabled people who were "diseased, maimed, mutilated, or in any way deformed, so as to be an unsightly or disgusting object" from showing themselves in public.[11] Ironically, disabled people with "disfigured, disabled, or exaggerated bodies" were displayed as "oddities" in county fairs for the enjoyment of spectators.[12]

The early 1900s saw the rise of eugenics, "the science of the improvement of the human race by better breeding,"[13] according to Charles Davenport, a central figure of the movement in America. The belief was that certain "undesirable" human conditions like "feeblemindedness," epilepsy, and insanity were hereditary and should therefore be "bred out." Disabled people were on the front line of this attack, with seventy thousand disabled people in the United States undergoing forced sterilization without their consent after a 1927 Supreme Court ruling, *Buck v. Bell*, which states that governments have the right to forcibly sterilize people with disabilities.[14] Despite certain limitations, the ruling is still in place today. Most famously, the eugenics movement made its way to Nazi Germany, where disabled people made up one of the many groups targeted by Hitler in his campaign for racial purity. In 1933, people with what were believed to be "hereditary" conditions had to undergo compulsory sterilization. Hitler decided that the next step was to kill babies with congenital disabilities and later disabled adults. In total, the Nazi program Aktion T4 carried out the murder of 300,000 disabled people.[15]

After World Wars I and II, disabled veterans pressured the government to provide them with rehabilitation and vocational training as a way to thank and honor those who had sacrificed their lives and health for the country since they could no longer serve in the military. In the 1930s, economic growth, increased government assistance, and advancements in technology and medical care helped to bring disabled people closer to self-reliance. However, there was still a lack of accessibility in public spaces.[16] Significantly, in 1938, the Fair Labor Standards Act (FLSA) passed, with Section 14(c) legally allowing employers to pay disabled employees lower wages due to what was seen as limited productivity.[17] This was originally meant to incentivize employers to hire disabled people, but it resulted in unfair wages. As of February 2024, twelve states have phased out Section 14(c), and five states are in the process of doing so.[18]

By the Civil Rights Movement in the 1960s, disability rights advocates had joined forces with other minoritized groups to demand equal rights, treatment, access, and opportunities. Parent advocates were a big part of the disability rights movement, calling for their disabled children to be removed from segregated institutions and enrolled in schools where they could learn alongside other, non-disabled children.[19] When the Civil Rights Act passed in 1964, it protected against discrimination based on race, color, religion, sex, and national origin, leaving disability out of the picture despite the efforts of advocates. This exclusion pushed activists to call for laws specific to disability rights, which eventually led to the Rehabilitation Act of 1973 (Section 504), where, for the first time in US history, the civil rights of disabled people were protected by law. The law prevented disabled people from being discriminated against in federally funded programs, such as hospitals, public schools and universities, and public transit systems, and it also mandated equal access to public services. Crucially, this law focused on fixing the environment as opposed to fixing the individual.[20] Previously, for example, schools and libraries had been "available" to the public but not accessible to disabled people.[21] The law was signed in 1973 but was delayed due to the enormous financial costs it required of the government, such as updating public buildings to meet the new standards. Disability activists, including Judy Heumann, Kitty Cone, Brad Lomax, Mary Jane Owen, Corbett O'Toole, and Hale Zukas, wrote letters and lobbied lawmakers, and in 1977, they organized sit-ins, including a twenty-six-day action at the San Francisco federal building known as the “504 Sit-In,” the longest non-violent civilian occupation of a federal building in US history.[22] That finally got the program moving.

Riding the momentum of this win, disability rights activists continued to organize and protest, fighting to represent and speak for themselves. In 1983, the World Institute on Disability was founded by Judy Heumann, Ed Roberts, and Joan Leon. It was one of the first international disability rights organizations led by people with disabilities. Judy Heumann, known as the “mother of the disability rights movement,” was the first wheelchair user to become a New York teacher. She sued the New York Board of Education in 1970 at the age of twenty-two after she was failed on her mandatory medical exam because she could not walk.[23] And Ed Roberts, known as the “father of the independent living movement,” successfully sued the state of California after the University of California, Berkeley, tried to reverse his acceptance after realizing that he was quadriplegic because it was unprepared to accommodate his needs. He became its first student to use a wheelchair.[24] Roberts went on to organize the first disability-led student organization in the United States, advocating for accessibility on campus, which later inspired him to found the country’s first independent living community. In his words, “No longer would we tolerate being spoken for.”[25] In 1988, a weeklong student protest at Gallaudet University, a university for Deaf and hard-of-hearing students, led to the election of the first Deaf university president.[26] On a national level, activists fought for specific laws like the Voting Accessibility for the Elderly and Handicapped Act of 1984, requiring accommodations for disabled people during elections, and the Air Carrier Access Act of 1986, prohibiting discrimination against disabled people by airlines, among others.[27] However, what was still missing was a wide-reaching and broad civil rights law that would protect the rights of disabled people in the United States.

In the 1980s, disability rights activist Justin Dart Jr. traveled extensively to collect stories about the injustices that disabled people faced. His ultimate goal was to create legislation that would address discrimination against disabled people in the United States.[28] Iowa senator Tom Harkin took this information and worked with other prominent leaders to author the ADA in 1990, thirteen years after Section 504 had paved the way. Dart is widely recognized as the “father” of the ADA. Businesses that disliked the new accessibility requirements lobbied against the bill. At one point, over a thousand disabled people gathered in Washington, DC, to protest, including an action known as the Capitol Crawl when protesters left behind their wheelchairs and crutches and crawled up the steps of the Capitol.[29] This protest was intended to be a physical demonstration of how inaccessible architecture impacted people with disabilities, forcing Congress to see disabled people. The late Michael Winter, who participated, said, "Some people may have thought it was undignified for people in wheelchairs to crawl in that manner, but I felt that it was necessary to show the country what kinds of things people with disabilities have to face on a day-to-day basis. We had to be willing to fight for what we believed in."[30]

The ADA passed four months later on July 26, 1990.

Today, the ADA extends protections to all private institutions and workplaces, ensuring "the equal treatment and equal access of people with disabilities to employment opportunities and to public accommodations," and intends to "prohibit discrimination on the basis of disability in: employment, services rendered by state and local governments, places of public accommodation, transportation, and telecommunications services."[31] This means providing accessibility in public services and infrastructure, such as ramps, elevators, automatic doors, handrails, and captions on TV and streaming services, which are accommodations that both disabled and non-disabled people benefit from. It also means mandating that private businesses and public services accommodate disabled employees, clients, and customers. Essentially, the ADA is landmark legislation because it mandates the "full participation, inclusion, and integration of people with disabilities in all levels of society."[32]

However, as you'll hear many advocates say, the ADA should be the floor, not the ceiling, of the disability rights movement. It is often poorly and inconsistently enforced across states, with multiple violations across the country.[33] While there are fines for non-compliance of up to $75,000 for a single ADA violation and $150,000 for additional violations, there are exceptions and exemptions, and many disabled people lack the time and energy to fight for our rights. Prejudice and bias against disabled people still exist within families, in media representation, and elsewhere. Enforcing laws is one thing; changing attitudes is another and is necessary to create lasting change.

In 2006, the United Nations (UN) adopted the Convention on the Rights of Persons with Disabilities (CRPD), the first legally binding instrument to address the rights of disabled people at the global level.[34] This was born out of a desire to shift from "viewing persons with disabilities as 'objects' of charity, medical treatment, and social protection toward viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society."[35]

The passage of the Affordable Care Act (ACA) in the United States on March 23, 2010, was also significant because it improved access to health care for people with disabilities and chronic conditions and addressed disability discrimination. Because of the ACA, young adults can stay on their parents' insurance until age twenty-six, and insurance companies can't deny coverage or charge higher premiums to those with pre-existing conditions or comorbidities.[36]

I've been honored to meet some of the notable figures mentioned in this chapter, including the late Judy Heumann and Senator Tom Harkin, as well as many other pioneering advocates whom I hope you will read about in history books to come. I've also been learning about the ways that disability has been downplayed in history and erased from historical figures, such as Mexican artist Frida Kahlo, who developed polio as a child and acquired physical disabilities from a bus accident when she was eighteen;[37] President Franklin D. Roosevelt, who also had polio; and Harriet Tubman, who developed epilepsy. This erasure of their disabilities makes their stories incomplete. It now falls upon our generation to remember and honor those who have come before us and to continue on the path they've laid out.

Where do we go from here? In the modern era of the disability rights movement, we are still trying to combat negative biases against disability. Newer terms like *ableism* are at the forefront of our conversations, and notions like disability intersectionality and disability pride—as well as movements like disability justice, which emerged in 2005 from a group of disabled activists of color called Sins Invalid that included Patty Berne, Mia Mingus, and Stacey Park Milbern and which we will learn more about in later chapters—give us valuable context and expand on our centuries-long fight for inclusivity and equity. The American Association of People with Disabilities (AAPD) highlights a few advocacy areas we can focus on: community integration, health care, employment, and political participation.[38] I share more strategies later, in the Anti-Ableism and Societal Change section.

We must also remember to let disabled people lead the way. Haben Girma, a disability rights lawyer, author, and speaker—and the first Deafblind person to graduate from Harvard Law School—reminds us, “The disability community is diverse, full of rich stories of talented people improving their communities.…It touches all of our lives.”[39]

We are long overdue to be living in a time when our doctors, family members, and government authorities no longer make decisions for us. It is time to reclaim our stories. We have the agency and dignity.

Reflection Questions

1. Are there areas of disability history that you’d be interested in delving into more deeply? Read books and articles, and watch videos that deepen your understanding. The Oscar-nominated film *Crip Camp* is a documentary that follows the journey of campers who became disability rights activists and played a crucial role in the Section 504 Sit-In.
2. Did you learn about disability history in school?
3. Were there parts of this history that surprised you?
4. Learn more about Ed Roberts, Judy Heumann, and other notable activists who have made or are still making disability history.
5. How have legislative milestones like Section 504 and the ADA shaped the landscape of disability rights? Where might there be opportunities for improvement?

CHAPTER 6

Models of Disability

We all see and talk about disability in different ways. You probably have your own "mental model"—or way that you view disability—even if you don't realize it.[1] And these ways in which we see and talk about disability reveal our beliefs and social attitudes.

Over the years, activists and academics have studied the history and culture of disability.[2] Disability studies scholars call the different ways people talk about disability *models of disability.*

As theoretical frameworks, I note that these models are meant to be viewed as tools—they are not exhaustive, they may overlap, and they will shift and develop along with society's changing attitudes.[3] In this chapter, I share eight different models of disability—though there are more—so that we can better understand the social attitudes toward disability and why it all matters. The medical model, charity/tragedy model, and social model are the three most frequently referenced by advocates.

First, the **medical model of disability** views disability as resulting from physical or mental "impairments" that are located in an individual, unconnected to external environmental or social factors, similar to the Merriam-Webster definition. The medical model sees disability as a defect, deficiency, or abnormality that negatively impacts an individual's quality of life and prevents us from being "normal." In the medical setting, disability is viewed as a health condition that needs to be treated or cured. In other words, disability is a problem that needs to be fixed. Let's take the example of a person who is unable to use stairs. The medical model of disability attempts to cure the person's condition rather than address the inaccessibility of the stairs.

The medical model of disability has been criticized by advocates because it stigmatizes disability. Historically, it is the reason many disabled people were institutionalized, because the medical model saw us "as useless and hopelessly dependent on others."[4] The medical model also focuses on costly treatment, such as surgery or drugs, that may not always be in the disabled person's best interest. A CEO of a large tech company once told me that deafness would cease to exist because of cochlear implants, without addressing Deaf culture or the high cost of some cochlear implants. Advocates and critics argue that instead of unnecessary medical interventions driven by the medical model, more resources and effort should be put into "simpler inclusionary practices like universal design and social inclusion."[5]

Second, the **charity or tragedy model of disability** views disability as a tragic experience and disabled people as needing other people's help and goodwill. It treats us as "victims of negative circumstance"[6] and "objects of pity and charity."[7] The charity/tragedy model is often used by non-disabled people and organizations, usually charities that paint disabled people as suffering passively and in need of donations and services to survive. In the case of a person not being able to use stairs, the charity/tragedy model would encourage charitable actions like raising money to address the condition that prevents the person from using stairs or physically carrying them up the stairs rather than providing step-free access or a chairlift.

The charity/tragedy model has been criticized for causing more discrimination against disabled people by taking away our agency to make our own choices, especially when the charitable donor or do-gooder calls the shots. It lowers disabled people's self-esteem when it makes us feel indebted to or reliant on others. Like the medical model, in which a medical professional makes the decisions and focuses on curing the individual, the charity/tragedy model is a reactive and top-down approach that tries to "save" the individual from our problems. In this case, the "problem" is the person's disability rather than inaccessibility and ableism.

Third, the **economic model of disability** defines disability as an individual's inability to work. In this model, the inherent worth of a person is tied