Plain Language Summary and Translation of Demystifying Disability: What to Know, What to Say, and How to be an Ally

by Emily Ladau

Plain Language uses:

- Short sentences.
- Words most people know.

We wrote this version so more people could read the book.

There are two parts to this translation:

- Summary
  - This will give you the **main points** of the book.
  - It is written in **bullet points.**
  - You can read this if you want to know what the book is about.
- Plain Language Version
  - This will give you the **whole book.**
  - It is written in **paragraphs.**
  - You can read this if you want to know all the information that is in the book.

Who made this?

- Emily Ladau wrote the book this translation is based on.
- Becca Monteleone made the plain language version.
- Becca and Emily worked together to make sure the plain language version said the same thing as Emily's book.
- Leah Mapstead was the **test reader.** That means she read what we wrote to make sure it made sense.
- We had a person who has a vision disability check our work to make sure people who use screen reader software can read it. Screen reader software reads the text on the computer screen out loud.
- We did our best to make this version easy to read for many people. But we are just a few people. We can't know what works best for everyone.
- We will update this version if people tell us there is something we can make better or easier to read.
- Is there anything we can change about this version to make it easier to read? Let us know! Email Emily at emlad729@gmail.com

You can buy the printed, digital, and audio versions of Emily's book by clicking here.

Before we begin, here are notes for people who use screen reading software. Screen reading software reads text on a screen out loud.

- Headings are used in this document. You can use headings to find the place you want to go.

- You can choose between reading the Summary and full Plain Language version at Heading Level 2.
- Chapter titles are all at Heading Level 3.
- If you have a problem navigating the document, email Emily at emlad729@gmail.com and let her know.

Contents

Summary

Summary: Introduction

- My name is Emily.
- I am a disabled person.
- I wrote this book.
- It answers questions you might have about disability.
- There are a lot of disabled people in the world.
- You might know someone with a disability.
- You might have a disability.
- People with disabilities are sometimes treated badly.
- The word “disability” makes some people feel:
  - Afraid,
  - Confused,
  - Embarrassed.
- I think people would not feel this way if they knew more about disabilities.
- Knowing more about disabilities could change how people act and think.
- This book will teach people more about disabilities.

- Anyone is welcome to read it.
- You can take what you learn from this book and use it in your life.
- All disabled people are different.
- I only know my own point of view about being disabled.
- I can’t include everything about disability in my book.
- There are a lot of disabled people who can teach you about disability.
- You can always learn more about disability.

Read the Plain Language Introduction

Summary: Chapter 1

So, What is Disability, Anyway?

- There are different ways to think about disability.
- You might think that disability:
    - Means you can't do something.
    - Is a normal part of life
    - Changes over time.
    - Is part of who you are as a person.
    - Affects how other people treat you.

How Should We Talk About Disability?

- The words we use to talk about disability matter.
- Not all people agree on what words to use.
- There are two common ways to talk about disability.
    - You can say "People with disabilities."
        - People say this when they want to remind others that they are not just their disability.
        - This is called "person-first language."

    - Or you can say “Disabled people.”
        - People say this to show that disability is an important part of who they are.
        - This is called “identity-first language.”
- Both ways of talking about disability are correct.
- People with disabilities can choose which way they like better.
- I used to always say “disabled people.”
- I didn’t like when people said “people with disabilities.”
- It made me uncomfortable.
- Some people told me they thought I should say “people with disabilities” instead.
- I didn’t like it when they told me what to call myself.
- Other people don’t get to choose the words I use.
- And I don’t get to choose what words other people with disabilities use.
- Disabled people should use the words they like.
    - People without disabilities also should decide what words about disability are correct to use. Listen to what disabled people want.
- Some groups of people with disabilities use certain words or phrases.

- When you can, it is important to ask people with disabilities what they like to be called.
- It’s okay to make mistakes in what you call people with disabilities. Just say you’re sorry and do better next time.

Just Say Disability

- Saying the word “disability” or “disabled” is okay!
- You don’t need to say other phrases like “physically challenged” or “special needs” when you mean “disabled.”
- Don’t use made-up words like “handi-capable.”
- Disability is not a bad word.
- And it’s not bad to be disabled.

There is No Normal

No one is “normal.” We all have different ways of:

- Thinking
- Communicating
- Moving.
- That means we all sometimes need help to get things done.
- But we have an idea of what “normal” is. We put labels on anyone who doesn’t fit that idea.

- We say that some people with disabilities “function” differently than people without disabilities. Two phrases we use are:
- ”High functioning,” which means they can do a lot of things. or
- “Low functioning,” which means they cannot do a lot of things.
- We don’t need these labels. It’s better to talk about what someone needs to do things instead of how they do them.

Think Before You Speak

- We use words describing disability in our everyday lives. We sometimes use them as insults. Using these words hurts disabled people. Some examples are:
    - Crazy
    - Dumb
    - Idiot
    - Imbecile
    - Insane
    - Lame
    - Moron
    - Slow
    - Stupid

- Practice using other words instead of these words.

Don’t Say These Words

- Some words are slurs.
    - This means they are very hurtful.
    - Don’t ever use them.
- Some slurs are:
    - Retarded (the R-word)
    - Midget (the M-word)
    - Mad
    - Crazy
    - Cripple
    - Gimp
    - Spaz
- Some disabled people will use these words to talk about themselves.
- But it’s not okay to use these words to talk about someone else.

What To Say

- Don’t make anyone with a disability use words they don’t want to use.

- Always ask a disabled person what words are right for them. Everyone is different.
- Read this table to help you learn more about what words you can use.

Read the Plain Language Chapter 1

Summary: Chapter 2

Understanding Disability as Part of the Whole Person

- I am disabled.
    - It is a part of me.
    - I have good and bad feelings about my disability.
- Anyone can be disabled.
- That’s not a bad thing.
    - Each person gets to choose how they feel about their disability.
- Disability is just one part of a person.

Intersectionality

- We all have many parts of who we are. They could be our:
    - Race
    - Gender
    - Disability
    - Age
    - Class
    - Sexuality
    - Ethnicity

    - And more.

- These are called our *identities.*

- All those parts work together to make us who we are. That is called *intersectionality.*

- Dr. Kimberlé Crenshaw made up the word intersectionality." She wrote about Black women. She said that Black women are not treated well because:

    - They are Black.

    - They are women.

    - They are Black AND women.

- You have to look at all the parts of who someone is to understand them.

- That's true with disability too.

- Disabled people don't all live the same lives.

- We need to listen to people with all kinds of identities.

Types of Disability

- There are many kinds of disabilities. You can:

    - Have a disability that falls into more than one group.

    - Have more than one disability.

- Disabilities can affect how you:

  - Talk
  - Read and write
  - Grow
  - Hear
  - Think
  - Take care of yourself
  - Learn
  - Feel
  - Move
  - See
- Two people with the same disability do not have the same lives.
- Some ways to understand different types of disabilities:
  - Can you see it?
  - Will it go away someday?
  - Did the person have it when they were born?
- Learning more about disability makes people less scared of disability.
- You can learn the names for the types of disabilities by clicking here.

Models of Disability

- Models are ways of thinking about disability. They help explain how to understand disability. Two big models are:

Medical Model

- The medical model says that disability means:
    - Something is wrong with a person who has a disability.
    - A part of their body is broken.
    - They can’t do some things.
- It says we should fix people with disabilities. This makes people think disability is bad.

Social Model

- The social model says that disability means:
    - The world isn’t made for people with disabilities.
    - The problem is that people with disabilities get left out.
    - It’s not a problem that our bodies have disabilities.
- There are other models of disability too.
    - Some of them say disability is bad.
    - Some say disability is good.

  - But no model has all the answers.

- Disability means a lot of different things.

[Read the Plain Language Chapter 2]

Summary: Chapter 3

An (Incomplete) Overview of Disability History

- History classes don’t talk about disability.
- But disabled people are part of history.
- I write about history in this chapter that:
    - Happened in the USA.
    - Started after 1900.
    - Has to do with disability rights.

Early 1900s

- It was hard to be disabled in the early 1900s.
- There were laws that said people with disabilities should not have babies.
- Some disabled people were forced to have surgery. It made it so they couldn’t have kids.
- A lot of people believed in eugenics.
    - Eugenics means thinking only some kinds of people should be in the world.
    - People who like eugenics think disability is bad.

1930s

- The Great Depression happened in the 1930s.
    - It was hard to get a job.
    - Many people did not have money to live.
    - Most disabled people did not work.
- Franklin Delano Roosevelt was president in the 1930s.
    - He used a wheelchair.
    - He hid his disability most of the time.
- The government made laws to help people.
    - Some of these laws did not help disabled people.
    - So disabled people fought back.

1940s

- World War Two started in the 1940s.
- Many soldiers who fought in the war got hurt.
- The US made programs to help disabled soldiers when they came back from the war.

1950s

- Dwight D. Eisenhower was president in the 1950s.

- He made Social Security Disability Insurance (SSDI).
    - SSDI gives cash to people with disabilities who can't work.

1960s

- John F. Kennedy was president in the 1960s.
- President Kennedy's sister started the Special Olympics in 1968.
- New laws made during the 1960s said:
    - People with intellectual and developmental disabilities should live in their communities.
    - Buildings have to be accessible.

1970s

- Many important disability rights events happened in the 1970s.
- Judith Heumann is a wheelchair user. She had to sue the New York City Board of Education to become a teacher. She won.
- Willowbrook was a home for disabled people. A news story showed that Willowbrook was hurting the people who lived there.
- New laws made during the 1970s said:
    - The government has to be fair to disabled people.
    - All disabled kids have the right to go to school.

- Something called the “Ugly Laws” ended. These laws said disabled people couldn’t be where other people could see them.
- Disabled activists fought for their rights.
    - Activists had a protest in San Francisco. They lived in a government office for one month.
    - They wanted clear rules for the law that said the government can’t be unfair to disabled people.
    - They won.

1980s

- The disability activist group called ADAPT started.
- The US hosted the Paralympics. This is a competition for disabled athletes.
- New laws made during the 1980s said:
    - The places where people vote have to be accessible.
    - Disabled people can’t be treated unfairly on airplanes.
- Deaf students had a protest at Gallaudet University. It is a school for people who are deaf. They wanted a deaf person to run the school. The students won.

1990s

- The US made the Americans with Disabilities Act.

    - This law says people with disabilities have to be treated the same as everyone else.

- The Supreme Court said you can’t make disabled people live in hospitals or nursing homes. They can live in their homes and communities.

2000s

- New laws made in the 2000s said:
    - Technology has to be accessible to disabled people.
    - Disabled people can save money without losing benefits. Benefits means money to help people live.
- The Autistic Self-Advocacy Network started.
- World Down Syndrome Day started. It happens every year on March 21.
- Tammy Duckworth is now a senator. She is the first woman with a visible disability to be a senator.
- Jenny Hatch has Down syndrome. Her parents wanted her to live in a group home. She didn’t want to live there. She fought against her parents. She won a court case against them.
- Leah Katz-Hernandez started working in the White House. She was the first deaf Receptionist for the West Wing of the White House.
- Ali Stroker won a Tony award for being on Broadway. She was the first wheelchair user to win this award.

- New challenges start:
    - The government tried to pass a law that hurts the ADA.
    - COVID-19 starts making people sick. Disabled people don’t get the best healthcare.

Many Movements

- There are a lot of groups in the disability community. Some big disability movements are:

Independent Living

- Wants disabled people to be able to live in the community.

Disability Justice

- Led by disabled people who have been left out of other disability advocacy groups.
- That means people who are left out because of their:
    - Race
    - Gender
    - Sexuality
    - Or another important part of who they are.

Self-Advocacy

- Led by people with intellectual and developmental disabilities.

Neurodiversity

- Believes all the different ways we think and act are good.
- Started by Autistic people. But includes anyone with a disability that affects how they think and act.

Psychiatric Survivors

- Led by people with mental illness.
- They have been hurt by doctors or hospitals. They don’t want this to happen to other people.

Read the Plain Language Chapter 3

Summary: Chapter 4

Ableism and Accessibility

- Ableism means treating disabled people worse than people without disabilities.
- Something caused by ableism is *ableist.*
- Ableism can happen anywhere and everywhere.
- Nondisabled people may not notice ableism.
- But disabled people notice ableism all the time.
- Examples of ableism:
    - A train station without an elevator to get to it.
    - A law that says it’s okay to pay disabled people less money for doing work.
    - A business that has a website that doesn’t work for blind people.
    - A comedian who uses words that hurt disabled people.
- Not everyone with a disability agrees on what’s ableist and what’s not ableist. That’s okay.
- Some people without disabilities don’t like when I talk about ableism.
    - They think I’m complaining.

  - But I just want a better world for people with disabilities.
- Sometimes disabled people think ableist things about ourselves.
  - We might think we are not as good as people without disabilities.
  - But that is not true.
  - Disabled lives are always worth living.

Watch Out for Ableism

- We can think about disability and the other reasons people get treated unfairly. They are connected.
- Example:
  - Seven Bridges was a 10-year-old Black boy with a disability.
  - Other kids bullied Seven.
  - They said mean things about his race and disability.
  - They hurt him.
  - Because he was hurt, Seven took his own life in 2019.
- Disability often gets left out of activism.
  - People say ableist things when they are speaking up for other groups of people.
  - Activists who don’t have disabilities often don’t mention disability.

- We can all learn to be less ableist.
    - It’s okay if you have been ableist before.
    - You can do better.
    - We all can.

Accessibility

- Accessibility means making places and things so disabled people can use them.
- Changes to make things accessible are called *accommodations.*
- Examples:
    - A quiet room at an event.
    - Workers choosing what hours they work.
    - Sending out your slides before a presentation.
    - Captions.
    - Sign language interpreters.
    - Seating areas for people who use mobility devices.
    - Large-print.
    - Braille.
- Disabled people get left out when things are not accessible.

- Many people will say they can’t make things accessible. They might say:
  - It costs too much to make something accessible.
  - It’s too much work to make something accessible.
  - Something will not look nice if I make it accessible.
  - It will take too long to make something accessible.
  - It’s not my job to make something accessible.
  - Disabled people don’t come here so I do not have to worry about accessibility.
- Those are excuses. When people say these things, it feels like they really mean:
  - Disabled people are not welcome here.
- I feel bad when I hear excuses for why something cannot be made accessible.
- The law says things and places need to be accessible.
- But it can be hard to know how to make things accessible.
- You can always ask experts about accessibility if you’re not sure what to do.
- A lot of accommodations are cheap or free.
- Access helps us all.

Examples of Ableism

- States with laws that say disabled people can have their kids taken away.
- Car services that won’t pick up people with wheelchairs or guide dogs.
- Schools that put students with intellectual disabilities in different classrooms than students without disabilities.
- Therapy that forces Autistic kids to act “normal.”
- Group homes and nursing homes that cut disabled people off from their communities.
- Meetings that are not accessible.
- Paying people with disabilities less money than people without disabilities.
- Thinking that all disabled people want to be cured.
- New COVID rules that say hospitals can choose not to help sick people if they have disabilities.
- Plans for emergencies like wildfires and hurricanes that don’t include disabled people.

Read the Plain Language Chapter 4

Summary: Chapter 5

Disability Etiquette 101

- Etiquette means rules for how to act. That means:
    - Having good manners.
    - Being polite.
    - Treating others with respect.
- *Disability etiquette* is how you treat disabled people.
- There are not a lot of special rules for how to treat disabled people. Just:
    - Treat others how you want to be treated.
    - Treat disabled people like human beings.
    - Be respectful.

What to Do

Think before you speak

- Don’t:
    - Ask questions about personal information.
    - Make rude comments or jokes.
    - Give a disabled person advice they didn’t ask for.
- Disabled people get asked a lot of questions.

- People want to know personal things about disabled people’s bodies and lives.
    - These questions about personal things can be hurtful.
- If you do want to share advice about disability that worked for you, first ask if it’s okay to do that.

Ask appropriate questions

- Examples of good questions:
    - Some people ask me about my wheelchair. They know someone who could use a wheelchair like mine and want to learn more about it.
    - Ask what people with disabilities need if you are having an event. Make sure the event is accessible.
    - You might have someone in your life with a disability. Asking them about their disability can make your friendship or relationship stronger.
- Always ask if it’s okay to ask a question about disability before you do.

Keep Your Hands to Yourself

- Respect disabled people’s space.
- Don’t ever touch someone without asking.
- That includes not touching:
    - Mobility equipment like wheelchairs.

    - Service animals that are helping people with disabilities.

Talk to Disabled People Like You Talk to Everyone Else

- Disability makes some people uncomfortable.
- Some people don’t know what to say to disabled people.
- But you can talk to a disabled person the same way you talk to everyone else.
- Tips:
    - Always talk to the disabled person themselves.
    - Don’t talk to the disabled person’s staff, interpreter, or family instead.
        - An interpreter is someone who translates what someone is saying into another language. Many deaf people use sign language interpreters.
    - Say your name before you start speaking to a blind person.
    - Gently tap a deaf or blind person politely on the shoulder to get their attention.
        - Not everyone wants to be touched. You can also wave to get a deaf person’s attention.
    - Use a pen and paper or texting to talk to a deaf person if there is no sign language interpreter.
    - Don’t shout at someone who is deafblind.

    - Speak clearly.
    - Or have a friend introduce you to start a conversation.
  - Don't rush someone who speaks slowly or uses a communication device.
  - Step back if the person you are talking to has to stretch their neck up to look at you because they are lower than you.
  - There's no one right way to talk to someone with a disability.
  - Just be yourself.

What Not to Do

Don't Talk Down to Disabled People

- Don't talk to disabled people like they are children.
- Some people with disabilities do need support to do things. That is okay.
- Treat everyone with respect, even if they need help.

Don't Help Without Asking

- Some people see a disabled person and think they need help.
- Don't try to do something for someone who didn't ask for help.
- This happens to me a lot.
  - People try to help me.

    - They think they are being nice.
    - But they are getting in my space.
    - They make it harder for me to do what I need to do.
- Disabled people know if we need help.
- Listen to us.

Don’t Stare. But Don’t Look Away.

- Disabled people get stared at a lot.
- It can feel hurtful when people stare at you because you have a disability.
- Some people turn away from disabled people.
- They don’t want to look at disabled people who look different than they do.
- Turning away from disabled people is hurtful too.
- It’s okay if you notice someone with a disability.
- But don’t stare at them.
- And don’t turn away from them.
- Just smile and keep going.

Don’t Pray Over Disabled People

- Don’t pray over a disabled person if they don’t ask you to.
- This happened to me once. A little girl asked Jesus to heal me.

    - I was embarrassed by this.
    - And I felt sad because it happened.
    - The little girl treated me like my disabilities are bad.
    - But I am not broken because I am disabled.
- Disabled people don’t need prayers to get rid of their disabilities.

Don’t Assume You Know Who Has A Disability

- You can’t always tell if someone has a disability just by looking at them.
- Disabled people don’t all look the same.
- If you can’t see someone’s disability, that doesn’t mean they are faking their disability.
- It’s not okay to make someone answer questions to prove they have a disability.

Don’t Use Accessible Things That You Don’t Need

- There aren’t a lot of accessible:
    - Parking spots.
    - Bathroom stalls.
    - Seats in places like movie theaters.
- Many people want to use these accessible things.

- Don’t use them if you don’t need them.
- When you use accessible things you don’t need, it makes it harder for disabled people.

Don’t Pretend You “Get It”

- I like when people take time to listen to me talk about disability.
- But I don’t like when people feel bad for me or other disabled people.
- And I don’t like when people without disabilities pretend to know what it’s like to have a disability.
- You can support disabled people. You can do this even if you don’t understand what it’s like.

What About Kids?

- Kids are curious.
- They ask a lot of questions.
- I usually like answering kids’ questions about disability.
- Other disabled people might not like doing this.
- Tips for adults:
    - Don’t tell a kid to be quiet if they have a question.
        - Kids should not feel embarrassed to talk about disability.

        - A disabled person might not want to answer a question from a kid. That’s okay.
        - If you can, try to answer the question about disability as best you can.
    - Don’t make a joke about disability.
        - Kids learn from the adults around them.
        - If you make a joke, they will think it’s okay to say something rude.

No More Bad Disability Etiquette

- It’s okay if you have done some of these rude things to people with disabilities.
- You can say you’re sorry.
- You can learn to do better.

What To Do If You See Something Ableist

- Every situation is different. But you should:
    - Be kind.
    - Explain why what they did was hurtful.
- You won’t always get it right.
- But that’s okay.

- You can help make the world a less ableist place.

Read the Plain Language Chapter 5

Summary: Chapter 6

Disability in the Media

- Media means:
    - TV
    - Movies
    - Books
    - Magazines
    - Ads
    - Radio
- There were not very many disabled people in the media in the past.
- Now there are more.
- But there are still not enough disabled people in media.
- And the ways disabled people are shown are not always good.
- Media doesn’t do a good job showing that all disabled people are different.
- The media also shows disability stereotypes.
    - Stereotypes are beliefs about a group that are not true.
- I explain those stereotypes in this chapter.

Inspiration Porn

- “Inspiration porn” is the name for a story that is:
  - About a disabled person.
  - For nondisabled people.
  - Told to make nondisabled people feel good.
  - Treating disabled people like things and not people.
- Many nondisabled people think inspiration porn is good.
- But inspiration porn is not good.
- It can make nondisabled people feel bad for disabled people.
- Types of inspiration porn:
  - Stories about a disabled person overcoming a challenge.
    - Shows disabled people doing something amazing.
    - Meant to make nondisabled people want to work hard.
    - Says anything is possible with a good attitude.
  - Stories about a disabled person just living life
    - Shows disabled people doing everyday things.
    - Meant to make nondisabled people feel good.
    - Says most disabled people can’t do everyday things.

    - Treats disabled people as special for doing everyday things.

- Both types of inspiration porn are wrong. Here is why:
  - A good attitude can not solve every problem.
  - Many disabled people live full lives.
- The media often shows disabled people in two ways:
  - As superheroes who do amazing things all the time.
  - As people who cannot do anything at all.
- Media like this can make disabled people feel bad.
- But disabled people don’t have to prove themselves to anyone.
- We are just like other people.

Not Your Good Deed

- If a nondisabled person is nice to a disabled person, the media treats them like they are special.
- It is good when nondisabled people are nice to disabled people.
- But being nice to disabled people does not make you a good person.
- Sometimes nondisabled people record videos of themselves being nice to disabled people.
- Doing this is wrong.

- Nondisabled people do this to show how great and kind they are because they are being nice to a disabled person.
- Taking a video to show that you are kind is not really being kind at all.
- Don’t share inspiration porn if you see it online.
- Or explain why inspiration porn is a problem if you do share it.

Pity Porn

- Pity Porn is a story that:
    - Acts like all disabilities are sad or tragic.
    - Tries to make you feel bad for disabled people.
    - Shows disability as being bad for disabled people and their nondisabled family and friends.

Mental Illness

- Media does not treat people with mental illness well.
- Media doesn’t always show the truth about mental illness.
- Media sometimes makes jokes about people with mental illness.
- Or media sometimes treats people with mental illness like they are violent and scary.
    - But that is not true.

Freaks

- Some media stories are about staring at people who look or act differently than what we think is "normal."
- In the past, there were "freak shows." Nondisabled people paid money to stare at disabled people.
- Now there are TV shows about "medical mysteries." They show people with illnesses and disabilities that doctors do not understand.
- These shows can have a bad effect on how nondisabled people treat the disabled people in their lives.

Sex and Love

- Many people think disabled people cannot have sex or fall in love.
- But many disabled people want all kinds of sex and love just like everyone else.
- There is not a lot of media about sex and disability.
- What we need is for disabled people to tell our own stories about sex and love.

Good Examples

- Some media about disability is good.
- Good media about disability is usually made by people who have disabilities.

- There is now more media with disabled models too. This is good.

- But media could be better at showing disabled people.

- We need more disabled people in the media. We need:

  - Disabled characters played by disabled actors.

  - Books written by disabled people.

  - Disabled models in ads.

Read the Plain Language Chapter 6

Summary: Conclusion

- I am glad you read this book.
- But there is still more to learn about disability.
- You can use what you learned in this to make the world better for people with disabilities.
- That is called being an ally.
- An ally supports a group of people they are not part of.

How to Be an Ally for Disabled People

- Think about why you want to help disabled people.
    - Do you feel bad for disabled people?
    - Do you think disabled people cannot do things on their own?
- These are not good reasons to help disabled people.
- Disabled people need the world to respect us.

It Takes Time to Be an Ally

- Being an ally takes work every day.
- Being an ally takes practice.
- You won’t always do a good job being an ally. That is okay.
- Keep working to support disabled people.

Nothing About Us Without Us

- Disabled people should be in charge of our own lives.
- Nondisabled people should not speak for disabled people. This means that:
    - Parents should not speak for disabled people.
    - Caregivers should not speak for disabled people.
    - “Experts” about disability should not speak for disabled people.
- Disabled people are experts of our own lives.
- Don’t talk over us.
- Don’t talk about us.
- Don’t talk for us.
- Talk to us.
- Talk with us.

Let Someone Else Speak

- Don’t always be the one in the middle of the conversation.
- Think about who has not had a chance to speak up.
- Make sure disabled people have a chance to share our thoughts.

Don’t Pretend to Have a Disability

- Some nondisabled people think they can learn about disability if they pretend to have one. They might:
    - Try wearing earplugs so they cannot hear like a deaf person.
    - Try wearing a blindfold so they cannot see like a blind person.
    - Try pushing themselves in a wheelchair so they can understand what it is like to have a physical disability
    - Try walking using crutches so they can understand what it is like to have difficulty walking.
- Pretending to have a disability is wrong.
- You cannot understand disability by pretending to have one.
- Doing this will not help you learn about a disabled person’s life.
- Listen to disabled people instead to learn about disability. You can:
    - Read books about disability.
    - Watch documentaries about disability.
    - Listen to podcasts about disability.
    - Invite disabled people to speak to your group.
    - Have conversations with disabled people.

Pay Disabled People for Their Work

- Teaching people about disability can feel good.
- But it can feel tiring too.
- Not every disabled person wants to teach people about disability.
- So, we should give credit to the disabled people who do this.
- Pay them for their work.

Say Sorry When You Make Mistakes

- Being an ally is not always easy.
- You will make mistakes.
- That’s okay.
- Say sorry.
- Learn from your mistakes.
- Do better next time.

Keep Learning

- Change is hard.
- I tell myself that I can make small changes.
- I can change one person’s mind about disability.
- And that is a good start.

- I hope you will make changes too.
- Thank you for letting me help you learn about disability.
- I hope you will keep learning.

Read the Plain Language Conclusion

Plain Language Version

Introduction

Read the Introduction Summary

One billion. That's how many disabled people are in the world. We are the world's largest minority.

That means you probably know someone is disabled. You might be disabled yourself. So, you can probably use the information in this book. Have you ever:

- Felt confused or embarrassed when talking about disability?
- Shushed your kid for asking "what's wrong?" with a person using a wheelchair?
- Shared a news story about a disabled person because it made you feel good?
- Felt like you were better than a person with a disability?

Don't worry! I'm not here to judge. You can use this book to find answers to some questions about disability that you aren't sure how to ask.

The word *disability* makes some people afraid or confused. Many people don't even know they think bad things about disability.

We have to do a lot of work to change how people think about disability. Nondisabled people treat disabled people in weird ways. Sometimes, they act like we’re precious gems. Sometimes they act like we’re aliens.

I am a disabled person. And I care about helping people change how they think about disability.

Here is a little about me:

I have more than one disability. I have:

- A physical disability
- A hearing disability
- Mental health disabilities

We’ll explain what those disabilities are in Chapter 3.

I use a wheelchair. I was born with a disability called Larsen syndrome (LS). It affects my muscles and joints. My mom Ellen also has the same disability. I have LS because she has it.

You might think it’s sad that we both have LS. We don’t. I think it’s great that my mom and I share this experience. She understands what my life is like.

My mom didn’t always think it was great. She and my dad, Marc, went to a medical expert before they had me. The doctor said I wouldn’t have LS.

But they found out I had LS when my mom was pregnant. My mom felt sad and worried. She thought I would blame her for giving me her disability. I don’t feel that way at all. But I know why she was worried. The world was not very respectful of disabled people when she was a kid. It is better now, but still not perfect.

When I was a baby, a woman saw that my mom and I have disabilities. My mom heard her say, “Look what that mom did to her baby.” That woman’s rude comment still hurts our feelings.

Society accepts and understands disability more now. But we all have more to learn. That is how we will make the world more accessible and inclusive.

Accessibility means that:

- Places,
- Products, and
- Services

can be used by disabled people.

Inclusive means everyone is welcome.

How do we make the world accessible and inclusive? ?

This is the way I think about it:

- *If the disability community wants a world that’s accessible to us, then we must make ideas and experiences of disability accessible to the world.*

This means disabled people need to share our stories. How can people understand disability if we don’t tell them about it?

Some disabled people don’t agree with me about sharing stories. It is a lot of work to teach other people about your life. It can be hard. Sometimes people won’t listen. We don’t want to always be teaching other people. We want to live our lives.

But right now,I still see many things that hurt disabled people online and in real life. So I think we need to be honest about disability. We need to share tips and advice. It is how we will move forward.

Someone who reads this book might change how they act. They could:

- Stop using disability as an insult.
- Call their government to advocate about disability issues.
- Add a ramp to their shop so people who cannot use stairs can get in.

All these changes can help make the world better for people with disabilities.

There’s No Test at the End

This book is for everyone. That includes disabled and nondisabled people. You can learn from it. You can become a better ally. An ally is a person who supports a group they are not a part of. Nondisabled people can be allies to disabled people. Disabled people can be allies to people with different disabilities.

This is not a textbook. I won’t cover everything about disability. And I am not a professor. I won’t give you a test about the book. Reading this book isn’t like taking a class that you can fail.

I hope you will take what you learn from this book and use it in your daily life. But you don't have to do everything right on the first try. It's okay if you get your language about disability wrong. It's okay if you watch a movie and aren't sure if it shows disability in a good way.

Some people think just being nice to disabled people makes them a good person. Including and supporting disabled people doesn't make you a good person. Don't read this book just to make yourself feel good about being nice to disabled people.

Learning about people who are different from you takes time. Don't be too hard on yourself.

Disability Is Not One-Size-Fits-All

When talking about people with disabilities in this book, I will say the "disability community." We are a beautiful and diverse community. Diverse means we are not all the same. This book does not represent every single person with a disability. We are each our own person. We have our own thoughts. Even people with the same disability have different experiences.

My family is a perfect example. My mom and my Uncle Jonathan have the same disability that I do. Our bodies are alike in a lot of ways:

- We are short.
- Our thumbs are rounded like spatulas.
- Our elbows are always bent.

- We have hearing loss.

But we are different too.

- My mom and I were born with cleft palates. This means there was an opening at the top of our mouths. My uncle wasn’t born with this.
- My mom and uncle can walk. I can’t.

We are in the same family. We have the same disability. But our lives are different.

Remember: meeting one disabled person means you’ve met *one* disabled person. If you have a disability, you are only the expert about your own life.

The same is true for this book. It is just one book about disability. It is my goal to share many ideas and experiences about disability. But the book is written by me. I am a person with a physical disability. People can tell I am disabled when they meet me. This affects how I look at and experience the world.

There is a lot more wisdom about disability out there. This may be the first book about disability you have ever read. It may be the 100th book about disability you have read. But you can always learn more. Keep reading. Keep learning. Keep going.

Chapter 1: So What is Disability, Anyway?

Read the Chapter 1 Summary

Disability is not a brave struggle or courage in the face of adversity. Disability is an art. It's an ingenious way to live.

-Neil Marcus, actor and playwright

- **This quote means:** Having a disability is not bad or sad. Disabled people find ways to be creative in a world that can be hard to live in because it is not made for us.

Disability. How does that word make you feel? What does that word make you think of? And what does it mean, anyway?

My mom says to look in the dictionary when I don't know how to begin explaining something. Here's what the dictionary says:

dis· abil· i· ty | \ ,dis--'bi-l-tē \ 1: 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.

There are laws that talk about disability too. Here's how the Americans with Disabilities Act talks about it:

The term "disability" means, with respect to an individual,

(A) a physical or mental impairment that substantially limits one or more major life activities of such individual;

(B) a record of such an impairment; or

(C) being regarded as having such an impairment.

These definitions say disability means that your body or mind is not able to do something. But this is only one way to think about disability.

So, how do I define disability?

Disability: a state of being; a natural part of the human experience.

But I'm just one person. I asked other disabled people to share what disability means to them. Their words will be in "quotation marks." I will explain what they mean below. Here's what they said:

Ellen Ladau, my mom:

- **"Disability isn't static. It evolves, both physically and emotionally."**
  - **This quote means:** Disability changes. It changes in our bodies. We change how we feel about disability.

Cara Liebowitz, writer and activist:

- **"Disability, to me, is a social identity, but it's also about having functional limitations."**
  - **This quote means:** Disability is part of who I am as a person. It also means I am not able to do certain things.

Imani Barbarin, writer and activist:

- **"Disability is a holistic experience, so it must have a holistic definition. Disability is not just a physical diagnosis, but a lived experience in which parameters and barriers are placed upon our lives because of that diagnosis."**
    - **This quote means:** Disability affects every part of a person. It's not just a medical issue. It also affects the way we are treated.

Jaipreet Virdi, assistant professor, University of Delaware:

- **"As a deaf person, I consider deafness a spectrum; the range of which defines an individual's identity and lived experience. Thus, deafness—and disability more broadly—is an oppression of difference rather than an impairment."**
    - **This quote means:** Being deaf can mean many things. Deafness is different for each person, which affects how we are treated.

Lawrence Carter-Long, author, artist, and disability media enthusiast:

- **"Once upon a time, disability was just a diagnosis. Thankfully through time, the notion has evolved to embrace broader concepts, like constituency, identity, and culture."**
    - **This quote means:** The word disability used to just mean a medical diagnosis. Now it also can be used to explain a community, culture, and identity.

Liz Weintraub, senior disability advocacy specialist:

- **"Disability means that there's something people can't do. I believe that there's something everyone can't do as well as they would like, except that people with disabilities have a label. But I am very proud of my disability, because that's who I am."**
    - **This quote means:** Everyone has something they can't do. But only people with disabilities get labels. My disability is part of who I am. I am proud.

As you can tell, disability means many things to different people. It changes. It is a part of being human.

How Should I Talk About Disability?

"One size fits all" is a myth. There is not one kind of clothing that will fit everyone.

There's also not one right way to talk about disability. But we need to think about the words we use.

How we *talk* shapes how we *think*. How we *think* shapes how we *talk*. That can be confusing. Whew!

How we talk about ourselves is personal. How someone talks about their own disability is *their choice.* We all need to respect that choice. Even if you have a disability too. Even if their choice is different from yours.

Keep that in mind. Now, let's talk about how to talk about disability.

First: Stop using the word *handicapped.* It’s an old word. Many disabled people don’t like it. It makes me uncomfortable. But old habits are hard to change. Sometimes I still say things like:

- “Handicapped bathroom”
- “Handicapped entrance.”

But there are better words to use:

- Talking to a person? Use “disability.”
- Pointing out a parking spot? It’s “accessible” parking.

In this book, I use two different terms:

- “Person with a disability”
- “Disabled person”

Using both terms honors two ways of talking about disability. Those ways are:

- Person-first language
- Identity-first language

Person-first language does just what it says. It puts the word “person” before the disability. Some examples are:

- A person with a disability
- A person with Down syndrome
- People who use wheelchairs.

Using person-first language shows that a disability is something a person has. It does not define who they are. It is about making sure people are not seen just for their disability. It is meant to be respectful.

Identity-first language says a person's disability is part of who they are. Some examples are:

- Disabled person
- Blind person
- Autistic people

In identity-first language, disability is not just something you have. It is part of what makes you who you are. It is about community, culture, and history.

Neither choice is wrong. But many people like one type of language more than the other. I like identity-first language because disability is absolutely part of who I am.

I didn't always know about the different types of language. I started thinking about what to call myself during a college class about special education. The teacher thought person-first language was the only right way to talk about disability. He wanted me to agree with him. I said that I did agree. But it made me uncomfortable.

People use person-first language to remind others that disability doesn't make you less than anyone else. It has been important for disability rights.

I have a hard time with person-first language. I don’t think mentioning someone’s disability means you are saying they are not a person.

Person-first language is not how we talk about other identities.

- You wouldn’t call me “a person who is Jewish,” right? You’d say I am Jewish.
- You wouldn’t say someone is “a person who is bisexual,” would you? You’d say they are a bisexual person.

It makes sense. Those are identities. They are part of what makes a person whole.

I used to talk a lot about identity-first language. I couldn’t understand why anyone would want to use person-first language. I pushed against it whenever I had the chance.

But then I realized something. I didn’t dislike people with disabilities who used person-first language. I think everyone should use the language that feels right to them.

What I didn’t like was when nondisabled people told me person-first language was right and identity-first language was wrong.

I would call myself a “disabled person” and people would tell me:

- “Oh, you shouldn’t talk about yourself that way.”
- “I don’t even think of you as disabled.”

Hearing people say that made me feel bad. It was like a whole part of who I am was being erased. I know people don’t say these things to be mean. But it doesn't feel good that they have to ignore my disability to think about me as a human.

I still like using identity-first language. But now I know that I don't like being told what to call myself. So I shouldn't tell other people what to call themselves.

There is no right or wrong personal choice about identity-first language and person-first language. But there are some important things to know:

- **Many people with intellectual and developmental disabilities use person-first language.**
  - It came from the People First Movement.
  - They use it to show that people with disabilities should be treated like everyone else.
- **Many people in the Autistic community use identity-first language.**
  - So, you say "Autistic person" instead of "person with Autism."
  - Using a capital "A" in Autistic shows that it is part of a culture and community.
  - In this book, I use the capital "A" unless I am quoting someone else.
  - Autistic activist Lydia X. Z. Brown said this in 2011:
    - "**These are not qualities or conditions that I have. They are part of who I am. Being Autistic does not subtract from my value, worth, and dignity as a person. Being Autistic does not**

diminish the other aspects of my identity. Being Autistic is not giving up on myself or limiting myself or surrendering to some debilitating monster or putting myself down. Being Autistic is like being anything else."

    - **This quote means:** Autism is not something Brown has that is separate from the rest of them. It is part of who they are. It does not make them a bad person or worth less.

- **Many people who are deaf or blind use identity-first language.**
  - Some people use "deaf" or "blind" to mean their disability.
  - Some people use it to mean their identity.
  - Some people capitalize the "D" or "B" to talk about identity.
  - Sometimes people will use both. So they would write:
    - d/Deaf
    - b/Blind
    - d/Deafblind
  - Some people who are deaf or blind don't identify as disabled.
  - Jenny Lay-Flurrie is the chief accessibility officer at Microsoft. She identifies as both deaf and disabled. She said:

        - **“Disability is a part of being human. It’s a part of me. I grew up with declining hearing and am now profoundly deaf. I’m proud to be a member of the deaf and hard of hearing community, and learn from my friends daily. It’s a label that assists but does not define me or anyone else. My name is Jenny, and I happen to be deaf.”**
            - **This quote means:** Lay-Flurrie is proud to be deaf. But deaf not the only thing she is. She is not defined by it.
    - I use the lowercase “d” and “b” in this book unless I am quoting someone else.
- **Sometimes identity-first language is not appropriate. It can be tricky to know when!**
    - For example, don’t call someone a “Down syndrome person” or a “muscular dystrophy person.”
    - Other people might tell you it’s okay to use identity-first language . For example, you can say “bipolar person” or “dyslexic person” if the person who has that disability said you can use that language to describe them.
    - Don’t worry if this seems confusing! One thing you can do is to use person-first language until someone tells you what they like to be called. If you have a chance, ask!
- **Don’t ever use someone’s assistive devices to describe them.**

  - It is rude. It makes someone seem like an object.
    - Don’t say “the cane guy.” Say “the guy who uses a cane.”
    - Don’t say “the hearing-aid lady.” Say “the lady who wears hearing aids.”
  - I have been called “the wheelchair” many times. People have said:
    - “Watch out for the wheelchair.”
    - “I have to load the wheelchair onto the bus.”
    - Once a security guard yelled “Wheelchair person! Hey! Wheelchair person!” to get my attention.
  - “Wheelchair person” is *not* identity-first language. You can say:
    - “Wheelchair user,” or
    - “Person who uses a wheelchair.”
  - A person is a person. Not a piece of equipment.
- **I do not like when people use these phrases:**
  - “Confined to a wheelchair”
  - “Wheelchair-bound”
  - I am not stuck in my wheelchair. I am not bound to it. I use it to move.

Phew! It’s okay if this feels like a lot to take in. It’s totally normal to worry that you’ll mess up what to say. If you get it wrong, just:

- Apologize
- Move on
- Try to do better in the future.

You'll learn over time!

Just Say It: "Disability"

I say what I mean. I don't like when people use euphemisms. That's when they use gentle words to talk about something they think is bad. Instead of saying "disabled" they'll say things like:

- *Physically challenged*
- *Special Needs*

You might have said these things. You might have thought it was respectful. Why?

- Were you taught that the word *disabled* is rude?
- Does the word *disability* make you uncomfortable?

I get it. We've been taught that disability is a bad thing. But you should say what you mean. A lot of disabled people think that. Not saying the word *disabled* doesn't mean my disability goes away. Neither does writing it like this:

- DisAbled
- DisAbility.

But it’s still about respecting people and the word choices. Kayla McKeon is an advocate with Down syndrome. She calls herself “differently abled.” She says:

- **“I like to say differently abled because I like focusing on what I can do rather than what I can’t do.”**

I respect McKeon’s choice even though I call myself disabled.

What I really don’t like is when nondisabled people make up their own words.

- Diff-ability?
- Other-abled?
- People of special abilities?

I’ve heard them all. I wish people would stop doing this. Call me what I am. I am disabled.

Ask people what they want to be called. It’s that easy. You can say:

- “Would it be okay to say that you’re disabled? Or is there another term you like better?”

If you can’t ask the person, just say “disabled!” It’s not a bad word, I promise!

These are examples of euphemisms. People are usually trying to be nice when they say them. But they don’t work well. They don’t mean what people think they mean.

Differently abled

No one is exactly the same. Some people can:

- Sing
- Solve puzzles
- Cook
- Do gymnastics

Everyone is differently abled. Not just disabled people.

Handi-capable

Does anyone seriously use this? Please don't.

Mentally or physically challenged

It's true that some things are hard to do for people with disabilities. But the reason things are hard is not always because of disabilities. Things can also be hard because of:

- The way people treat us,
- Places that aren't built for us,
- Laws that don't protect us.

These challenges aren't about our bodies or minds.

Special Needs

Why are the needs of people with disabilities “special?” Everyone has needs. No one has their needs met in exactly the same way.

Twice exceptional

People sometimes say this about students with disabilities. It describes someone who is really good at some things and needs help with other things. But it doesn’t make sense. Everyone is good at some things and not at others. That’s not *exceptional.* That’s *human.*

Normal Doesn’t Exist

I have a question for you. What does “normal” mean? Can you think of anyone you know who you would call normal?

If you said “yes,” think again. We all have different ways of:

- Thinking
- Communicating
- Moving.

That means we all need help to get things done.

But many of us get stuck on labels. We have an idea of “normal.” We stick labels on anyone who doesn’t fit that idea. That’s how we got *functioning labels.*

Disabled people sometimes get called *high functioning* or *low functioning.* This happens a lot at school or with doctors.

I’ve been called high functioning. That’s because I can write and speak. This label is not a compliment. It makes it seem like I’m better than people who don’t write or speak.

Noor Pervez is an Autistic advocate. He told me why functioning labels are wrong and hurt people. Pervez said:

“‘Low functioning’ is used to deny agency to disabled people who have high support needs, while ‘high functioning’ is used to deny resources to people who can mask their disability well. Any person’s support needs can shift from year to year, or even day to day, making ‘functioning’ a flawed concept.”

- **This quote means:** People labeled “low functioning” don’t get to make choices for themselves.
- People labeled “high functioning” don’t get the support they need.
- What people can do changes over time. No one’s functioning stays the same.

I think we should stop using functioning labels. They are based on the idea that all people should do the same things or act the same way. They split people into categories. They judge people by what they can and can’t do. I don’t think we should do that.

It is better to talk about needs, abilities, and disabilities. For example:

Instead of saying a student is “low-functioning,” say what help they need.

You don’t need to put a hurtful label on that student. Use clear language. It is simple and respectful.

Think Before You Speak

Most of us have said things like:

- “That’s insane!” when we were excited,
- “Ugh, moron,” when someone made us mad, or
- “This is lame” when we were disappointed.

These words are ableist. They make disability seem like a bad thing.

Words have histories. Some words may have been okay in the past but are not okay now. Some words were always hurtful. Some hurtful words about disability are:

- Crazy
- Dumb
- Idiot
- Imbecile
- Insane
- Lame

- Moron
- Slow
- Stupid

It can be hard to stop using these words. I say these words sometimes. I can't take them back after I say them. But I can try to stop saying them in the future. We all can. We can practice using other words instead.

We also use disability words to talk about feelings or situations. You've probably heard these before.

Imagine two people are talking about their friend. Their friend is trying to ask someone on a date. One person says:

- "He's obviously *paralyzed* by fear of rejection."
- "No way! He's totally using that excuse as a *crutch* not to ask for her number."
- "Well, she's clearly *blind* to his crush on her."
- "Seems like his attempts to get her attention fell on *deaf ears."*

In this conversation, they don't mean their friend is deaf, blind, or paralyzed. They are using disability as a *metaphor.* This means they are using words that describe disabilities, but they are really talking about something else. They could have the same conversation without those words:

- "He's obviously *frozen* by fear of rejection."

- “No way! He’s totally *leaning on that* as an excuse not to ask for her number.”
- “Well, she’s clearly *oblivious* to his crush on her.”
- “Seems like she *isn’t noticing* his attempts to get her attention.”

See? All it takes are little changes to make sure you are not using hurtful language.

Find a Better Insult

Disability is not an insult. *Do not* use disability as an insult. I hear people say things like:

- She’s so bipolar.
- They’re acting Autistic.
- Quit being so OCD. (OCD means obsessive-compulsive disorder.)

They use diagnoses as insults. It’s not okay. It hurts people. If you are going to insult someone, use a different word. But it’s better if we’re kind to each other instead of using any insulting words.

Drop These Words

Some words aren’t just insults: they’re slurs. A slur is a very offensive word. Here are some examples:

- “Retarded” (the R-word)

    - This word is very hurtful to people with intellectual disabilities. Many people use this word anyway.
    - Once I was on a date and the guy said, “I’m so retardedly attracted to you.” I was offended when he said that. I didn’t go out with him again. It was a reminder that some people don’t know how much pain slurs cause.
- “Midget” (the M-word)
    - This is a slur against people with dwarfism. Many people use this word. Some towns even use “midgets” as a mascot. Don’t be like these towns.
    - Instead, say:
        - “Little person”
        - “Person with dwarfism”
        - “Short-statured”
    - Rebecca Cokley is the program officer for the US Disability Rights portfolio at the Ford Foundation and a member of the Little People of America. She told me the M-word came from the term *midge.* That’s a word for a small fly. She said,
        - **“It was co-opted and commodified by the carnival, sideshow, and circus industry to describe people with various types of dwarfism. It was a word used to sell us as a product to a**

    curious public. It is not a word we, as a community, ever chose for ourselves.”

    - **This quote means:** It is a word that was used by people without disabilities in circuses and carnivals. They would make money by putting people with dwarfism on display. Little people do not use the m-word.

- Slurs against people with mental illness include:
  - “Mad”
  - “Crazy”
- Slurs against physically disabled people include:
  - “Cripple”
  - “Gimp”
  - “Spaz”

Sometimes people “reclaim” slurs. That means they decide to use words that other people have used to hurt them or people like them in the past. Some people say this helps them “take back power” so now they are in control of how that word gets used.

I do this. My mom and I joke about being “cripples.” We use that word with each other. People close to us might use it too.

But it is not okay for nondisabled people to use “crippled” to mean “disabled.”

You might know a disabled person who calls themselves “crippled.” You can only use that word if they say it’s okay. And you can only use it with them, not with all disabled people.

It’s never okay to force disabled people to use words they don’t want to use. If you’re not sure if a word is offensive, pick a different word.

What to Say

Always ask a person what words are right for them. But you can use this table as a guide.

- **When you see this symbol ° it means these disabilities often get put in a group together. But they are not all the same.**
- **When you see this symbol * it means someone might want to call themselves these words. You can use them if they tell you it’s okay. Only use them with that person.**

Say This	**Not This**
• disability/disabled • person with a disability/disabled person	• differently abled (unless preferred) • handi-capable • handicap/handicapped • special needs (unless preferred)

● has a disability ● is disabled	● afflicted by ● suffers from ● victim of
● person who is able to	● high functioning
● person who is unable to ● person with high support needs	● low functioning
● neurodivergent° ● person with Autism/Autistic person° ● person with a cognitive disability/cognitively disabled person° ● person with an intellectual disability/intellectually disabled person° ● person with a learning disability/learning disabled person°	● mentally challenged ● mentally handicapped ● mentally retarded ● slow ● special-ed

● able-bodied (if not physically disabled) ● does not have a disability ● neurotypical (if not neurodivergent) ● nondisabled	● normal ● regular
● person who uses a wheelchair ● wheelchair user	● wheelchair-bound ● confined to a wheelchair
● little person ● person of short stature ● person with dwarfism/dwarf	● midget
● person with a mental health disability ● person with mental illness/mentally ill person ● person with a psychiatric disability/psychiatrically disabled person	● crazy* ● disturbed* ● insane* ● lunatic* ● mad* ● psychotic*

• person with a physical disability/physically disabled person	• cripple* • gimp* • invalid* • spaz*
• accessible parking/restroom	• disabled restroom • handicapped parking

Chapter 2: Understanding Disability as Part of the Whole Person

Read the Chapter 2 Summary

Disability must be considered within an intersectional framework because it cuts across political, social, and cultural narratives and identities. An intersectional lens challenges the historically white, cisgender, heterosexual understanding of disability to more accurately reflect the narratives as told by lived experiences of disabled people.

-Sandy Ho, Community Organizer

- **This quote means:** People are many things all at once. Disability touches all the different parts of who we are. Those parts might be our race, gender, or sexuality. We have not done a good job thinking about disability and these other things together. We need to change that.

I have a lot of different feelings about disability:

- On one hand, disability is part of who I am:
    - My disability is important to how I think and move.
    - My disability defines me. (But I don't want it to be the only thing that defines me. Confusing, I know.)
    - I am proud to be disabled.
    - Having a disability makes me part of a culture and community.
- On the other hand, being disabled can be hard:

    - I have pain every day.
    - It is hard that some people do not accept me.
    - I don’t accept myself sometimes.

But I’m disabled. It’s part of me.

Anyone can become disabled at any time. That’s not a bad thing. Disabled people are pretty cool, in my opinion. Disability is personal. It means something different to everyone:

- Some people think disability is an identity.
- Some people think disability is part of who they are, but they do not call it part of their identity.
- Some people have disabilities but don’t want to call it part of their identity.

Each person gets to choose for themselves.

Imagine you are a pizza. All pizzas have crusts. That’s what they have in common.

But there are many different toppings for pizzas. And no two slices of pizza are the same, even if they have the same toppings.

That’s how people are too. We all have something in common. We’re human. But we have things that make us unique too.

What disability means to someone depends on who they are. Some things that matter are:

- If a person has a disability or not.
- The type of disability a person hase.
- Whether a person was born with a disability or got it later in life.
- Whether other people can tell a person has a disability. This is called having a “visible” disability. More on this later!
- Where a person is. Are they:
    - At home?
    - In a safe space?
    - With new people?
- How other people around a person think about disability.
- How a person’s culture thinks about disability.
- A person’s other identities.

What is Intersectionality?

Intersectionality was first used by Dr. Kimberlé Crenshaw in 1989. She used the word to talk about what it was like to be Black and be a woman. She said that Black women are:

- Sometimes treated unfairly for being Black,
- Sometimes treated unfairly for being a woman, and
- Sometimes treated unfairly for being *both* Black and a woman.

Those two parts of who they are *intersect.* You can't think about one without thinking about the other.

Many social justice activists think about the importance of intersectionality. We use it to talk about the different parts of who we are. That might be our:

- Race
- Gender
- Disability
- Age
- Class (This has to do with how much money you have.)
- Sexuality (This has to do with who you choose to have or not have romantic and sexual relationships with.)
- Ethnicity (This has to do with your culture.)
- And more

These things are sometimes called *identities.*

Disability intersects with all other identities. That means that anyone can be disabled. We need to listen most to people who are *marginalized*. That's someone who is treated unfairly because of who they are. Some people are treated unfairly for more than one identity.

How your identities overlap with disability changes how people treat you. For example, I am:

- Disabled
- Straight (this means having romantic or sexual feelings for people who are not the same gender as you)
- White
- Jewish
- Cisgender (this means I identify with the gender doctors thought I was when I was born)
- A woman

My life is different from a disabled person who is:

- Black, or
- Transgender (This means a person identifies with a gender different from the one doctors thought they were when they were born), or
- Muslim, or
- Indigenous (This means your family has always lived in the place where you live. Often their homes or land were taken by other people whose families were not from that place. Sometimes it is also called being "native.")

I don’t have those identities. The identities that I do have mean that I am what many people think about when they think of disability. I look like what people assume disabled people look like.

This means I have *privilege.* Privilege is having an advantage over someone with a different marginalized identity. For example:

- Nondisabled people have privileges that disabled people do not.
    - Disabled people have a harder time finding a job.
    - Only 1 in 5 disabled people had a job in 2019. More than 3 in 5 nondisabled people did. This is privilege.
- Disabled people can have privilege too.
    - I am white. I have privileges that people of color do not.
    - I can speak. I have more privilege than people who do not speak.
    - We are complex. We can’t talk about disability if we don’t talk about all our identities together.

Crystal R. Emery is a filmmaker and writer. She wrote an article for *Time* in 2016. She said,

“As an African American female with a disability, a wheelchair-riding quadriplegic, I exist as a triple threat to our society’s normative conceptions (white, male, able-bodied). …My gender, race, and disability all contribute to the ways in which I obtain and maintain power—not through my intersectional identity but through my search to become human in ways not easily codified. In spite of my reimagined relationship with these identity markers, the world has a lot to catch up on.”

- **This quote means:** Emery is an African American female who uses a wheelchair. She says that these identities challenge how people with privilege think about her as a person. She wants other people to catch up with how she thinks about identity.

So how do we catch up? How do we stop thinking all the wrong ideas we have about disability? About disabled people who are marginalized in other ways? How do we make a more inclusive, accepting world?

We have to think about our privileges. We have to think about the wrong ideas we have about others. We all need to do this.

D'Arcee Neal is a student getting a doctoral degree. He reminded me that disabled people can treat people unfairly too. He said, **"being part of one marginalized community doesn't absolve you from understanding discrimination toward marginalized people whose experiences are different than your own."**

- **This quote means:** People who are treated unfairly because of who they are can still exclude other people because of who they are. Even if you are a person who is treated unfairly, it is still important for you to treat other people fairly.

Neal said he can only speak based on his experience. He is:

- Black
- Queer (someone who is not straight)

- Physically disabled
- A man

He told me **“People need to recognize that being Black means you’re perceived as being criminal, whether you have a disability or not.”**

- **This quote means:** People see that he is Black and judge him in a bad way. They think that because he is Black, he must be a criminal.

“When I tell people I have cerebral palsy, they’re surprised because that’s not the first association they made with why I’m a wheelchair user. When I was younger, the very first question most white people would ask upon meeting me was ‘When were you shot?’ They immediately jumped to the conclusion that I had a spinal cord injury as a result of gang or gun violence.”

- **This quote means:** Neal has cerebral palsy and uses a wheelchair. White people assume he uses a wheelchair because he was shot. They think this happened because he is Black. They assume Black people are in gangs or around guns.

People assume Neal’s life is hard because of how he looks. Someone once told him, **“I would kill myself if I were you.”**

(Don’t ever say this to a disabled person. Ever.)

Neal said, **“He told me that my life is too difficult.”**

Neal never spoke to the person who said this to him again. That person judged Neal. He assumed things about his life because of Neal's identities.

Neal does have hard things in his life. But it's not because of who he is. It's because of how people treat him.

Neal shows us that not all people with disabilities have the same lives. We need to remember that as we think more about disability.

Types of Disabilities

There are many kinds of disabilities. Some disabilities fit in more than one category. Some people have more than one disability. Two people with the same disability can have different experiences.

Here is a list of common types of disabilities:

- **Chronic Illnesses** affect your health throughout your life. There are many different kinds.
- **Communication Disorders** can affect the way you:
    - Talk,
    - Read,
    - Listen, or
    - Write.
- **Developmental Disabilities** affect how your mind and body grow and change as you get older.

- **Hearing Disabilities** affect how you hear.
- **Intellectual Disabilities** can affect how you:
    - Think,
    - Talk,
    - Interact with other people,
    - Take care of yourself.
- **Learning Disabilities** affect how you learn.
- **Mental Health Disabilities** can affect how you:
    - Think,
    - Feel, or
    - Act.
- **Neurological Disorders** can affect your nervous system. Your nervous system is how your brain tells your body what to do. It affects how you:
    - Move,
    - Think, or
    - Feel.
- **Physical Disabilities** can affect:
    - How you move,

    - How you complete tasks, or
    - How long you can do things.
- **Vision Disabilities** affect how you see.

You can learn more about different types of disabilities by looking at the information in the **Further Reading and Resources** section of the book**.**

Apparent and Nonapparent Disabilities

You may think all disabled people look a certain way. Movies and TV often show disabled people who all look the same. (We will talk more about that in Chapter 6.) But disabled people do not all look the same.

Some disabilities do look a certain way. But you can't assume if a person has a disability from how they look. You can't see some disabilities at all.

Apparent or Visible Disability

- This is a disability that other people can notice. It may mean someone who looks or communicates differently than you. Some examples of apparent disabilities are:
    - A person who walks unevenly,
    - A person who uses a wheelchair,
    - A person who uses a white cane,
    - A person with a limb difference wearing a prosthetic (an object a person can wear when they don't have a certain body part. For

    example, a person without an arm might wear a prosthetic arm so they can grab things.),

  - A person with a stutter.

Nonapparent or Invisible Disability

- This is a disability other people may not notice. You may not know a person has a nonapparent disability unless the person decides to tell you. Some examples of nonapparent disabilities are:
  - A person with a learning disability,
  - A person with a mental illness,
  - A person with chronic pain. That means the pain does not go away.
- Some people with invisible disabilities decide to “pass” as nondisabled. That means they let others assume they don’t have a disability.
- The same disability can be visible or invisible. My mom and I have hearing loss. If it’s quiet when you talk to us, you might not notice. If we’re somewhere loud, you might be able to tell we have hearing loss when you talk to us and we have trouble hearing what you are saying.

No disability is more “real” than any other type. My disability is visible. That doesn’t mean my disability matters more. No disability makes anyone less of a person either. Having a disability that impacts you more than someone else doesn’t make you worth less than anyone else.

Temporary Disabilities

- This is a disability that will go away over time. An example is a broken bone.

Acquired Disability

- This is a disability that you get after you are born. Examples of acquired disabilities are:
    - Losing your hearing,
    - Becoming paralyzed,
    - Getting a brain injury.
- A lot of people will get disabilities as they get older. Some people with disabilities call nondisabled people **temporarily able-bodied.** That is because we will all probably have a disability at some point in our lives.

Nondisabled people can be scared of getting a disability. I understand that. They are scared because they don’t know what it’s like to have a disability. But those fears can make them treat disabled people badly. That’s why we need to talk about disability more. It helps people understand disability and be less afraid of it.

Choose Your Model

Models are ways of thinking about disability. They have to do with who we are and the world around us. They help explain what disability means. Let’s start by talking about the two most common models of disability: the medical model and the social model.

The Medical Model

- The medical model of disability is also called the “individual model.” It says disability is a problem that a person has.
- The medical model defines disability as a diagnosis or an *impairment*. An impairment has to do with how your mind or body work. Impairments make it hard or impossible to do something.

Part of the medical model of disability makes sense. For example, I have a disability called Larsen syndrome. Having this disability affects who I am and how I move around the world. It affects my muscles and joints. It means I can’t do certain things. It causes my body to be in pain.

- But there are some problems with trying to understand disability through the medical model:
    - It makes people think disability is always bad.
    - It says disability should be cured or fixed.
    - It ignores the ways disabled people get treated in society.

The Social Model

- The social model of disability is a response to the medical model.
- It says disability is not a medical condition. It is caused by the way people with disabilities are treated in society.
- An example of the social model of disability:

  - If you use a wheelchair and go somewhere that is not wheelchair accessible, you are disabled because you can't get in. The problem is not that you use a wheelchair. The problem is that the place you want to go is not built for you.

Both models of disability can be right. I use them to think myself and my disability:

- I think about the **medical model** when I:
  - Drop something and can't reach to pick it up.
  - Wake up with chronic pain and think, "I feel *soooo* disabled right now."
  - These are times when disability is about my body and how it works.
- I think about the **social model** when I:
  - Try to go to a restaurant that only has stairs.
  - Hear someone make a rude comment about my wheelchair.
  - These are times when disability is about other people's attitudes toward it.

Other Models of Disability

There are lots of other ways to think about disability. Here are a few:

Charity Model

- Defines disability as a tragedy.

- Says disabled people need nondisabled people to pity them and do good deeds for them.
- Treats disabled people as “inspiration” for nondisabled people.

Cultural Model

- Defines disability as a culture.
- Focuses on how disabled people form a community.
- Talks about disability history and how it affects peoples’ lives.

Economic Model

- Defines disability as not being able to make money or be productive.
- Says people who can’t work are burdens on society.

Human Rights Model

- Defines disability as a human rights issue.
- Talks about how disabled people have been treated in society.
- Focuses on writing laws about inclusion and equality. Equality means giving everyone the same chance to live a good life.

Religious Model

- Sometimes defines disability as a punishment or a curse from God.
- Sometimes defines disability as a blessing for people who can handle the challenges that come with it.

- People have tried to pray to “heal” me or told me to pray. That is not cool.

Models of disability can help us understand disability. Some of these models say things about disability that are wrong or hurtful. Some say more positive things. But no model of disability is completely right. Disability means many things. We need to think about it in more than one way.

Chapter 3: An (Incomplete) Overview of Disability History

Read the Chapter 3 Summary

“As ‘invisibles,’ our history is hidden from us, our heroes buried in the pages, unnamed, unrecognized. Disability culture is about naming, about recognizing.”

-Cheryl Marie Wade, “Disability Culture Rap”

- **This quote means:** People with disabilities are left out of most of the history we learn about. We can celebrate and honor disability by sharing our history.

Think about all the history classes you’ve taken. I bet they did not talk about disability. We didn’t talk about disability history when I went to school.

Some famous people from history had disabilities.

- Did you know Harriet Tubman was disabled?
  - She was a leader of the Underground Railroad. She helped slaves to freedom. A slave owner hit her in the head with a weight. That caused her to have epilepsy.
- Did you know Frida Kahlo had physical disabilities?
  - She was an artist. She had polio and was in a bus accident.
- Did you know President Franklin Delano Roosevelt (FDR) was paralyzed?

  - He got polio when he was 39. He used a wheelchair to get around.

Have you heard of people named:

- Justin Dart Jr. and Yoshiko Dart?
- Bradley Lomax?
- Anita Cameron?
- Lois Curtis?

These people are important to disability history. You'll learn about them in this chapter.

Only a few states have laws that say schools have to teach disability history. The first state to do this was Virginia. Young disabled advocates helped pass this law.

Disability history touches all people and places. It shouldn't be a special subject.

The disability community has a long history. For example:

- An early record of disability was in ancient Sparta. Ancient means it happened a very long time ago. Disabled babies were left to die. Spartans were fighters. They thought disabled babies were worthless since they couldn't fight in wars.
- Disabled veterans first got support in the 1600s. The Pilgrims in Plymouth said soldiers who got hurt would get help from the government.

- PT Barnum started something called “freak shows” in the 1800s. He put people with physical differences on display and the public paid money to stare at them.

I can’t write about all of disability history in this chapter. I will focus on things that:

- Happened in the United States,
- Started after 1900,
- Have to do with disability rights.

These are events that matter to me as a disabled person. I hope you’ll want to learn more.

The Early 1900s

The early 1900s were not a good time for disabled people. A lot of people thought disabled people should not exist.

There were new laws written about this. Indiana passed a law in 1907 that said disabled people should be sterilized. This means they were forced to have surgery that stopped them from having babies. More than half of the states in the US made laws about sterilizing disabled people.

This is called eugenics. Eugenics means thinking the world would be better if only certain types of people lived in it. This belief is based on people thinking that some types of people are good and some are bad. For example, people who believe in eugenics think people with disabilities should not have children, because they believe that having a disability is bad.

The people who believed in eugenics were:

- Nondisabled
- White
- Straight (this means having romantic or sexual feelings for people who are not the same gender as you)
- Cisgender (this means identifying with the gender you were given when you were born)

They thought society would be better if only people who were like them had babies.

Carrie Buck was a teenager in Virginia in 1927. She lived in an institution. An institution is a big building where many people live together away from their families. Nursing homes are examples of institutions. She was put there because she had a baby when she wasn't married. Her mother also had a baby before she was married.

Doctors decided Buck shouldn't have more babies. They wanted to sterilize her. Buck did not want to be sterilized.

Buck went to the U.S. Supreme Court to fight being sterilized. The Supreme Court judges decided that some people could be sterilized even if they don't want it. They said this did not break the law. Oliver Wendell Holmes Jr. was a judge on the court. He wrote that, **"Three generations of imbeciles are enough."**

He meant that it was a good thing to sterilize Buck. He didn't want more children with disabilities in the US. This is eugenics.

The 1930s

Franklin Delano Roosevelt (FDR) became president in 1932. He is the only president who had a visible physical disability.

He usually hid his disability in public. He worried people wouldn't want a leader with a disability.

Many people know about FDR's disability now. There is a statue of FDR using a wheelchair in Washington, DC.

FDR was president during the Great Depression. Not many disabled people had success like FDR. It was hard to get a job at this time. Many people couldn't pay for what they needed to live. Almost no disabled people had jobs.

The government made programs to help people find work. Disabled people were not treated fairly by these programs. Some disabled people decided to protest the unfair treatment. That means they fought back. They formed the League of the Physically Handicapped. This is one of the oldest disability rights groups.

Several laws that impact people with disabilities were passed in the 1930s:

- Social Security Act of 1935

    - Provides money to support children with disabilities.
    - Funds vocational rehabilitation (VR). VR helps people with disabilities find and keep jobs.
- Fair Labor Standards Act of 1938
    - Says employers with special permission can pay disabled workers less than other workers. Usually, it is people with intellectual or developmental disabilities who do these kinds of jobs. They often make a few cents per hour.
    - The rule to pay disabled workers less was supposed to help create more jobs. But now it means people with disabilities earn less money.

The 1940s

World War Two started in the 1940s. The war created many new jobs for American people. This meant more people had money to live. But disabled people were still not treated fairly.

Many soldiers were hurt during the war. There were more disabled veterans coming home. The U.S. passed a law called the Disabled Veterans Rehabilitation Act in 1943. It helped disabled veterans find jobs.

The first “National Employ the Physically Handicapped Week” was in 1945. President Harry S. Truman said employers need **“to exercise every appropriate effort to enlist public support of a sustained program for the**

employment and development of the abilities and capacities of those who are physically handicapped."

- **This quote means:** Businesses need to train and hire people with physical disabilities.

The name of this week became "National Disability Employment Awareness Month." It now happens every October. It celebrates the talents people with disabilities bring to their jobs.

Other disability groups started during the 1940s.

- The National Federation of the Blind
  - The first and largest national advocacy group for blind people.
- Paralyzed Veterans of America (PVA)
  - Formed by World War Two veterans with spinal cord injuries. This organization works for rights for disabled veterans.

The war affected the mental health of many veterans. The U.S. passed the National Mental Health Act of 1946 to try to make mental health care better.

The 1950s

President Dwight D. Eisenhower updated laws in the 1950s. These changes meant new support for people with disabilities.

- He gave more money to vocational rehabilitation.

- He changed Social Security to:
    - Protect people from losing their benefits if they couldn’t go to work.
    - Create Social Security Disability Insurance (SSDI). SSDI gives cash to people with disabilities who can’t work for a year or more.

Some conservative politicians don’t like SSDI. They think people who get cash from the government won’t want to work. This is an ableist way to think. Progressives say SSDI is important. People use it to pay for what they need to live.

The 1960s

President John F. Kennedy made laws to protect the rights of people with intellectual and developmental disabilities in the 1960s.

He signed the Mental Retardation and Community Mental Health Centers Construction Act. It is also called the Community Mental Health Act (CMHA). This law creates places for people to get care in their community.

President Kennedy’s sister founded the Special Olympics in 1968. The Special Olympics is a sports organization for athletes with intellectual and developmental disabilities.

Loretta Claiborne is a Special Olympics athlete. She has an intellectual disability. She told me the Special Olympics changed her life. She used to be bullied and got into fights. Now she shows people what she can do. She is helping change attitudes about disabilities.

The Architectural Barriers Act was passed in 1968. It was the first law that said some buildings need to be accessible.

1970s

Many important disability rights events happened in the 1970s.

1970

Disability activist Judith Heumann sued the New York City Board of Education. She was 22 years old and trying to be a teacher. She was not allowed to teach because she used a wheelchair. Heumann fought against this. And she won.

1972

A reporter named Geraldo Rivera did a news story on Willowbrook State School in New York. Willowbrook was an institution for disabled people. Willowbrook treated the people who lived there horribly. The building was not clean. People did not have food or clothes. Most people watching did not know about Willowbrook. The story about Willowbrook became a scandal. But Willowbrook stayed open until 1987. Many disabled people still live in institutions.

1973

The Rehabilitation Act was passed. It did many things, such as:

- Create the U.S. Access Board to make rules on building accessible places.

- Make it illegal for the federal government to treat people with disabilities unfairly.

1974

The last “Ugly Law” was ended. Ugly Laws is the name for laws that were created to stop people from begging for money in the streets. They said people who were begging did not look like they should be allowed to be in public. This law affected a lot of people with **visible disabilities.**

1975

The Education for All Handicapped Children Act was passed. It said all disabled kids have the right to go to school. This law is now called the Individuals with Disabilities Education Act. It is a good law, but more work needs to be done to make the law better.

1977

Even with all this progress, there were still problems. The Rehabilitation Act had passed in 1973. Section 504 of this law said people with disabilities could not be discriminated against. *Discriminate* means to treat unfairly. But there were still no rules about how to use this law in 1977. It was up to a government office called the Department of Health, Education, and Welfare (HEW) to create these rules.

Disability activists were tired of waiting for the rules to be made. They started protests on April 5, 1977. Disabled people began sit-ins at HEW offices around the country. This means they protested by refusing to leave the offices until the government listened to them. The longest protest was in San Francisco. It lasted almost 30 days. That is the longest sit-in in U.S. history. It is called the 504 Sit-In.

The 504 Sit-In brought many people together. One group that helped during the protest was the Black Panthers. The Black Panthers connected with the disability activists doing the sit-in through a man named Bradley Lomax. He was a disabled Black Panther and disability activist. The Black Panthers did many things, including bring food to the 504 Sit-In.

Some of the activists went to Washington, DC to continue their fight. Finally, the rules for Section 504 were signed on April 28.

Judith Heumann wrote, **"The public was stunned. People weren't used to thinking of us as fighters—when they thought about us as all...We were a people who were generally invisible in the daily life of society."**

- **This quote means:** People were surprised to see disabled people being activists. People with disabilities are usually ignored or left out, so society does not think they can advocate for themselves.

1978

Wade Blank helped 19 young disabled people escape from their nursing home in Denver, Colorado. They found ways to live in their community instead. This group was known as the "Gang of 19." They held a protest in 1978. They wanted buses that wheelchair users could ride. They inspired a future for disability activism.

The 1980s

The Gang of 19 became a group called American Disabled for Attendant Programs Today (ADAPT) in 1983. Anita Cameron is a member of ADAPT. She has been arrested more than 130 times while protesting for disability rights. She said, **"If you're messing with our civil rights, you're going to hear from ADAPT."**

The Paralympic Games came to the US in 1984. The Paralympics are a sports event for disabled athletes from all over the world.

Two important laws passed in the 1980s:

- Voting Accessibility for the Elderly and Handicapped Act of 1984
    - This law says polling places have to be accessible. Disabled people have the right to vote.
- Air Carrier Access Act of 1986
    - This law says airlines can't treat disabled people unfairly.

These laws are not always followed. For example:

- Many disabled people have trouble voting. For example, someone might:
    - Not be able to get to the polling place.
    - Learn that no one knows how to use the accessible voting machine for people with vision impairments.

- I have had problems flying on planes. I am scared my wheelchair will be broken. It gets treated like a suitcase and placed in cargo.

There were more fights for rights in the 1980s. One took place at Gallaudet University. Gallaudet is a school for d/Deaf and hard of hearing students. A hearing person became president of the university in 1988. The students had a protest called Deaf President Now (DPN). They did not want a hearing person leading a university for people with hearing disabilities. Greg Hilbok was one of the leaders of the protest. He told me: **"It started as a campus issue where deaf individuals made their assertion known that a deaf person is fully capable of being a college president. It led to an explosion of awareness on accessibility and our language, American Sign Language, and created ripple effects that are part of a worldwide civil rights movement."**

- **This quote means:** DPN wasn't just a protest about having a deaf person as college president. It got people to think more about accessibility and American Sign Language. It had an impact on disability rights around the world.

The 1990s

The Americans with Disabilities Act (ADA) was ready to be signed in 1990. Many people had helped make this happen, including:

- Senator Tom Harkin
- Congressman Major Owens

- Disabled activist Justin Dart, Jr.
- Justin's wife, Yoshiko

Justin Dart, Jr. is known as the Father of the ADA. He and Yoshiko spoke to disabled people around the U.S. They learned about what issues mattered most. They used those conversations to help create the ADA.

The ADA had a problem passing through the House of Representatives. Protesters came to DC in March 1990. A group of disabled people climbed the US Capitol Steps without their mobility aids. They wanted to make a point about the barriers they faced. This event is called the "Capitol Crawl."

ADAPT activist Anita Cameron was there. She gave an interview to *New Mobility* magazine about it. She said, **"I felt that we were crawling our way into the history books."**

Jennifer Keelan-Chaffins was there too. She was 8 years old at the time. She was one of the first protestors to climb the steps. She yelled, **"I'll take all night if I have to."**

I have watched a video of Keelan-Chaffins climbing the steps many times. It makes me feel proud.

Keelan-Chaffins founded JKCLegacy.com and wrote a children's book. It's called *All the Way to the Top: How One Girl's Fight for Americans with Disabilities Changed Everything.* She told me, **"As a young child who got to be involved so closely in this movement, I realized I had a great responsibility not just**

to represent myself but also to represent my generation, and future generations of people with disabilities."

- **This quote means:** Jennifer felt like she was representing people who were young when the ADA was passed. This was very important to her.

The ADA passed a few months later. President George H.W. Bush signed it into law on July 26, 1990. Justin Dart, Jr. was with him. President Bush said, **"Let the shameful wall of exclusion finally come tumbling down."**

- **This quote means:** People with disabilities must no longer be left out or treated unfairly.

I was born 1 year and 3 days after the ADA was signed. I feel lucky that I was born after all this disability activism. But there is still work to do to make the world better for people with disabilities.

In 1999, the Supreme Court heard a case about disabled people living in institutions. It is called the Olmstead decision. It was a case about two women:

- A Black disabled woman named Lois Curtis
- A white disabled woman named Elaine Wilson

Elaine and Lois lived in institutions. The Supreme Court said disabled people have the right to live in the community instead of institutions.

One of the Supreme Court judges, Ruth Bader Ginsburg, wrote that forcing disabled people to live in institutions **"perpetuates unwarranted**

assumptions that persons so isolated are incapable or unworthy of participating in community life."

- **This quote means:** Forcing people to live in institutions is wrong. It makes others think they can't or shouldn't live in their community.

The 2000s

A lot has happened between 2000 and 2020. Here are some important events:

2002

Vermont is the first state to close sheltered workshops. Sheltered workshops are places where only disabled people work. Often they make less money than nondisabled people.

2006

Ari Ne'eman and Scott Michael Robertson found the Autistic Self Advocacy Network. It is an organization run by and for Autistic people.

2010

President Barack Obama signs the Twenty-First Century Communications and Video Accessibility Act into law. This law means more technology is accessible for people with disabilities.

2011

The United Nations declares March 21 World Down Syndrome Day.

2012

Tammy Duckworth is elected to the U.S. Senate. She is the first woman with a visible disability to become a senator.

The U.S. does not sign the Convention on the Rights of Persons with Disabilities. It has been signed by 126 other countries.

2013

Jenny Hatch wins a court case against her parents. Jenny has Down syndrome. She wanted to live in the community. Her parents wanted her to live in a group home.

2014

The Achieving a Better Life Experience (ABLE) Act passes. This law lets disabled people save money. Before ABLE, people with disabilities could lose their benefits if they had too much money.

2015

Leah Katz-Hernandez becomes the first deaf receptionist in the White House.

2017

The ADA Education and Reform Act is proposed. It would make it harder to protect people under the ADA. It has not been made into law.

Disabled activists protest in Congress. They stop the Senate from taking money away from Medicaid.

2019

Ali Stroker wins a Tony Award for her role in the Broadway show *Oklahoma!* She is the first wheelchair user to win this award.

2020

The COVID-19 pandemic begins. Doctors and politicians talk about not giving disabled people healthcare to treat COVID-19. Disabled people fight for our lives.

Many Movements

There isn't one big "disability community." We don't always have the same goals. There are many groups. It is called "cross-disability" work when these groups work together.

I can't write about every group of disabled people. But it is important to know that we are not all the same. We have different experiences and different fights for our rights. Below are some of the biggest movements led by people with disabilities.

Independent Living Movement

This movement was started by Ed Roberts. Roberts was the first wheelchair user to go to University of California, Berkeley. Roberts and other disabled students worked together as a group. They called themselves "the Rolling Quads." They formed the Physically Disabled Students' Program. They supported disabled students and pushed for accessibility.

This group became the Berkeley Center for Independent Living in 1972.

Centers for Independent Living (CILs) are organizations that advocate for disabled people to have the support they need to live in their community instead of institutions or nursing homes. There are now many CILs in the U.S. and around the world.

Roberts was interviewed on a television news show called *60 Minutes* in 1989. He said, **"What's a life living in an institution or nursing home? Not much of a life. Yet we spend billions and billions of dollars on these. What we have to do is break that money loose from very strong special interests and move it into the community and deal with quality-of-life issues. We do not want to be segregated."**

- **This quote means:** It costs a lot of money to run nursing homes and institutions. But people do not have good lives there. The money spent on nursing homes and institutions should instead be used to support disabled people to live in the community. That is where disabled people want to live.

That is what the Independent Living (IL) movement is all about. Disabled people should be able to live in their community.

The IL movement is important to me. It's how I became an advocate. I interned at my local CIL. I sat on the board of the National Council on Independent Living.

But the IL movement is not perfect. It has mostly been led by white people. It focuses mostly on physical disability. It needs to change to welcome everyone.

Disability Justice Movement

The people with the most privilege have been at the center of disability rights. That means some people have been left out. That includes people who are disabled and have other marginalized identities. That might have to do with their:

- Race,
- Sexuality,
- Gender,
- Or some other part of who they are.

Activists created disability justice to include people who are left out of disability advocacy work.

Disability rights and Disability Justice are not the same thing.

The group Sins Invalid wrote a book called *Skin, Tooth, and Bone: The Basis of Movement is Our People* to explain Disability Justice. It says:

"While a concrete and radical move forward toward justice for disabled people, the Disability Rights Movement simultaneously invisibilized the lives of disabled people of color, immigrants with disabilities, disabled people who practice marginalized religions (in particular those

experiencing the violence of anti-Islamic beliefs and actions), queers with disabilities, trans and gender non-conforming people with disabilities, people with disabilities who are houseless, people with disabilities who are incarcerated, people with disabilities who have had their ancestral lands stolen, among others."

- **This quote means:** The disability rights movement has left some disabled people out. That includes:
    - People of color
    - Immigrants
    - People who practice certain religions like Islam
    - Queer people
    - Trans and gender-nonconforming people
    - People who are houseless
    - People who are in prison
    - Indigenous or native people

Disability Justice helps me think about my privilege as a straight white woman. I can support marginalized disabled people. Not all disability experiences are the same. That is a main idea for Disability Justice.

Mia Mingus is a writer and organizer. She wrote that Disability Justice is about **"moving away from an equality-based model of sameness and 'we are just**

like you' to a model of disability that embraces difference, confronts privilege, and challenges what is considered 'normal' on every front."

- **This quote means:** Disability Justice celebrates all the ways we're different. It says normal does not exist. Disabled people don't have to be like nondisabled people to deserve respect.

Self-Advocacy Movement

People with intellectual and developmental disabilities (I/DD) have been treated badly by society. Many people think that people with I/DD can't or shouldn't decide what they want in life. People with I/DD are treated like they aren't worth as much as others. This belief is wrong.

The self-advocacy movement fights back against this idea.

A small group of people with I/DD formed People First in Oregon in 1974. It was named People First to remind others that people are not only defined by their disabilities. It grew into a movement. Self-advocates say people with disabilities should live in their communities.

Roland Johnson was a leader in the self-advocacy movement. He led a group called Speaking for Ourselves in Philadelphia. He wrote **"People need to be out in a community, because dollars are spent in an institution—every head is in an institution, a dollar is spent there and not in the community…The services need to be in the community and not in an institution."**

- **This quote means:** It costs a lot of money to keep people in institutions. That money could be used to support people to live in their community.

There are now more than 1,200 self-advocacy groups in the U.S.

Max Barrows is a self-advocate. He works for Green Mountain Self-Advocates and was on the board of the organization Self Advocates Becoming Empowered. He said, **"Who knows us better than we know ourselves? People with disabilities need further opportunities to take the lead on work, policies, and decisions about our lives."**

- **This quote means:** People with disabilities need to be in charge of work, policies, and decisions about our lives. We know our lives better than anyone else.
- Most people think it's okay for other people to make decisions for people with I/DD. They think that a parent, teacher, or doctor should make decisions for people with I/DD.

The self-advocacy movement is changing this.

Neurodiversity Movement

Many people think some people have "good" brains and some people "bad" brains. They think only some people think and act "normally."

Neurodiversity means all our brains are different. This is a good thing.

People with disability-related brain differences are "neurodivergent."

People without these differences are "neurotypical."

Sara Luterman is an Autistic activist and journalist. She told me why neurodiversity matters to her. She said, **“I always had this concept of myself, like maybe I was just a bad person. People just didn’t like me and I didn’t understand why, so thinking I was a bad person was the logical progression for me. Neurodiversity gave me the ability to realize that that’s not the case. I just have a different kind of brain, but it’s morally neutral. There’s no good or evil involved.”**

- **This quote means:** Luterman used to think autism made her a bad person. Neurodiversity helped her understand that her brain is different, not bad.

The neurodiversity movement is not about neurotypical people. Dr. Jessica M.F. Hughes wrote, **“Neurodiversity is a ‘big tent’ concept that includes every person in the world and centers the experiences of those who are neurodivergent, but the neurodiversity movement is much smaller in scope. Autistic self-advocates are leading the contemporary neurodiversity movement.”**

- **This quote means:** Neurodiversity includes everyone. But the neurodiversity movement focuses on people who are neurodivergent. Autistic self-advocates lead the neurodiversity movement.

Neurodiversity celebrates difference. It is not something that needs to be fixed or cured.

Autistic activist Jim Sinclair wrote, **“The tragedy is not that we’re here, but that your world has no place for us to be.”**

- **This quote means:** Being autistic is not a problem. The problem is autistic people are left out of society.

Psychiatric Survivors Movement

Psychiatric survivors are people with mental illness. They have been hurt by the doctors, hospitals, or institutions that were supposed to help them. Some people are given treatment they don't want.

This movement is also called:

- The consumer movement
- The ex-patient movement

It was started in the 1970s. It was led by "ex-mental patients."

Judi Chamberlin was one of these leaders. She wrote a book called *On Our Own: Patient-Controlled Alternatives to the Mental Health System.* She wrote that they were, **"taking a label of shame and attempting to transform it into one of pride."**

- **This quote means:** They called themselves "ex-mental patients" on purpose. That label meant something bad before, but they decided to use it to show that they were proud of who they were.

Being proud to have a mental illness is called Mad Pride.

People in the psychiatric survivors movement don't always agree about how to advocate. They have a lot of ideas about what should happen. But they all agree that mentally ill people should be in charge.

Leah Harris is a psychiatric survivor. They told me people with mental illness should help each other. They said, **“It’s an innovation and a gift to the world. It’s so different from the existing system of psychiatric care. It’s about meeting a person where they are and providing support that is noncoercive. It’s about holding space and listening nonjudgmentally.”**

- **This quote means:** Mentally ill people supporting each other is good. It is not the same as medical care. People aren’t forced to do any treatments. They don’t judge each other.

Leah wants people to know about the movement. They say, **“beautiful things have emerged from it.”**

Chapter 4: Ableism and Accessibility

Read the Chapter 4 Summary

"Staying alive is a lot of work for a disabled person in an ableist society."

-Alice Wong, editor of *Disability Visibility: First-Person Stories from the Twenty-First Century*

- **This quote means:** Our world was made for people without disabilities. That makes it hard for disabled people to live.

Have you heard these words before?

- Sexism
- Racism
- Ageism
- Homophobia
- Transphobia
- Xenophobia

They are all words that mean one group is treated worse than another group. This is called *discrimination*.

- Sexism is treating someone unfairly because of their sex or gender.
- Racism is treating someone unfairly because of their race.
- Ageism is treating someone unfairly because of how old they are.

- Homophobia is treating someone unfairly because they are homosexual. This means they have romantic or sexual feelings for people who are the same gender as they are.
- Transphobia is treating someone unfairly because they are transgender. This means they identify as a different gender than the one they were called when they were born.
- Xenophobia is treating someone unfairly because they are from a different country than you.

The word for discrimination against disabled people is *ableism*. It means people with disabilities are treated worse than people without disabilities.

What is Ableism?

This is how I define ableism:

"Ableism is attitudes, actions, and circumstances that devalue people because they are disabled or perceived as having a disability."

- **This quote means:** Ableism is when people are treated badly because they:
    - Have a disability, or
    - Other people think they have a disability.
- Ableism is not just about how people think and act. It is also about how our society is not made for disabled people.

We say something caused by ableism is *ableist.*

Ableism has always happened. But we didn’t start using the word until the later part of the 1900s.

Sometimes it can be hard to describe ableism. It is part of our everyday life. Nondisabled people may not even notice it.

Ableism is something disabled people always have to deal with. It never goes away for us.

I don’t think it will be easy to get rid of ableism in the world. It is all around us.

Here’s an example of ableism:

The subway in New York City does not have many elevators. When I ride it, sometimes I am the only wheelchair user. People are surprised to see me. They will say things like:

- “Wow, it’s amazing how you get around in that chair.”
- “It’s so good to see people like you out.”

This is ableism. They think disabled people don’t use the subway. They may think I don’t have anywhere to go.

More wheelchair users could take the subway if every station had an elevator. Then, people would not be surprised to see me.

But there are not a lot of elevators because so many people think disabled people don’t have anywhere to go.

That is an example of how if people think in ableist ways, they build ableist things. These things cause more people to think in ableist ways.

There are still laws that treat disabled people unfairly. One of these laws is the Fair Labor Standards Act. It says disabled people can be paid less than nondisabled people.

This happens in places called “sheltered workshops.” Only people with disabilities work in sheltered workshops. Their jobs are to do the same thing over and over again. They only make a few cents per hour. A nondisabled person would be paid more money to do the same work.

One sheltered workshop in New Mexico is called Adelante Development Center. They were sued in 2019 because they didn’t pay enough money to the disabled people who worked there. Suing means they took them to court to try to make them pay money for what they did wrong.

Some people like sheltered workshops. They think we need them. They say the people who work there could not get a job somewhere else.

Places that run sheltered workshops (like the company Goodwill) think they’re doing a good deed. They are also getting a good deal because they don’t have to pay their workers a lot of money.

Disabled people don’t deserve to make less money just because they have disabilities. We can think about this problem using the *social model of disability*, which we talked about in Chapter 1. The social model says disabled people are not worse off because we have disabilities. We are worse off because we are not treated fairly.

Paying disabled people less than nondisabled people is not okay. It is ableist.

Some companies don’t care if disabled people can’t use their products and services. For example:

- A blind man sued Domino’s Pizza in 2016. Domino’s website didn’t work with his screen reader. A screen reader is a computer program that reads words on the screen out loud. The court said Domino’s had to fix their website so it would work with screen readers. Domino’s fought back. They tried to take the case to the Supreme Court. Luckily, the Supreme Court said no. They agreed that Domino’s needed to fix their website.
- Some businesses think it’s okay to tell jokes about disabled people. A nondisabled comedian named Tom Segura had a TV show on Netflix. He used the R-word in a joke. The CEO of Netflix said this was okay because Tom is a comedian. But the R-word hurts disabled people. Using the word shouldn’t be funny to anyone.
- It can be hard to point out ableism all the time. I get tired of doing that. Some people don’t like that I talk about ableism.

Sometimes I think something is ableist but another disabled person doesn’t think it is. That’s okay. Not all disabled people think the same. It’s ableist to think that all disabled people share the same thoughts.

It’s mostly nondisabled people who don’t like when I bring up ableism. For example:

- I say I can’t get into a building because it has stairs. Nondisabled people say I am complaining.
- I say a line from a play is ableist. Nondisabled people say I am overthinking it.
- I say a news story celebrating a disabled person doing an everyday activity is bad because it treats them like they are worth less than nondisabled people. Nondisabled people say I am bitter and not kind.

Some people think that disabled people who bring up ableism are “bitter cripples.” Bitter means angry for being treated unfairly. Being called bitter is an insult. I have been called bitter for saying what I think.

But I’m not bitter. I just want a more accepting and loving world for everyone, including disabled people.

Ableism is everywhere. Sometimes disabled people *internalize* it. That means we think that disabled people are worth less than nondisabled people because that is what everyone around us thinks. I have had a hard time with this. I have:

- Been embarrassed to ask for help doing something my body couldn’t do.
- Said “I’m sorry” when I can’t go somewhere with stairs because I cannot walk.

- Worried that I do not deserve romantic relationships because I am disabled.

I have to remind myself that my disability is not bad. It is not embarrassing. I am not hard to be around because of it. If someone thinks of me that way, it’s their problem. Not mine. Disability does not make a person worth less.

But ableism is hard to deal with. A lot of disabled people believe ableist ideas about themselves. They believe our lives are not worth living.

That is not true. Disabled lives are always worth living.

Mind Your Ableism

I fight against ableism. But I’ve been ableist to other disabled people. I’m not proud of it, but it happens. It will probably happen again.

We all need to work to be less ableist. Sometimes that means thinking about how ableism is connected to other kinds of discrimination.

One example is the sad story of Seven Bridges. Seven was a Black 10-year-old with a disability. He wore an ostomy bag. That’s a bag you wear on your stomach to collect body waste.

Seven was bullied. His classmates said racist and ableist things to him. They choked him. They made fun of his ostomy bag.

In 2019, Seven took his own life.

Seven was treated this way because of his race *and* disability. It’s not just one or the other.

Black disabled activist Imani Barbarin wrote about Seven. She said we need to **“create space for disabled Black, Indigenous, and people of color to feel like they’re not alone in all the intersections [they] inhabit.”** This work **“is lifesaving, and it’s time we get to it.”**

- **This quote means:** Some people are treated unfairly because of both racism and ableism. They feel like other people are not fighting for them. They feel alone. It’s time to make sure they are included in activism. It will save lives.

Sometimes people will say ableist things when they are fighting against other kinds of discrimination. For example, they will say racism is a “sickness” or a “disease.” They are trying to say racism is bad and we need to get rid of it. But when they say this, they are actually calling racism a kind of disability. This is a problem because:

- Racism is a bad thing. Disability is not a bad thing.
- You are responsible for changing or fixing your racist behavior. Disability is not something you need to change or fix.
- We need to get rid of racism. We don’t need to get rid of disability.

Disability often gets left out of other activism. For example:

- In 2017, an organization called the Women’s March created their “Unity Principles.” They didn’t mention disability. Many disability activists asked them to include disability in their work. I was one of them.
- TIME’S UP is an organization that fights back against sexual harassment. Sexual harassment means treating someone in a sexual way that they don't

want. It could mean saying something sexual or touching them in a way they did not say was okay. The page on their website about who is included in the work they do does not mention disability. Disabled people experience sexual violence 3 times more often than nondisabled people. Sexual violence means being forced to do sexual things you don't want to do. Not mentioning disabled people in work against sexual violence means more people could be hurt.

Don't worry if you have been ableist in the past. I think we can all learn to be less ableist. Dominick Evans does too. He is a filmmaker, consultant and online streamer. He said, **"I don't personally like dismissing people for being ableist. It's embedded in our culture, and I had to learn to be better, so how can I expect nondisabled people to know how to be better? What gets me is when people learn the harm they've caused, and double down about it."**

- **This quote means:** Our world is ableist. Evans had to learn to be less ableist. We need to give nondisabled people a chance to learn too. What he doesn't like is when people know they are being ableist and do it anyway.

This quote sums up what I want you to learn from this book. I believe you *can* do better and be less ableist. We all can. It's time to change.

Access and Inaccessibility

Most people think of ramps and elevators when they think about access. But accessibility is much more than that.

Accessibility means that:

- Places,
- Products, and
- Services

can be used by disabled people.

Sometimes, to make things accessible, we must make changes. These changes are called *accommodations.*

There are many kinds of accommodations. For example, you could:

- Set up a quiet room at an event. This can be used by people with sensory overload.
- Let your workers choose what hours they work. They can make a schedule that is right for their body.
- Send out your slides before a presentation. People can take their time to read and process them.
- Have live captions and sign language interpreters at events.
- Set up seating areas that people with mobility disabilities can easily use.
- Print info in large-print or Braille.

A lot of people don’t think about accessibility. Without it, disabled people are left out.

It’s like everyone else has a secret password to a cool new place. I don’t have the password, so I am not allowed inside the place. Or if I can get in, I don’t have the password for the bathroom. I can never really get comfortable. That’s what not having access feels like.

It can be really frustrating. The world was not made for disabled people. It hurts me every time something is not accessible.

Sure, sometimes my disability means that I get to go to the front of the line somewhere or pay less for a ticket to a museum. This may seem like I am getting special treatment because of my disability. But accessibility is not about special treatment. It is about making things equal. Everyone should get the same chance to do things. And that means I should not have to do things like go into any buildings through the back door by the dumpsters because the front door is not accessible to people who use wheelchairs.

Inaccessibility makes things hard. Friends have told me I couldn’t hang out with them. Dates I went on with men have been ruined. There are many places I can’t go.

It makes me tired.

I hear a lot of excuses about why things can’t be accessible. People will say:

- It costs too much.
- It’s too much work.
- It will look ugly.

- There’s not enough time.
- That’s not my job.

Sometimes they’ll say, “People with disabilities don’t come here. There’s no point to making it accessible.”

These excuses are what people say when they really mean: “Disabled people are not welcome here.”

It hurts to hear these things. It makes me think I am a burden. A burden is something hard or annoying you have to deal with. I have to remind myself that disabled people are not a burden or a problem. Inaccessibility is the problem.

Rebekah Taussig wrote a book called *Sitting Pretty.* She wrote about how hard it is that so many things are not accessible:

“Many days, I feel too vulnerable to leave my house, too fed up to subject myself to the gamble of strangers interacting with me, too tired to fight to occupy a corner of space. Inaccessibility over time tells me that I do not matter, I’m not wanted, do not belong. This land wasn’t made for me. So I stay in, keep to myself, avoid, cancel plans, carry anxiety in each fold and bend of my body, feel very alone and trapped and helpless.”

- **This quote means:** It’s too much work to be in a world not built for disabled people. Rebekah often feels better off staying home instead of dealing with inaccessibility. This makes her feel alone and trapped.

It shouldn't be this way. Making things accessible is not just the right thing to do. It's the law. But there is still a lot of work to do to get it right.

It can feel overwhelming to think about making things accessible. You may worry that you'll mess up. You may worry about breaking the law.

But disabled people aren't trying to attack you or get you in trouble when we ask for accessibility. We just want an equal chance.

So where can you start to learn about what accessibility is and how to make things accessible? It's not hard to learn what you need to do.

You can always ask if you're not sure. Two of my favorite resources about accessibility are:

- The ADA National Network
- The Job Accommodation Network (JAN)

They both have free information that can answer your questions.

You may want to ask a disabled person directly about how to make things accessible. That can be very helpful. But you need to respect that someone talking to you about accessibility is *work*. If you can, pay them for their time and knowledge. Hire a disabled consultant.

A lot of times, you can make something accessible for very little money. Many changes are free to make. For example, you could:

- Buy a portable ramp to put over some stairs so that people with mobility disabilities can get in and out.

- Ask people coming to your event to not wear scented products like perfume so that people who are sensitive to certain smells will not get sick.

Sometimes, the things that people think are “solutions” don’t actually make things accessible. They can make things worse. For example:

- Offering to carry a wheelchair user up the stairs does not make your event accessible. The stairs cannot be used by everyone.
- Telling a blind person to have someone read handouts out loud to them is not access. The handouts cannot be used by everyone.

Access helps us all. We call this the “curb-cut effect.” Curb cuts are ramps that connect the sidewalk to the road. They were made for wheelchair users. But they help many people. Curb cuts are helpful for:

- Baby strollers,
- Shopping carts,
- Suitcases,
- Roller skates.

The world needs more solutions like curb cuts.

More access means more people are included.

Here is a story that happened to me about a place becoming accessible. A new coffee shop opened in my neighborhood. When I went to visit, I couldn’t get inside. I called the owners. They agreed to put in a ramp. I wasn’t sure it would actually happen. They called me a few months later. They wanted me to know they put in the ramp. I wondered what took so long, but I was still glad they called me. I felt like the owners of the shop really wanted to include me. I wish they built the ramp before they opened the shop. But I am always happy when people make things accessible.

What Does Ableism Look Like?

I could write a whole book about ableist things that have happened to me. But ableism isn’t just my story. It is something that all disabled people experience. There’s no way to cover it all. But I want to share a short list of examples. I hope you will see how ableism is everywhere.

- Most states have laws that say people with disabilities can have their children taken away.
- Many rideshare drivers will not pick up riders with mobility equipment or service animals.
- Most students with intellectual disabilities do not go to class with their nondisabled classmates. They are segregated. That means they only go to school with other students with disabilities. In 2015, only 16% of students with intellectual disabilities were in the regular classroom 80% of the time.
- Autistic kids are expected to act in ways that nondisabled people think are “normal.” They are often forced to do therapy to change how they act in ways that might hurt them.

- Hundreds of thousands of people with disabilities do not live in their communities. They live in institutions like nursing homes or hospitals. Many of them have intellectual and developmental disabilities.
- Disabled people are left out of many large group meetings. These meetings are not accessible. They don't have supports like:
  - Interpreters
  - Captioning
  - Braille
  - Large print materials
  - Digital materials
- Americans with disabilities make less money than people without disabilities. If the average nondisabled person made $100, the average disabled person would make less than $70.
- Many nondisabled people think all disabled people want to be "cured" or "fixed."
- Since 2015, more than 800 disabled people have been murdered by the people who are supposed to take care of them. The news often reports on these murders. The stories make it seem like disabled people are a burden and that makes it okay for people to kill us.
- During COVID-19, many states and countries created new rules. They said that hospitals could choose not to help sick people if they had disabilities.

- The United Nations did a survey about disaster planning in 2013. Disaster planning means preparing for big emergencies like hurricanes or wildfires. They surveyed over 5,000 people from 137 countries. They found that 85% of disabled people were not included in disaster planning.

These facts may feel overwhelming. But remember, knowing about ableism is the first step to working toward a world that is less ableist.

Chapter 5: Disability Etiquette 101

Read the Chapter 5 Summary

“Overthinking is one enemy of disability etiquette, but so is making assumptions about what a person wants and needs. Of course disabled people want to be treated like everyone else, but when we say that, we don’t mean ‘treat every person exactly the same.’ We mean ‘recognize our humanity and meet us where we’re at.’”

-Kyle Khachadurian, cohost, *The Accessible Stall* podcast

- **This quote means:** Some people think too much about how to act around people with disabilities. But other people assume all disabled people want or need the same things. Disabled people want to be treated like everyone else. But that doesn’t mean we’re all the same. It means we want you to treat us like the unique people we are.

Etiquette means the rules for how to behave. That can be:

- Having good manners
- Being polite
- Treating others with respect.

Disability etiquette means how you treat disabled people in your everyday life.

There are not a lot of special rules for being around disabled people, though. It’s all about the Golden Rule, which is to treat others as you want to be treated.

You wouldn’t want someone to be rude or mean to you, right? Just keep that in mind.

I am going to go over some do’s and don’ts for how to act around disabled people. I can’t cover everything. But you can use these tips in all your interactions.

Don’t overthink it. You don’t have to treat disabled people like they are different from nondisabled people. Just treat us like human beings.

Disability Etiquette Do’s

All of these tips are based on respect. Be thoughtful about what you say. It makes a big difference.

Do Keep Your Nosy Questions, Rude Comments, and Advice to Yourself

Every time I leave the house someone says something about my wheelchair. People say things like:

- Don’t run me over!
- Slow down, speed racer!
- You got a license for that thing?
- You’re gonna get a speeding ticket!

When people say these things, they think it’s the first time I’ve ever heard that joke. It’s not. I hear these jokes about my wheelchair all the time.

One time a man took the joke too far. My mom and I were rolling side by side in our wheelchairs down a hallway. He blocked our path and told us to race for him. We told him to leave us alone. He followed us to our car. He told us he was sorry for bothering us. He even tried to give me dad money to say sorry. He got angry when we wouldn’t take the money. Don’t be like this guy.

Disabled people get asked a lot of rude questions too. People ask me things they don’t need to know the answer to. For example:

- In high school, my crush asked me how I put on my pants.
- Men on dating apps ask if I’m able to have sex before they even say hello.
- People on elevators ask if I can walk.

Getting asked these questions makes me tired. These questions aren’t always just things people don’t need to know. They’re harmful.

Andrew Gurza is a disability awareness consultant. He remembers his high school gym teacher asked him if his disability would affect how long he was going to live.

Gurza told me, **“I was fifteen at the time, and I was so extremely embarrassed. I had never had to consider my own mortality before. I was**

so angry, I left her classroom crying. All the other kids saw me leave. I was mortified."

- **This quote means:** That question was the first time Gurza had to think about dying. It made him angry. He started crying and left the classroom. He was embarrassed that other kids saw that.

People are curious about disability. But disabled people don't owe you answers to your questions. Especially if they don't know you. Autistic activist Jim Sinclair says that disabled people are not **"self-narrating zoo exhibits."** That means we don't have to teach nondisabled people about ourselves.

Are you not sure if it's okay to ask your question? If you wouldn't ask a nondisabled person the same question, don't ask a disabled person.

Don't give someone advice unless they ask you for it. This happens to physically disabled people all the time. We joke that we'll talk about chronic pain or muscle weakness and someone will tell us:

- "Have you tried yoga?"
- "You should do acupuncture!"
- "My sister's dry cleaner knows a guy who hosts events that could totally fix you!"

People are trying to be helpful when they say these things. But it feels like they're talking down to me. I know what is best for my body best just like you know what is best for your body.

Maybe you have a real suggestion that can help someone with a disability. You can say, “Can I share what worked for me?” If they say yes, tell them your advice. If they say no thanks, don’t.

Do Ask Appropriate Questions

Some questions you should never ask. But sometimes it’s okay to ask questions. Deciding if it is okay depends on:

- Where you are,
- How well you know the person,
- Why you are asking the question.

For example:

- Sometimes strangers will ask me about my wheelchair. They know someone who could use a wheelchair like mine. I am happy to answer their questions because I want to help. Other people who use wheelchairs might not want to answer questions about them. That’s okay too.
    - Don’t just ask a question. First, say, “May I ask you a question about…” instead of just asking your question.
- Sometimes it’s important to ask questions about disability. For example, if you are having an event, you need to ask about accessibility and accommodations.
    - You can say, “I want to make sure what I’m planning works for you. Is there anything I can do or any accommodations you might need?”

- When you are friends or a partner of someone with a disability, asking thoughtful questions about it can show you care. You can learn how to support them. You can build trust.
    - Make sure the person is comfortable talking about it. You could say, “Is it okay if I ask a question about your disability?” If they say they do not want to talk about it, make sure to respect that.

Do Keep Your Hands to Yourself

People often don’t respect disabled people’s personal space. Strangers will lean on my wheelchair. They treat it like an armrest. They think it’s harmless. But it’s not. My wheelchair is part of me. It’s how I move. I feel trapped when someone leans on it.

When I was in school, I used to get out of my wheelchair and sit at a desk. My teacher would lean on my wheelchair during class. It made me uncomfortable. But I felt like I couldn’t say anything.

You wouldn’t lean on a person you don’t know, would you? It’s the same with wheelchairs. You might lean on a friend, but you need to make sure it’s okay first.

Don’t move someone’s mobility equipment without asking either. Don’t start pushing someone’s wheelchair if they haven’t asked. It can be scary when someone else takes control of how you move. Would you push someone who doesn’t use a wheelchair? I don’t think so.

Some disabled people don’t like being touched. It can be uncomfortable. Ask before you shake someone’s hand or hug them.

I like to hug people. But first, I ask, ““Are you a hugger or more of a handshake person? Neither is okay too!”

Some people like:

- Fist bumps
- Elbow bumps
- High fives
- No touch at all

Let people do what makes them comfortable.

It’s also not okay to touch service animals. They are doing their job to support their handler. Petting a service animal can make it lose focus. That can be dangerous for the person the animal is helping.

For example, imagine a service dog guiding their blind handler down the street. If you pet the dog, it might not notice something is blocking the street. Their handler could fall or get hurt.

I talked to Dr. Anjali Forber-Pratt. She is a wheelchair user and has a service dog named Kolton. She said, **“When he is working and somebody goes to pet him, it is a problem because it confuses him. He then thinks that it is off-duty play time and will be paying more attention to the person trying to pet him than to me. If he is in the middle of a task for me, like carrying**

something, he might drop it, and we have to start the command sequence over again. Don't pet service dogs when they are working!"

- **This quote means:** Kolton gets confused when people pet him while he's working. He thinks that means it is play time. He stops paying attention to Dr. Forber-Pratt. He might drop something he's carrying for her. Don't pet service dogs.

Dr. Forber-Pratt said if you really want to pet a service dog, **"Always ask the handler first. Sometimes there are occasions when Kolton is off duty and it is allowed during play time, but it's important to respect the handler's wishes!"**

- **This quote means:** Ask the handler if you can pet a service dog. Sometimes they are not working. They are allowed to play. But you need to listen to what the handler says.

Do Talk to Disabled People Like You Talk to Everyone Else

A lot of people are uncomfortable talking to people with disabilities. People worry about what to say to them and how to say it. My advice is simple: Talk to a disabled person the same way you talk to everyone else.

Always talk to the disabled person themselves. Don't talk to their staff, support person, or family instead.

I talked to writer and activist Kings Floyd about this. She told me about a night she went out with her sister Isabel. Floyd uses a wheelchair and her sister is nondisabled. At dinner, the server thought Floyd couldn't speak for herself.

“She took Isabel’s order first and then asked her ‘What is she having?,’ referring to me. Isabel remained silent, looking intently at the waitress and then at me. I coolly answered ‘I’d like the carbonara, please, with mushrooms. I’ll also have a lemonade and a side Caesar salad. We are still thinking about dessert.’ The waitress nodded, uninterested and avoiding eye contact…Later, when she came back with the check, she handed it to Isabel after I had already clarified I was paying. Thankfully, the improv show was amazing and saved the night, but the waitress’s tactless assumptions left me feeling truly disrespected, as though she believed my voice didn’t matter.”

- **This quote means:** The server asked Isabel what Floyd was going to eat. She should have asked Floyd. Floyd answered for herself. The server also thought Floyd couldn’t pay the bill because she’s disabled. Floyd felt like the server was disrespectful. She felt like her voice didn’t matter. Later, they went to an improv show. It made the night better.

Always be direct and respectful. Conchita Hernández Legorreta is a blind activist. She said you need to introduce yourself when talking to a blind person. **“Say your name before speaking…[Making] a blind person guess who you are is super-rude. Also keep in mind that many people with low vision can see some things but faces are still very difficult, so do not assume we know who you are.” It’s as simple as saying, “Hi, it’s [full name] speaking.”**

- **This quote means:** Say your name before you start talking to a blind person. A blind person or person with low vision might not know who is speaking if you don't

If you want to talk with someone who is blind or deaf, respect their personal space. To get someone's attention, you could tap them on the shoulder.

But not everyone wants to be touched. Christine Liao is a deaf advocate. She says you can get **"in the d/Deaf person's line of vision and making a gesture, like a wave, to let them know you are there and wanting to communicate."** She says the **"two most common ways folks suggest to get a deaf person's attention—a tap on the shoulder or flickering the lights—be saved as a last resort."**

- **This quote means:** You can wave at a deaf person to let them know you want to talk. Only tap someone or flick the lights If there's no other way to get their attention.

Some deaf people have sign language interpreters. Look at the person, not the interpreter. You don't need to ask the interpreter "Can you please tell them…?" Just have your conversation.

If there is no interpreter, use a pen and paper or type out your message on your phone.

How do you start a conversation with someone who is d/Deafblind? Elsa Sjunneson is a partially Deafblind author and activist. She told me people think she can't be part of conversations because of her disability. This isn't true. She said, **"The best ways to get my attention are to speak clearly (not**

shouting) and say ‘excuse me’ or ‘hello.’ It can also help if you wave your hand in my visual field, but it depends on where I’m sitting.”

- **This quote means:** Just say “hello” in a clear voice. You don’t need to shout. You can also wave, but Sjunneson might not see that.

You can also have a friend who knows both you and the deafblind person introduce you.

Some people stutter or speak slowly. Others use communication aids like letter boards or devices to type on. Don’t rush them or try to guess what they want to say.

Eva Sweeney is a sex educator with cerebral palsy. She uses a laser pointer attached to a baseball cap to spell out words on a letterboard. She told me, **“Just talk to us like you would anyone else. You might have to wait to hear our response, but it is not that different than talking to someone who is verbal! People communicate in a variety of ways, so be open-minded to new ways of communicating and connecting with someone.”**

- **This quote means:** Talk to Sweeney like you would talk to someone who uses their voice to talk. It’s not that different. Be open-minded. People talk in a lot of different ways.

Is the person you are talking to shorter than you? Are they sitting in a wheelchair? If you are standing and they have to stretch their neck up to look at you, take a few steps back. You can sit so you are at eye level with them. I don’t mind if people kneel to talk to me. Some people don’t like that though.

Whatever you do, don’t make it a big deal. Once a woman in high heels wanted to talk to me at a fancy event. She crouched down. But her shoes made her keep losing her balance. It was awkward. She could have just stayed standing up straight.

Use clear words and sentences to talk to someone with a cognitive disability. Explain longer words or words they may not know. Don’t speak more loudly or slowly unless they ask.

Just remember this one thing: there’s no “right way” to talk to anyone. We get taught rules about how to talk to people like:

- Shake hands
- Make eye contact
- Make certain faces

But not everyone can or wants to follow these rules. The best thing to do is just to be yourself.

Disability Etiquette Don’ts

No matter what, respect is key.

Don’t Talk Down to Disabled People

Disabled people are often *infantilized.* That means they are treated like they are much younger than they are. Disabled kids get treated like babies.

Disabled adults are called “cute” or patted on the head. This happens a lot to people with developmental disabilities like:

- Intellectual disabilities
- Autism
- Other disabilities that affect how people think and talk

Julia Bascom is the executive director of the Autistic Self Advocacy Network. She told me that a lot of people think people with developmental disabilities can’t:

- Think
- Learn
- Make their own choices.

Bascom said, “But that just isn’t true. That belief is dehumanizing, and responsible for a huge amount of mistreatment.

You should always *presume competence.* That means believing that people can do things like speak for themselves or make decisions. Some people need support, but that doesn’t mean they can’t do something.

“The reality is that people with developmental disabilities, including people with the most significant disabilities, have rich and complex inner lives. No matter how significant our disability is, we can and do learn, think, and feel. We might do these things differently, or more slowly, or with more effort compared to other people. Our complexity and competence may

not be obvious in ways that people expect. We might need a lot of support. Presuming competence is the idea that, regardless of these things, we are fully human with the same rights as everyone else and, with the right support, we can express ourselves, participate in our communities, and make our own decisions."

- **This quote means:** People with developmental disabilities are treated like we aren't people. But we are. It doesn't matter what disability we have. We learn, think and feel. Doing things differently or with help doesn't mean not being able to do them. We have the same rights as everyone else. Believe we can do things and make our own decisions.

Some people treat all disabled people this way. They think if someone has a physical disability, they also have a cognitive disability. It's not a problem to get someone's disability wrong. It doesn't matter whether someone has a cognitive disability or not. The problem is treating anyone like they are less than human because you think negative things about disability.

Everyone should be treated with respect.

Don't Help Without Asking

It takes me a while to put on a jacket. I have to wiggle my arms and flip it over my head. It might look like I can't do it on my own. But I can. I have done it a lot of times in my life. But strangers will always try to help. They'll grab my jacket without asking and try to put it on me.

They think they are being kind. But they are in my personal space. They are making it harder for me to get my jacket on. I didn’t ask for help. But I worry it is rude for me to tell them I don’t want help.

I think it’s rude to try to help someone who didn’t ask for help.

How I look affects how people treat me. I am a small young white woman. I look friendly. People look at me and see someone who looks like they always need help. Not everyone has the same experience. I once saw an elderly Black man in ripped clothing and an old wheelchair in New York City. He asked many people to help him reach his tote bag that was hanging on the back of his chair. He shook a cup of coins while he asked. People acted like they couldn’t hear him.

He didn’t ask me for help. Maybe he thought I couldn’t help because I used a wheelchair too. I asked if I could do anything. He accepted. I was happy to help. But it shouldn’t have come to that. People shouldn’t have ignored him because of how he looked.

Sometimes people won’t take no for an answer. Walei Sabry is a blind disability rights activist. He told me a story about walking to the train with another blind classmate after school. **“All of a sudden, out of nowhere, two strangers decided to take it upon themselves to help us. Without saying anything, they each grabbed one of us. I started to ask the man who grabbed me to let go, telling him that we were fine. They insisted on helping and there was a back and forth for a few minutes. The gentleman that grabbed me finally said, ‘I don’t understand. We are just trying to**

help you.' To which I replied, 'We didn't ask for your help!' They finally got the point but they weren't happy about it. As the man walked away, he yelled, 'You two are the worst blind people in New York!'"

- **This quote means:** Two strangers grabbed Sabry and his classmate. Sabry told them to let go. The strangers said they wanted to help. Sabry told them he didn't ask for help. The strangers got mad that Sabry and his friend didn't want their help.

Disabled people know what we need. Listen to us. This is important to remember for someone having a mental health crisis too. Leah Harris is a psychiatric survivor. They said helping someone in crisis doesn't mean doing whatever you think is right. It means you should **"ask the person what they need in that moment, or how you can support them. And if the person is not able to articulate that, then you can offer some suggestions. If you have lived experience, you can offer to share with the person what helps you in similar moments. But please, avoid the urge to 'fix' and make it better without first centering what the person in crisis wants and needs."**

- **This quote means:** Ask someone what they need. Give suggestions if they can't answer. If you have gone through something similar, tell them what worked for you. But don't try to fix things without knowing what that person wants.

Don’t Stare, But Don’t Look Away

With my power wheelchair, I’m easy to notice in a crowd. I’m comfortable with people looking at me. Sometimes people stare. It could be because my wheelchair is big and purple. I think my wheelchair looks pretty cool.

But I get other kinds of stares too. When I’m with another disabled person (like my mom), people look at us like we just escaped the circus. It’s like I’m on display.

Disabled people get stared at a lot. Here are some examples:

- Some disabled people get stared at for “stimming.” That means doing repeated movements or sounds. The book *Welcome to the Autistic Community* says **“People stim for all sorts of reasons. We stim to help balance out our senses, show how we feel, or focus on things. Stimming can help us feel better, and it’s also a great way to have fun.”** Stimming isn’t bad. Staring at people who are stimming is.
- Pamela Rae Schuller is a comedian with Tourette syndrome. This disability means her body moves or she says things without meaning to. These are called tics. She says **“People stare, laugh, point, ask questions, and even try to record me. Through my comedy, I’m trying to help people become more comfortable with differences. But every now and again I lose my cool. Once, when a woman started videotaping me on the subway, I took out my phone and taped her back. If I ended up on the internet, I wanted to definitively know the face of who put me there, somebody who was all**

too comfortable causing me pain and making fun of me because of my disability."

  - **This quote means:** People are rude when Schuller has tics. Someone tried to record her on the subway while she was having tics. Schuller recorded the woman back. She wanted to have proof that the person thought it was okay to make fun of her.

- It also hurts when people won't look at you because of your disability. Carly Findlay is an appearance activist. That means she speaks up for disabled people who look different from non-disabled people. She has a skin condition called ichthyosis. She said, **"I can't think of a day outside of the house when I haven't been stared at, intruded upon, or abused because of my appearance. Sometimes people look away—which can hurt as much as the stares."**
  - **This quote means:** Findlay is stared at or made fun of a lot because of how she looks. It also hurts when people don't want to look at her because of how she looks.

It's okay if someone catches your eye because of how they look or act. But you don't need to stare or to turn away. Act like you would when anyone else passes on the street. If they catch you staring, just smile and move on. Do better next time.

Don't Pray Over Disabled People

Once I was staying in a hotel. I was in a town to interview for my dream job. I was in the hotel lobby to get breakfast. A young girl and her mom asked if I needed help with my cereal bowl. I said yes. They helped me and I said thank you.

Instead of walking away the girl said, “Mommy, can I pray for her?” She prayed for Jesus to heal me. Everyone in the lobby watched uncomfortably. I said thank you and quickly left. I was so embarrassed.

I tried to laugh about it. But I felt sad. I had been excited for my big interview that morning. But this girl made me remember that some people think my disabilities are bad. They think my body is a mistake. I wish I could find that girl and take back saying thank you. I want them to know that I am not broken. I don’t need prayers to be fixed.

Don’t Assume You Know Who Has a Disability

You can’t tell if someone has a disability by looking at them. Just because someone doesn’t “look” disabled to you doesn’t mean they don’t have a disability. Don’t spend time worrying if someone is disabled or not. Just always use disability etiquette and think about accessibility.

Sometimes people get told they are “faking” their disability if they don’t look a certain way. This happens a lot with accessible parking spots.

Lacey Henderson is a Paralympic athlete and an amputee. People have thought she was nondisabled before. She told me, **“When I was in college, I drove a green Volkswagen Beetle, wore big sunglasses, and blasted music wherever I went. Once, I was running to return a library book and a woman accosted me at my car, shouting that I was in an accessible spot. I had put my placard up already, but maybe she didn’t see it. I was like, ‘I**

have a prosthetic leg,' and she acted as though I really inconvenienced her, because how in the world could a cute girl in a little car who is enjoying life also have a disability that qualifies her to have a placard? Of course, as a young woman in my twenties, I was apologetic (because we're taught to be accommodating and not let people feel uncomfortable with us), but I wish I had been told by someone that I didn't owe any of these people any answers."

- **This quote means:** Henderson drove to the library to return a book when she was in college. She parked in an accessible spot. A woman yelled at her because she thought Henderson didn't "look" disabled and should not be parking in that spot. She was young, cute, and drove a fun car. The woman was still mad even after Henderson told her she had a prosthetic leg. She wishes she didn't feel like she had to explain her disability to this stranger.

Henderson is right. Disabled people don't owe answers about their disabilities to anyone. No one should assume they know who has a disability and who doesn't.

But don't pretend someone doesn't have a disability when you know they do. You don't need to bring it up, but don't avoid it if it comes up in conversation.

Don't Use Accessible Items That You Don't Need

Imagine going somewhere and you:

- Can't find a parking spot

- Can’t use the bathroom
- Can’t find a place to sit

This happens to disabled people a lot. There aren’t a lot of accessible parking spots, bathroom stalls, or seats. Many people want to use them. Disabled people will spend extra time and effort planning outings or getting to places early so they can make sure it’s accessible. That is not something nondisabled people have to do.

I make a plan everywhere I go in case there is an accessibility problem. I plan extra time to:

- Find parking
- Use the bathroom
- Find an elevator
- Get seating

If you don’t need these accessible things, don’t use them. You’re making it harder for someone who does need it.

Remember to not judge other people who use accessible things. You don’t know if they have a disability. You can’t see all disabilities.

It’s sometimes okay to use the accessible stall in the bathroom. I understand if:

- You have a baby stroller.
- All the other stalls are full and you really need to go.

But that stall is not for you to:

- Have extra room for your luggage.
- Change your clothes.
- Have four people in there at the same time.

If there’s a long line for the bathroom and the accessible stall is open, ask if anyone else in line needs it before you use it.

It’s never okay to park in an accessible spot unless you have a permit. Not even for a minute. Not even while you’re waiting for another spot to open. It’s also not okay to park on the blue lines between accessible spots. Those lines are to make room for people to get in and out of their cars and vans. If you break the rules, someone with a disability could get stuck and not be able to get back into their car. Don’t do this.

Don’t Pretend You “Get It”

I like when people take time to listen and understand other people. But I don’t like when people say they know what I’m “going through.” These kinds of people pity me and look down on me.

Maddy Ruvolo is a transportation planner who is chronically ill. She talked to me about how people react to her disability. **“There have been many occasions when I tell people I have chronic fatigue and they are like, ‘Ugh, yeah, I get so tired, maybe I have that too.’ I know it comes from a place of trying to relate, but it feels very dismissive of my experience.”**

- **This quote means:** Ruvolo has chronic fatigue. That is a disability that makes you feel very tired all the time, even when you rest. Other people try to relate to Ruvolo. They say they feel tired too. But they don’t have chronic fatigue. That makes Ruvolo feel like they don’t understand her disability.

Feeling bad for someone with a disability may not be the right way to react either. Ruvolo said, **“Sometimes, people respond by saying things like, ‘Oh I’m so sorry.’ I know they’re coming from a good place, but I’d rather not be in a position of having to say ‘Oh, yeah it’s totally fine’ and assuage their feelings.”**

- **This quote means:** People tell Ruvolo they’re sorry about her disability. She has to comfort them and tell them it’s okay. That is a hard position to be in.

Ruvolo says the best thing to do is just say “Thank you for sharing.”

You can support someone with a disability without pretending you’ve had the same experience. Sometimes people will tell me about when they used a wheelchair after they got hurt. They tell me “I totally know what you’re dealing with.”

It doesn’t feel good when people tell me that. Having a disability is not the same as healing from an injury. Maybe you used a wheelchair after you broke your leg. Maybe you found out that some places are not accessible. But you haven’t lived your whole life being treated unfairly because of disability.

I know these people are trying to be nice. I want to ask them these questions:

- What are you doing to help other people now that you know more about living with a disability?
- Will you fight to make places more accessible?
- Will you speak up about disabled people being treated unfairly?

You may not know what it is like to have a disability, but you can help spread awareness.

What About Curious Kids?

Kids are curious. They stare at people who are different from the people in their lives. They ask questions that would be rude to ask if they were adults.

I don’t mind when kids ask me questions. That’s how they learn about the world. Sometimes the questions can be pretty funny, too. I am happy to show a kid my wheelchair or explain what my disability is. Hopefully, I can teach them something in a friendly way.

Not all disabled people want to answer kids’ questions and that’s okay. Don’t take it personally if a disabled person won’t answer your kid’s question.

I have some ideas for how to make it less awkward if your kid has a question. I can tell you what I think as a disabled person. But I have been the adult in charge when a kid asks an awkward question, too. Once I took my 8-year-old neighbor to the movie theatre to see *Frozen 2.* The ticket-taker at our movie theatre has a facial difference. My neighbor asked him “What happened to your face?” The ticket-taker answered the question nicely. But I was embarrassed. I didn’t know what to say. I thought my neighbor was comfortable with all people with physical differences since she spent time with my mom and me. I told her that no one looks the same. Being different makes the world a beautiful place. But I also told her it’s not nice to shout out nosy questions. I think she got it.

Did I handle this as well as I could have? Did I get through to my neighbor? I don’t know. I hope so. These moments are hard.

Here’s the advice I have:

- Don’t shush a child or tell them they’re rude if they have a question. This could make them embarrassed around disability. If the disabled person doesn’t want to answer, don’t ignore the question. Answer honestly. Here’s an example:
    - The child sees a disabled person and says, “Why does he walk funny?”
    - You could say, “I don’t know why. He could have something called a disability that affects his legs. It’s okay to be curious. But it’s not nice to say someone who walks differently than you is walking ‘funny.’”
- Don’t make a joke or a mean comment. Kids learn from the people around them. If you say something mean about disability, they will think disability is bad.
    - Here’s an example. Once a kid saw me and asked “Mommy, what happened to her?” The mother pulled him away from me and said, “You can’t ask things like that; these people will run you over.”

I asked my parents for advice. I wanted to know what to do when someone asks questions about your disabled child. My dad said, **"There are no hard-and-fast rules. Your instinct as a parent might be to want to take the opportunity to educate, especially if it's a child who said something. You'll want to defuse the awkward situation. And if a child is scolded or the adult in charge gives a harmful response, your urge might be to correct it. But also recognize that your response might not be well received. So it's best to decide on a case-by-case basis when to let it go and when it might actually be a teachable moment."**

- **This quote means:** Every situation is different. Sometimes you can teach people about disability. Sometimes you need to let it go.

My mom agreed. She thought about what it was like to raise me. She said, **"Dad and I wanted to help you understand that, yes, you have a disability and, yes, people are going to ask questions or treat you differently, because that's reality, unfortunately. It was important for us to make sure you knew that you shouldn't be ashamed of yourself, to teach you how you could respond in the moment, and to support you unconditionally."**

- **This quote means:** My parents wanted me to learn that having a disability means people will ask me questions about it. People will treat me differently because of it. But I should be proud of who I am. My parents wanted to always support me.

No More Bad Disability Etiquette

Are you worried that you have done some of these rude things? You probably have. But it's okay. Don't feel bad. You can start doing better now.

If someone tells you you are being ableist, listen to them. Don't try to make excuses for why you were ableist. Think about how the disabled person is feeling.

It might seem hard to do this if something happens with a stranger. But it can be simple. Here's an example. Once my mom was waiting in a long line at the store. The woman behind her said, "You're so lucky you don't have to stand in this line." My mom just sighed. That was a rude comment. As my mom was leaving, the woman said, "Hey, I really shouldn't have said that. I'm sorry."

You have more options if you do something ableist to someone you know. You can spend time thinking about what happened. You can think about what you did or didn't do that hurt that person. Then you can talk to them about it and say you're sorry.

The other person might not want to talk about it. That's okay too. Just move on.

If you did something ableist a long time ago that you're still thinking about, you can do something about that too. You don't have to start being extra nice to all disabled people. And you shouldn't bring up something that hurt someone else just to make yourself feel better. But sometimes having a good conversation can help you grow. You can better understand a disabled person’s perspective. And it might help them feel better too.

Calling Out and Calling In Ableism

What should you do if you see something ableist? I try to be kind when I tell someone they are being ableist, but also make sure they understand why I am talking to them about it. I want to get through to people, so I try not to hurt their feelings. Here are some examples:

- Someone uses ableist language while talking to you. You can:
    - Let them finish what they are saying.
    - Say something like, “I just want you to know that [the word they said] is discriminatory toward disabled people. That’s not okay. You could say [a non-ableist word that means the same thing] instead.”
- Someone does something ableist in a large group or in public. You can:
    - Call or message them afterward if it’s someone you know.
    - Say something like, “Hey, I wanted to touch base with you about something I noticed that concerned me. Is now a good time?”
    - If it’s a stranger, you can send them an email telling them what bothered you. You can offer to talk with them more.
- Someone is being ableist to a specific person. You should:
    - Let the person experiencing ableism take the lead.

    - Think about what you can actually contribute.
    - This can be tricky. Don’t say something just because it makes you seem like a good person. Can you actually help the situation? Does the person want you to?
    - If someone is in danger, do what you can to help if you feel safe.

Every situation is different. You won’t always get it right. But be more aware. It can make the world a better, less ableist place.

Chapter 6: Disability in the Media

Read the Chapter 6 Summary

"Indeed, the history of disabled people in the Western world is in part the history of being on display, of being visually conspicuous while being politically and socially erased."

-Rosemarie Garland-Thomson, professor of English and bioethics

- **This quote means:** Nondisabled people stare at disabled people. They treat us like we're a show for them to watch. But they pretend we don't exist when we want to be treated fairly.

My mom Ellen was a kid in the 1970s. One day she saw an ad for a kids' TV show called Zoom. The ad showed a guest star named Dee. And Dee had Larsen syndrome just like my mom! My mom was surprised. She had never seen anyone else with Larsen syndrome other than her brother. The TV station helped my mom get in touch with Dee. They sent letters to each other. They're friends on Facebook now.

After that, my mom didn't see anyone else that looked like her in the media until she was older.

Media includes things like:

- TV
- Movies

- Books
- Magazines
- Advertisements
- Radio

Things got a little better when I was a kid in the 1990s. I remember seeing kids with disabilities like me two times in books or TV:

- When I was little, my mom got me a book called *Patrick and Emma Lou.* It was about two kids in physical therapy. At the end, Patrick is sad about his disability. Emma Lou tells him, “You’re just you, Patrick, and I’m just me.” Reading that made me smile.
- I watched a girl who used a wheelchair on *Sesame Street.* Her name was Tarah Schaeffer.

When I was 10, I got to be on *Sesame Street* too. While I was on the show, I talked about what it is like to have a physical disability. I met Elmo and Big Bird and Oscar the Grouch. It is one of my best memories. I got recognized by people I didn’t know a few times from being on the show. That made me feel like I made an impact. Having people who actually have disabilities in the media makes a difference.

It is hard to find good examples of disability in the media. Disabled people are treated like only their disability matters. They aren’t shown as being real people with personalities.

Most of the time there are no people with disabilities in media at all. An organization called GLAAD wrote a report about who was shown on TV. Here’s what they found:

- They looked at 879 characters on TV.
- 27 of those characters had a disability.

That’s only 3%. That is a lot less than the number of disabled people in the world.

Media doesn’t do a good job showing that all disabled people are different. The same kind of disabled people get shown over and over. They are:

- White
- Straight
- Cisgender
- With a physical disability
- Usually in a wheelchair.

But disabled people look many ways. We come from many kinds of backgrounds. Media needs to show that.

Keah Brown talks about this in her book *The Pretty One.* She says, **“There is nothing inherently wrong about telling the stories of the white and male wheelchair users—their stories are important—but there are also other stories worth telling.”**

- **This quote means:** It’s okay to tell stories about white men who use wheelchairs. But you shouldn’t only tell stories about them. Other disabled people have important stories to share too.

Another problem is disability *stereotypes.* Stereotypes are beliefs about a group of people that are not true. For example, it’s a stereotype that disabled people can’t date or get married. It is not true, but a lot of people think it is. When the media use stereotypes about disability, people think they are true. That changes how nondisabled people think about disability. It also changes how disabled people think about ourselves.

I explain those stereotypes in this chapter. Sometimes they are called “tropes.” Knowing about tropes can help us figure out how to show disability better.

Inspiration Porn

“Inspiration porn” is a term for a certain kind of story. That story is:

- About a disabled person.
- For nondisabled people.
- Told to make nondisabled people feel good.
- Disabled people are *objectified* in inspiration porn. Objectified means they are treated like *things* and not *people.*

Here are some examples of inspiration porn:

- A news story about a paralyzed person who stands up and walks across the stage at their graduation.

- A picture of a wheelchair user exercising with the phrase “What’s your excuse?” written on it.
- A book about a character who “gets over” their disability to do something that seemed impossible.

Many nondisabled people think inspiration porn is good. But there are many problems with it.

Stella Young explains it well. She was a disability activist who made the term “inspiration porn” popular. She gave a TEDx talk about it, saying, **“We’ve been sold the lie that disability is a Bad Thing, capital B, capital T. It’s a bad thing, and to live with a disability makes you exceptional. It’s not a bad thing, and it doesn’t make you exceptional.”**

- **This quote means:** We are told disability is always bad. Disability is not bad. Having a disability isn’t a big deal. Living with a disability shouldn’t make you special.

Inspiration porn is a problem. It makes nondisabled people feel bad for disabled people. It makes people think:

- “Wow, at least my life isn’t *that* bad.”
- “If that person can live with their disability, I can do anything.”

Inspiration porn is everywhere. You have probably seen it before. Here are examples of a few different types.

Overcoming a Challenge

Think about this:

- A photo of a person with a prosthetic leg running on a track. The photo has writing on it that says something like:
    - "Your excuse doesn't count."
    - "The only disability is a bad attitude."

This kind of inspiration porn is supposed to make you want to work hard. It makes you feel guilty that you aren't doing enough. You might think it just means, "anything is possible" if you have a good attitude.

But Stella Young says this is wrong. **"No amount of smiling at a flight of stairs has ever made it turn into a ramp. Never. Smiling at a television screen isn't going to make closed captions appear for people who are deaf. No amount of standing in the middle of a bookshop and radiating a positive attitude is going to turn all those books into Braille. It's just not going to happen."**

- **This quote means:** A good attitude can't fix everything. It won't change the world to be more accessible to disabled people.

But people still think disability is something you can get over by having a good attitude. They think people are disabled because they don't try hard enough not to be. But that isn't true.

Living Life

When most people get married or graduate from school, it's an event they share with their family and friends. When disabled people do these things, their stories often get shared with millions of strangers. Stories like:

- A paralyzed person getting out of their wheelchair for the first dance at their wedding reception.
- A person with Down syndrome graduating high school.

But why do these stories touch people's hearts?

Because some people don't believe that disabled people can live full lives. They don't think we can graduate or get married. So, they think it's special when we do. But many, many disabled people can and do reach these goals.

Not everyone thinks this kind of story hurts disabled people. Some people think I'm being rude when I am talking about inspiration porn because they think I am attacking someone's happy moment. They think I must be angry that I didn't achieve the same thing. That's not true. I think we should celebrate good things. But these stories are a problem. It wouldn't be news if the same thing happened to a nondisabled person.

Big Expectations

Expectations are what someone thinks you can and should do.

The media often shows disabled people in two ways:

- **High expectations** mean disabled people are expected to do amazing things all the time.
- **Low expectations** mean disabled people are not expected to be able to do anything at all.

Most of the time, the media shows us in one of these ways. We are supposed to be either superheroes or nothing. These expectations don’t let us just be people like everyone else.

This can be hard for disabled people. My mom once told me about a news story she saw about disabled veterans climbing mountains. We felt like failures for not being able to climb mountains.

But disabled people don’t have to prove themselves to anyone. We are just like other people.

Not Your Good Deed

Nondisabled people who are nice to disabled people get treated like saints in the media. Some examples of this kind of story:

- Nondisabled students vote to make a disabled student their homecoming queen.
- A nondisabled person asks a disabled person to marry them.

These stories are supposed to make you feel good. You are supposed to think the world is a good place if these kinds of things happen. But why is being nice to a disabled person a news story? Why does loving a disabled person make you a hero?

My family knows about this. My dad Marc is nondisabled. My mom and I are disabled. People treat my dad like he’s a hero for helping us. Someone even called him “Saint Marc.” This is wrong because it:

- Treats all the things my mom and I do to help my dad like they don’t matter.
- Makes it seem like my dad is only important because he is our caregiver.

My dad does more things than some other dads and husbands. But that’s not the only thing that matters about him. He is more than just a person who loves and takes care of disabled family members.

Sometimes, a nondisabled person will film themselves being nice to a disabled person. But:

- They may film the disabled person without asking for permission, which is wrong.
- Helping a disabled person should not be a big deal that needs to be recorded on video.
- It’s wrong to share a private moment online or in the news.
- The focus is on how great and kind the nondisabled person is.

When stories like these are just used to make people feel bad for not being nicer to people or to get a lot of views online, they aren’t really about being kind at all.

What Should You Do?

When you share media that is inspiration porn, you are sharing stereotypes about disability. So, what can you do instead? You can ask these questions:

- Does the media you want to share show the disabled person as a whole human being? Are they doing something that's really inspiring?

OR

- Is the disabled person in the story just being used to make me feel good? Am I feeling inspired because I think disabled people can't do everyday things?

If you answered "Yes" to the second set of questions, that's probably inspiration porn. Don't read or watch it. Don't share it. Or if you do share it, explain why it's bad. That's how we can get other people to change how they think about disability.

Pity Porn

Pity means feeling bad for someone. Pity porn is media that treats all disabilities as sad or tragic. It is supposed to make you feel bad for disabled people.

Physical Disability

Media will treat disability like it's the worst thing that could ever happen to someone. It is shown as being bad for both disabled people and their nondisabled friends and family.

- The annual Labor Day telethon for the Muscular Dystrophy Association (MDA) is an example of pity porn. It was on TV every year from 1966 to 2010. It was hosted by the comedian Jerry Lewis. It was Lewis's job to make people watching feel bad for kids with muscular dystrophy so they would give money to MDA. MDA used the money to look for a cure for muscular dystrophy. Kids with muscular dystrophy were called "Jerry's Kids" on the show. He made it seem like their lives were awful. He even said in an article that they were "half a person" because of their disability. Disability activists didn't like the telethon. But it started again in 2020.

- In *A Christmas Carol* by Charles Dickens*,* there is a character named Tiny Tim who is a little disabled boy. We are supposed to feel bad for him because he is sick and poor. The main character, Ebenezer Scrooge, is a grumpy man who sees Tiny Tim's sad life and learns that he should be happy with his own life. I don't think this story is teaching a good lesson.

- An author named Jojo Moyes wrote a book called *Me Before You.* The book was also made into a movie. The main character's name is Will. He is a happy nondisabled man. Then he becomes paralyzed. He thinks this means his life will now be sad and pointless. He and his caregiver Louisa fall in love. But Will still thinks he will never have a happy life. He decides to end his life. He says that having a disability is worse than being dead. Some people think *Me Before You* is a love story. But it isn't. The main message of the story says that disabled lives are not worth living.

Mental Illness

Media also does not treat people with mental illness well.

s.e. smith is a writer who identifies as mentally ill. smith wrote an article about disability in kids’ books. They said:

“Mental illness is frequently dealt with in very troped, and often harmful, ways, illustrating that creators didn’t take the time to research, learn about the lived experiences of the communities they are writing about, or think about the responsibility involved in depicting mentally ill people, an already marginalised group within our larger culture.”

- **This quote means:** The way mental illness is shown in kids’ books is hurtful. The people who write these books don’t always know the right facts about mental illness. It can make the way people treat people with mental illness even worse.

Magazines often have stories about celebrities’ mental health. They treat it like it’s a joke. One example of this is how media talks about the singer Britney Spears. They make fun of her mental health or use her story to make money. When we read these stories, it’s easy to forget that Spears is a real person. She doesn’t just exist to entertain us.

Mental illness is also shown as scary in the media. If someone does something violent, the media will say they are “mentally ill” or “crazy.” This makes people think everyone with mental illness is dangerous. But that’s not true.

People with mental illness are more likely to *be hurt by others,* not hurt them.

Freaks

Some media stories are about staring at people who look or act different than what is considered "normal."

This has been happening for a long time. There used to be something called "freak shows." Leonard Cassuto writes about them in the book *Keywords for Disability Studies.* He writes: **"Human oddities, whether alive, dead, or stillborn, were confined (often against their will) and categorized through theatrical display."**

- **This quote means:** People who look different were put in shows so other people could stare at them. These people could be living or dead. Some people were forced to do it. They had no choice.

Freak shows made money for nondisabled people. Freak shows do not exist anymore, but you can see similar things on TV or social media.

- One example is shows about "medical mysteries." People like to watch them to see bodies and minds that look or act "weird" and "different." And this can change how people treat disabled people in their real lives.

Melissa Blake is a writer and advocate. She has Freeman-Sheldon syndrome. It is a visible disability that affects how she looks. She says, **"My decision to be so visible and so open about my life and my disability has, indeed, shown me quite a nasty side of people. I've lost count of the number of**

times people have mocked my appearance. These trolls never offer a critique of what I've written; they always go for the insults about my looks. We live in such an appearance-focused society, so if you don't look a certain way, the trolls pounce on that."

- **This quote means:** Blake has been made fun of for how she looks many times. Many people who are mean to her don't say mean things about her writing. They just insult how she looks instead.

Blake fights back against the people who make fun of her. She said, **"Their words hurt, but they've actually motivated me. To be more vocal. To speak up. And, yes, to show my face (hi, selfies!) any chance I get. I may not be able to change everyone's point of view, but I'm determined to show the world that disabled people are here and we're not going anywhere!"**

- **This quote means:** Blake speaks up more now. She puts pictures of herself online. She wants to celebrate herself and prove that disabled people should not have to hide themselves.

Sex and Relationships

A lot of people think disabled people either:

- Can't have sex or fall in love.
- Don't want to have sex or fall in love.
- Shouldn't have sex or fall in love.

There is not a lot of information in the media about sex and disability. And some of the information you can find is wrong. Some people think disabled people are:

- Children
- Breakable
- Not attractive to anyone

Other people *fetishize* disability. That means they treat disabled people like they only exist for sexual reasons. The people who do this are called "devotees."

Disabled people can be sexy and sexual! We can have active, healthy sex lives.

Disabled people can be:

- Cisgender
- Heterosexual
- Lesbian
- Gay
- Bisexual
- Transgender
- Queer

- Intersex (when a person has body parts that are not what doctors usually call “male” or “female.”)
- Asexual (not wanting sexual relationships with anyone.)
- And more.

Some disabled people don’t want to have sex. Some want to have a lot of sex. We all like different things. Just like everyone else.

There is some media about disabled people having sex or falling in love. But there’s not a lot. We are still fighting for the world to see that we can have sex and fall in love too.

The Netflix series *Love on the Spectrum* is a reality show. It is about Autistic people finding love. A lot of nondisabled people liked it. But some Autistic people were not fans. I spoke to Haley Moss about it. Moss is an autistic attorney and activist. She said, **“I think what’s problematic about the show is it views autistic people solely through a neurotypical gaze—what people want to assume and believe autistics are all about. We’re just as human as anyone else (which the show tries to capture); it just ignores a lot of aspects of who we are.”**

- **This quote means:** The show is made by and for people who are not autistic. It focuses on how autistic people are “different” or “weird.” But autistic people are human like everyone else. The show could do a better job showing that.

A lot of media treats disabled people like they should be trying to be “normal.” So how do we fix that?

Marianne Eloise is autistic. She wrote an article about *Love on the Spectrum* for *Cosmopolitan UK.* She wrote, **“What Love on the Spectrum has shown autistic people need, more than anything, is the opportunity to tell our own stories, to not be observed and fetishised.”**

- **This quote means:** Autistic people should get to tell their own stories. Their stories should not be told by nondisabled people.

The whole disability community needs this too.

Good Representation

There are good examples of disability in media too. Showing real disabled people is always the best first step for good representation. We know our lives best.

We have always been telling our own stories. But we don’t always have support to share them. But that is changing. More media is putting disabled people in charge of telling our own stories.

Not all media will do a perfect job of showing disability. For example:

- A news story may use the words “special needs” instead of “disability.” But it makes a good point about ableism.
- A movie may send a bad message about overcoming a disability. But what happens to the disabled character seems like something that could happen

to a disabled person in real life. Representations of disability can be good and bad at the same time.

Netflix has a TV show called *Special.* It is written by and starring Ryan O'Connell. He has cerebral palsy. Watching the show makes me feel like someone else understands what it's like to have a physical disability. It can help nondisabled people understand too.

It makes me happy to see real wheelchair users in ads. A store called Ulta Beauty had an ad with a wheelchair-user named Steph Aiello. Someone took a picture of a young wheelchair user named Maren staring at the ad in awe. I wish I could have seen something like that when I was a kid.

I also love seeing disabled models like:

- Aaron Philip. She is a Black transgender model with cerebral palsy. She's worked with brands likeDove and Sephora.
- Madeline Stuart. She's a model with Down syndrome. She has been in fashion shows in places like New York to Paris.
- Jillian Mercado. She's a Latinx model with muscular dystrophy. She models for Beyoncé's clothing line!
- Nyle DiMarco. He's a deaf activist and actor. He won *America's Next Top Model* in 2015.

The modeling world isn't perfect. Most of the time, models have to look a certain way. They only get modeling jobs if they have "normal" good looks.

But even if they look a certain way, having disabled models still makes a difference.

Nondisabled people should stop pretending to be disabled in movies and TV. Angel Giuffria is an actor with a limb difference. She told me **"At this point in time, where there is such a discrepancy in representation of people with and without disabilities in the media, it's doing a true disservice to the audience to not see accurate or genuine representation or depiction of people with disabilities in daily life."**

- **This quote means:** There are not a lot of disabled people in the media. This means that the media is not always correct about people with disabilities. People deserve to see real disabled people in the media.

Giuffria hopes the media will show all types of humans one day. She said, **"I think at that point, we no longer have to worry about who's playing what or whom because it will be truthful and genuine. But right now is not that time. I think until we get to that point, we need to continue to work toward having disabled actors play disabled characters."**

- **This quote means:** One day, all types of people will appear in the media. But we're not there yet. So, we have to keep fighting for disabled people to play disabled characters.

We need more:

- Disabled characters played by disabled actors.
- Books written by disabled people.

- Disabled models in ads.

We need more disabled people in the media.

Actor Ryan J. Haddad agrees. Haddad has cerebral palsy. He told me, **“Lived experience trumps any sort of research that one can do about what it is to be disabled. We have perspective as people who live disabled lives that no writers who aren’t disabled, no directors who aren’t disabled, no producers who aren’t disabled can impart to an actor who isn’t disabled. If a character is disabled and I’m disabled, all I’m thinking about is how to intentionally bring truth to the words and actions of that character. I don’t have to think about putting on disability because I just am. There’s this barrier between a nondisabled actor and a disabled character that can’t really be penetrated, though Hollywood would have you believe otherwise and gives awards to people who seemingly masterfully portray disability just because they were able to do all those things at once.”**

- **This quote means:** Disabled people know the most about disability. When disabled actors play disabled characters, we don’t have to think about how to pretend to have a disability. We just focus on telling the story truthfully. That’s not something a nondisabled actor can do because they do not understand what it is like to have a disability. But we still give awards to nondisabled actors who pretend to be disabled.

A nondisabled actor playing a disabled character is not inclusion in the media. It’s just a way for the media to make money by showing famous nondisabled people pretending to be disabled.

One day I hope only disabled people will play disabled roles. We won’t have to fight for it anymore. I also hope disabled people will be included in media that is not just about disability.

Giuffria said **“We need to better integrate actors with disabilities into all roles by opening up casting parameters and giving disabled actors the opportunity to audition for more than roles purely about disability.”**

- **This quote means:** Disabled people should get to play all kinds of roles. Not just roles about disability.

That would be the best kind of representation. The media would look like our world. It would celebrate disability as a part of what makes us human.

Conclusion

Read the Conclusion Summary

I am glad you read this book. But there is a lot more to learn about disability. No one can ever know everything about disability. But we should keep trying to learn. And we should take what we learn and make positive changes to how we act and how we treat people. That is called being an *ally.* An ally supports a group of people they are not a part of.

What do you need to do to be an ally to disabled people?

Think about why you want to support disabled people. Don't do it just because you feel bad for us. Don't do it because you feel guilty if you do not have a disability.

Do you want to help people with disabilities? Think about why. Reyma McCoy McDeid is an Autistic advocate. She says, **"If you do not belong to a particular marginalized community and you want to help that community, why do you associate the word 'help' with that community? That really needs to be unpacked before you approach that community."**

- **This quote means:** You may want to help a group of people you are not part of. But before you do, you should think about why you think that group needs help.

Many people think disabled people are helpless. They think we can't do things for ourselves and always need someone else's help. You might think this too. Try to stop thinking this way. Disabled people don’t need to be saved by nondisabled people. We need the world to respect our rights.

McCoy McDeid says you should be more than an ally to people with disabilities. **“To be an ally is to help people who are marginalized in some capacity to make the most of their life in this unchanged system. To be an accomplice, on the other hand, is to work side by side with people who are marginalized, to confront the system and contribute to shifting it accordingly.”**

- **This quote means:** Being an ally means helping people who are treated unfairly. Being an accomplice means working with them. It means helping to change the systems that treat them unfairly.

Sometimes the word *accomplice* means helping someone do a crime. Here it means helping people make changes.

Whatever you call it, you can help make change for people with disabilities. Here’s how.

Being an Ally is a Process

Being an ally takes work every day. It’s not something you do once.

Here’s an example: You want to stop using ableist words. You also want to help other people learn that ableist words are bad. Some days:

- You stop yourself from saying something ableist.
- You don’t notice when you or someone else says something ableist.

- You teach someone why what they said was ableist.

Fixing what you say one time doesn't mean your job as an ally is done. Making changes like this can be hard. It takes practice. Some days you'll get it right. Other days you won't. Being an ally means you keep working on supporting people who are treated unfairly.

Nothing About Us Without Us

"Nothing about us without us" is a slogan that the disability community uses. It means disabled people should be in charge of our own lives. We get left out of conversations about our lives too often. People assume we can't speak up for ourselves. They might think we don't have our own thoughts.

- Reporters talk to parents or "specialists" instead of us.
- Doctors and teachers talk to caregivers instead of us.
- Law makers talk to nondisabled "experts" on disability instead of us.

But disabled people are experts on our own lives. Don't speak over us. Or about us. Or for us. Speak to us and with us.

Nondisabled people often say they are advocates "for" the disability community. It's good to be an advocate. But disabled people need to be in charge. Stand with us. Don't speak up for us without us.

Let Someone Else Speak

If you have privilege, don't use it to always be in the middle of a conversation. Think about who else should get a chance to speak up. This means you should:

- Step back and listen.
- Speak up when other people are ignoring what disabled people have to say.
- Make sure disabled people have a chance to share our thoughts.

This is something both disabled and nondisabled people should do. We need to learn when to step up and when to step back. Naomi Ortiz is an author and artist. She works on Disability Justice, intersectionality, and self-care for activists. I asked her about letting someone else speak. She said, **"[It] is not a one-time thing. It's a series of choices to build relationships, learn together, disagree without silencing the other. It's about building up our capacity to honor difference and appreciate the messiness."**

- **This quote means:** It takes time to learn when it is someone else's turn to speak. We need to learn together. We won't always agree with other people about what they're saying. But when we don't agree with someone who thinks differently, we shouldn't just make them be quiet. We need to learn to be thankful for the ways we are not the same.

Don’t Pretend to Have a Disability

Some trainings about disability will have nondisabled people pretend to have disabilities to learn what it’s like. They may have you:

- Wear earplugs.
- Wear a blindfold.
- Push yourself in a wheelchair.
- Walk using crutches.

You may think you can understand disability by doing these things. But you can’t. It won’t help you learn about a disabled person’s life. It could actually end up making you afraid of disability.

In college, the resident assistant (RA) in the dorm where I lived asked if she could borrow my wheelchair. She wanted to use it for a disability awareness event. She made an obstacle course for people to wheel through because she thought it would teach people about disability. I would have been stuck in my room while they played games with my wheelchair. This made me feel like the RA didn’t really care about teaching nondisabled people about disability. She just wanted them to have fun pretending to be me. I told her that she could not use my wheelchair.

Don’t pretend to have disabilities to learn about them. Listen to disabled people instead. You can:

- Read books about disability.

- Watch documentaries about disability.
- Listen to podcasts about disability.
- Invite disabled people to speak to your group.
- Have conversations with disabled people.

Give Credit to Disabled People for Their Work

Many people with disabilities take time to teach the people around them about disability. They share stories of painful things that have happened to them. They teach about ableism. They push for change. It can feel good to teach people. But teaching about disability can also be tiring. It can be hard to do it over and over again. Not every disabled person wants to teach people about disability.

So, we should give credit to the disabled people who do take time to teach others. Pay them for their work. Disabled people need to earn money too!

Say Sorry When You Make Mistakes

Being an ally isn’t always easy. You may not know what to do. You may make a mistake. That happens to all of us.

It can be hard to say you’re sorry when you make a mistake. You may get mad or uncomfortable. But think about how what you did may have hurt someone else.

Say sorry when you can. Learn from your mistake. Don’t make the same one in the future.

Mia Mingus is a Disability Justice activist. She writes a blog called *Leaving Evidence.* She wrote that saying sorry if you make a mistake is not enough. **"True accountability is not only apologizing, but understanding the impacts your actions have caused on yourself and others and then making amends or reparations to the harmed parties. But most important, true accountability is changing your behavior so that the harm, violence, and abuse does not happen again."**

- **This quote means:** Saying sorry is not enough. You need to understand how your mistake hurt others or yourself. You should make it up to them. You also need to change how you act in the future so you don't hurt people again.

Being an ally is something you work on every day.

Keep Learning

Ableism is everywhere. It teaches us that disability is bad. It can be hard to change how we think. Sometimes it might feel like the world will always be unfair for people with disabilities. I have felt that way.

But I remind myself that I can make small changes. I can change one person's mind about disability. And that is a start.

I hope this book will be a start for you to make changes too. Thank you for letting me help you learn. Keep going.