Inclusive Language Playbook: Writing About Disability





Table of Contents -

Introduction	.3
What Is a Disability?	.5
Understanding Diverse Perspectives on Disability	.5
Individual Perspectives on Disability	.6
Person-First and Identify-First Language	.7
Language Choices1	1
Simple Word Swaps1	2
More Complex Language Choices1	4
Neurodiversity1	9
Additional Topics2	21
Inspirational Framing2	22
Self-Diagnosis2	23
Helpful Resources2	25
Acknowledgements2	26

Introduction

t CommunicateHealth (CH), we're deeply committed to <u>equity-centered health communication</u>. This includes developing health communications that make everyone feel seen, included, and respected. And that can be especially important when writing for or about disabled people.¹

As we've emphasized in previous publications, language especially as it relates to identity — is both extremely powerful and evolving extremely quickly! Although there's no generalizable approach to writing about disabled people, there are some words and phrases that we can all agree are best to avoid — and some considerations that can make a big difference when you're writing for this audience.

According to data from the Centers for Disease Control and Prevention (CDC), up to 1 in 4 adults in the United States reports living with at least 1 disability.²





The reality is that disabled people must deal with inequities created by ableism every day. And as health communicators, we have a responsibility to do our very best to create health communication materials that respectfully reflect the identities and experiences of our disabled audiences. That is, inherently, an equity-centered approach — and it's very important in this space.

A quick disclaimer here that this is not meant to be an exhaustive resource — and, as always, we don't claim to have all the answers. Rather, this is meant as a jumping-off point to capture some best practices and considerations as we continue to learn from disabled people about their health information-related needs and preferences.

Finally, this is the second in what we hope to be a series of playbooks on inclusive language. If you haven't already, be sure to check out <u>Inclusive Language Playbook: Writing for LGBTQ+</u> <u>Communities</u>.

¹ For the purposes of this playbook, we're mostly using "disabled people" (identityfirst language) instead of "people with disabilities" (person-first language). This is a very intentional choice, following the lead of disability community leaders, and we acknowledge it may not be everyone's preference. We explore the conversation about person-first language vs. identity-first language in detail on page 12.

² <u>https://www.cdc.gov/disability-and-health/articles-documents/disability-impacts-all-of-us-infographic.html</u>

What Is a Disability?

Let's start with the basics: What is a disability? CDC defines disability as **any condition that makes it more difficult for people to do certain activities and interact with the world around them**. Disabilities can shape many aspects of how people perceive and move through the world, including:

- Vision and hearing
- Movement
- Social relationships
- Thinking, learning, and remembering
- Communication
- Mental health





Understanding Diverse Perspectives on Disability

Activists and scholars have created models of disability — different ways of explaining what disability is and how it affects our lives. Here are just a few examples:

- The **medical model** views disability as a health problem caused by impairments or limitations within a person's body. This model focuses on treatment, addressing symptoms to help the disabled person care for themselves and move through the world more easily. Critics of the medical model argue that it frames disability as something wrong with the person that needs to be normalized or corrected.
- The social model focuses on the fact that, like health literacy, disability involves interactions between people and systems. The social model argues that disability is created by barriers in society, not by individual limitations alone. Ableism the belief that disabled people are inherently inferior contributes to these barriers. Essentially, society makes people "disabled" by making it hard (or even impossible!) for them to access public spaces and participate in social life.
- The **human rights model** argues that disability is a valuable part of human diversity, and disabled people deserve the same rights as non-disabled people. Like the social model, the human rights model highlights the obstacles that disabled people face in society. The human rights model also celebrates how disability can be a source of pride, identity, and community for disabled people.
- The disability justice model focuses on intersectionality, examining ableism as it relates to other types of oppression. Conceived by the Disability Justice Collective, a group of queer disabled activists of color, disability justice centers the needs and lived experiences of multiply marginalized disabled people. For example, disabled people of color may experience both racism and ableism. Disability justice emphasizes that all bodies are unique and essential, and all have strengths and needs that must be met.

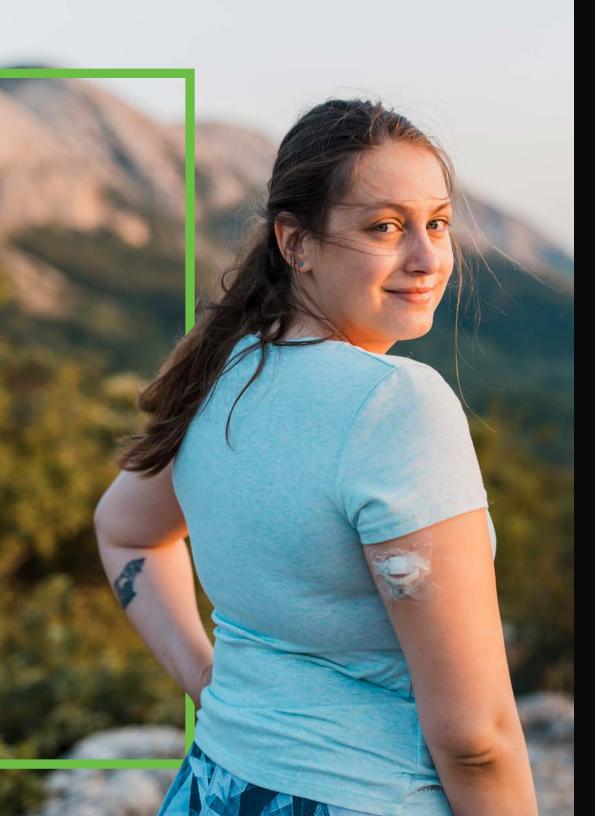
The social, human rights, and disability justice models challenge us to eliminate ableism and work toward a world in which disabled people can thrive. Of course, even in an ableism-free world, living with a disability would come with challenges, and it's important to acknowledge that reality. But reflecting on how stigma, discrimination, and bias affect the well-being of disabled people is a great place to start.



Individual Perspectives on Disability

Everyone who has a disability has their own **relationship with disability**. Some people see disability as an important part of who they are, while others may not see themselves as having a disability at all. And many people fall somewhere in between! Many factors can shape how people perceive their disability. For example:

- **Family and cultural views on disability.** Cultural ideas about disability shape the views that family members pass on to disabled people. For example, if a well-meaning parent or guardian teaches their child to hide or minimize aspects of their disability to avoid discrimination, the child may learn to feel ashamed of their disability.
- **Experiencing ableism.** People who have experienced discrimination and stigma because of their disability may internalize negative beliefs about their condition.
- Intersecting identities. Other aspects of a person's identity like race and gender — can shape their experience as a disabled person. For example, disabled people of color are likely to face multiple types of discrimination.
- Access to a diagnosis and resources. Because of bias in our health care system, it can be harder for people of color, women, and transgender or nonbinary people to get an accurate diagnosis and the support they need to thrive. On the other hand, getting a diagnosis can lead to stigma and discrimination.
 - **Participating in activism, self-advocacy, or online disability communities.** People who engage in advocacy or communities focused on disability are more likely to see their disability as an important part of who they are.



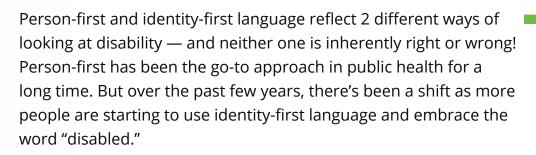
These factors also shape how people think about treatment options for their disability. Even within disability communities, people may disagree on what treatment options are helpful or harmful — or what conditions should be treated at all.

So when you're writing about these emotionally charged topics, **take time to learn about different points of view.**

Person-First and Identify-First Language

There are 2 main approaches to writing about people who have disabilities: person-first and identity-first language:

- Person-first language (e.g., people with disabilities, person with epilepsy) emphasizes the person's humanity, reminding us that people are more than their disability.
- Identify-first language (e.g., disabled people, epileptic person) centers disability as part of a person's identity.



Why do some people prefer the identity-first approach? We certainly can't speak for everyone — but for some, especially people who have experienced ableism or discrimination, using identity-first language is a way to reclaim disability as an important part of their identity. In the same way that LGBTQ+ people have reclaimed the word "queer," some people have embraced identity-first language to challenge stigma — and many find healing in the visibility that language brings.

So which one do I use?

It's tricky, right?! The key is to learn about your audience and take your cue from them. Talking to your audience directly through research is the best way to find out what language they prefer. It's worth noting that style experts agree: The Publication Manual of the American Psychological Association (APA), Associated Press (AP) Stylebook, and other commonly used guides recommend following audience preferences on person-first and identity-first language.

If you don't have time or budget for audience research, try less formal ways to learn about your audience. For example, you could consult resources created by and for your audience — advocacy org websites are a great place to start.



As a rule of thumb, **you might consider using identity-first language if**:

- Your audience has expressed a strong preference for identity-first language. For example, many Deaf and autistic people prefer identify-first language because they see their condition as an important part of who they are.
- Your audience is involved in disability advocacy or online disability communities.
- You're writing about issues related to equity, social justice, or disability rights.

Person-first language is still usually the default in public health and health care. So **if you're writing for a broader audience or you can't find out what language your audience prefers**, person-first may be the safer bet.

Keep in mind that **people who share the same disability are bound to have different opinions on language**. There's no universal experience of disability, and language is always evolving. The best we can do as health communicators is to listen to our audience and follow their lead.

Language Choices



Simple Word Swaps

Writing about disability can be complex. In the table below, we've offered suggestions for which words to use — and which to avoid.

Use this	Instead of this	Tips and notes
Intellectual and developmental disability (IDD) People with intellectual and developmental disabilities (IDD)	Mental retardation Mentally retarded	"Retarded" was once used as a clinical term to describe people with IDD. Today, it's a slur.
Disabled people, people with disabilities	Handicapped, crippled, spastic, invalid, challenged	These older terms may be offensive to some readers.
Nondisabled people, people without disabilities	Able-bodied people, healthy people, normal people	Keep this in mind when writing about people who don't have disabilities.
Wheelchair user, uses a wheelchair	Wheelchair-bound, confined to a wheelchair	Words like "bound" and "confined" imply that using a wheelchair is inherently negative. Saying that someone "uses" a wheelchair carries a more neutral connotation.

Simple Word Swaps (continued)

Use this	Instead of this	Tips and notes
Typical	Normal	Disabled people are often stigmatized because their bodies or minds don't conform to medical or social standards of normalcy. Using "normal" — even in a medical context — implies that there's a correct way to be. "Typical" is a neutral alternative.
Disabled people, people with disabilities	Euphemisms like differently abled or handicapable	Some disabled people feel that euphemisms like "differently abled" are patronizing and offensive. Though these terms are often used with good intentions, activists have argued that they can reinforce the idea of disability as something to hide.
Neurodivergent person	Neurodiverse person	A "neurodivergent" person is someone whose way of thinking and processing diverges from the norm. Just like "diverse," "neurodiverse" is an adjective that's only used to refer to a group of people — in this case, a group of people with different ways of thinking and processing. For more on neurodiversity and related terms, see page 19.
Little person, person of short stature, person with dwarfism	Midget, dwarf	Similar to "retarded," "midget" is now considered a slur. While some people may use the word "dwarf" to describe themselves, "little person," "person of short stature," and "person with dwarfism" are more commonly accepted terms.
Non-apparent disability	Invisible disability	"Invisible disability" is often used to describe disabilities that aren't apparent or visible. Some disabled people prefer "non-apparent" disability, which encompasses a broader range of conditions that may not be immediately noticeable.



More Complex Language Choices

The following terms are sometimes used in a medical context. While some people like and identify with them, others may find them offputting. If you're writing about these topics, take time to consider your language thoughtfully. If you can, do some research to find out how your audience feels about these terms and what language they prefer.

Impaired, impairment

We often hear phrases like "visually impaired," and "impairment" comes up in legal definitions of disability. While some people use these terms to describe their experience of disability, others dislike "impairment"-based language. The concept of impairment compares disabled people to a normative standard, and some disabled people reject this framing.

Try this: Ask your audience how they would describe their disability or health condition and follow their lead.

Early intervention

This term refers to treatment options or services for very young children with disabilities. Speech and occupational therapy are common examples of early intervention services. We recognize that this term is so embedded in our health care system, it's not going away anytime soon. But for some disabled readers, early intervention implies that health care providers are "intervening" to normalize children or make them less disabled.



If you're wondering, "wait, that kind of is the goal of early intervention, right?"... well, that's exactly why this topic is so complex. There's a fine line between helping a child thrive and helping them assimilate into a society designed for nondisabled people. And when it comes to early intervention, parents or guardians must make big treatment decisions before their kids are old enough to give consent.

Try this: "Early support" is framed more positively, as it focuses on supporting the child rather than "intervening." Consider introducing this new term with an example (e.g., "early support services like speech therapy").

High-functioning, low-functioning

Health care providers may use "high-functioning" and "low-functioning" to assess how a disabled person, well, functions compared to nondisabled peers. Historically, the term "low-functioning" has been used to deny disabled people rights and autonomy. On the flip side, "high-functioning" has been used to dismiss people's struggles and to reinforce a harmful expectation that everyone should strive to pass for "normal." Plus, some disabled people have argued that functioning labels create a false binary, as symptoms or traits of some disabilities can fluctuate from day to day.

Try this: Some disabled people use the terms "low, medium, and high support needs" to describe their experience. This switch shifts the focus from how well someone is "functioning" compared to a normative standard to what support they need to thrive. Another option is to get more specific about what type of support people need. For example, instead of describing someone as "low-functioning," explain that they may need help with daily care tasks like feeding and dressing themselves.



Asperger's syndrome

From time to time, we still hear the older term "Asperger's syndrome" (often shortened to "Asperger's"). In 2013, Asperger's syndrome was taken out of the Diagnostic and Statistical Manual of Mental Disorders (DSM) and folded into the broader diagnosis of autism spectrum disorder (ASD). Plus, some people have criticized Asperger's terminology because of its **historical context.**

Try this: Our suggestion is to use "autism" unless you're writing for or about people who specifically identify as having Asperger's syndrome.

On the (autism) spectrum

In our experience, the phrase "on the spectrum" evokes mixed reactions. Some people self-identify with the phrase, while others dislike it. And some non-autistic people have used it in a derogatory way, much like "retarded." That said, since autism is often described as a "spectrum disorder," we doubt that "on the spectrum" is going away anytime soon.

Try this: As we mentioned earlier, many people prefer to describe themselves as "autistic" (using identity-first language). But, as with any disability, people see their relationship to autism differently based on their own experience. It's always a good idea to check in with your audience and ask what terms they prefer.

Special needs

While "special needs" is still widely used, some disabled readers may find it patronizing and othering. Similar to euphemisms like "differently abled," activists have argued that "special needs" perpetuates stigma.

Some health organizations use the term "special health care needs" to refer to disabilities and chronic health conditions. While this phrase doesn't carry the same baggage as special needs, some people may still object to the word "special" in a disability context.

Try this: Describe the group of people you're talking about more specifically. For example, instead of "children with special needs," you could spell out "children with disabilities and chronic health conditions." If you're describing support disabled people may need, like a wheelchair or ASL interpreter, "accommodations" is a potential alternative. And never use "special needs" as a modifier (e.g., "special-needs kids").

Nonspeaking, nonverbal

Both terms refer to people who don't communicate using spoken language or don't use spoken language as their primary form of communication. While "nonverbal" is more widely known, some people prefer "nonspeaking." The difference? There are some types of verbal communication that aren't speech, so some people feel that "nonspeaking" is more accurate.

Try this: When possible, ask your audience which term they prefer. In this case, your audience may include caregivers or loved ones as well as people who are nonspeaking/ nonverbal. Another option is to use "nonverbal or nonspeaking" on first mention, then use "nonverbal" throughout the rest of your material since it's the most widely known term.





Terms related to speech, hearing, and sight

English has plenty of expressions that use words like "hear," "see," or "voice" in a non-literal way (e.g., phrases like "hear Jane's story"). While many disabled people use these expressions, some may find them insensitive.

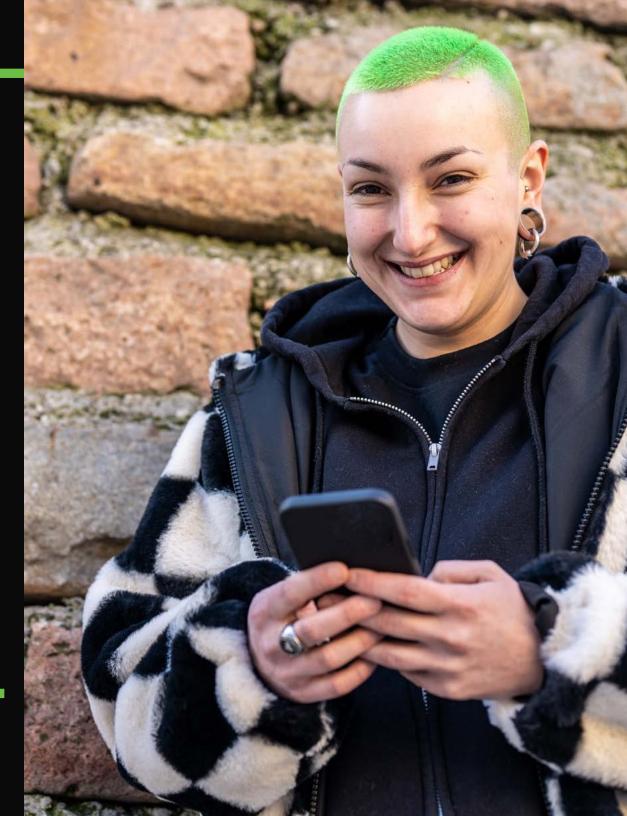
Try this: Consider asking your audience for input on phrases that refer to hearing, sight, or speech.

Terms with value judgments (e.g., victim, suffers from)

It's very common to talk about disabled people in ways that inherently make a value judgment about them and their condition. Terms like "stroke victim" or "birth defect" come with immediate negative connotations about individuals. Same goes for noting that people "suffer from" a disability or health condition. This makes a lot of assumptions about the disabled person — it's very possible they're not "suffering" at all. And even if they are, they should be the ones to communicate that.

Try this: Choose neutral language instead — for example, "person who has had a stroke" or "congenital disability." And rather than noting people are "suffering" from a disability or condition, just say they "have" it.

Neurodiversity



Neurodiversity is the idea that diversity in thinking and processing is natural and valuable to humanity. This paradigm challenges us to question our biases about conditions that are often stigmatized. The term often comes up in conversations about autism and ADHD (attentiondeficit/hyperactivity disorder). But many other conditions fall under the umbrella of neurodiversity — including intellectual and developmental disabilities, neurological disorders, and mental health conditions.

Let's unpack a few commonly used terms related to neurodiversity:

- **Neurodivergent:** Describes a person whose way of thinking and processing diverges from the norm
- **Neurodivergence:** A way of thinking and processing that diverges from the norm
- **Neurodiverse:** Describes a group that includes people with different ways of thinking and processing
- Neurotypical: Describes a person whose way of thinking and processing aligns with the norm (i.e., the "typical" expectations of society)
- Neurodiversity-affirming: An approach to providing health care, therapy, or support services that affirms neurodivergence as an important part of a person's identity

As public awareness of neurodiversity continues to grow, language is sure to evolve — so when you're writing about the topic, it's especially important to follow your audience's lead.

Additional Topics





Inspirational Framing

Popular narratives about disabled people are often designed to make us feel warm and fuzzy inside. (Imagine a poster with a photo of a smiling wheelchair user paired with a quote like, "The only disability in life is a bad attitude.") These images and stories frame disabled people as "objects of inspiration." Rather than centering the disabled person's experience, this inspirational framing highlights how the disabled person inspires or warms the hearts of others — merely by existing. While plenty of people have made this type of content with good intentions, it paints a one-dimensional picture that can reinforce stereotypes of disability as something inherently negative or something to be overcome.

In a similar vein, some pop culture narratives cast disabled people as "superheroes," framing their condition as a "superpower." While some disabled people may find these narratives empowering, others feel they're dehumanizing. Why? Superhero narratives can imply that disabled people are only worthy of admiration if they have a special "power," or if their disability gives them desirable skills. This can be a demoralizing idea for people who have experienced ableism in school and in the workplace. Many disability advocates say they would rather be treated as regular people who have strengths and weaknesses, just like anyone else.

Try this: Avoid narratives that portray disabled people as inspirational, heartwarming, or superhuman. Of course, it's great to celebrate the accomplishments of disabled people — but it's also important to center the disabled person's perspective.



Self-Diagnosis

Over the past few years, self-diagnosis has become a hot topic. Social media platforms like TikTok have created new ways for people to learn about disabilities, chronic illnesses, and mental health conditions. With all this content about oft-stigmatized topics at our fingertips, some health professionals have shared concerns that more people are diagnosing themselves via online research.

As health communicators, we know there's a ton of misinformation online — and when people are overwhelmed or have limited context about a topic, they may take social content at face value. An inaccurate self-diagnosis could steer someone down the wrong path, leading them to seek care that doesn't match their needs. Plus, people need a formal diagnosis to access some treatment options, accommodations, and other resources.

While we don't want to minimize these risks, we think it's worth considering the reasons why people may self-diagnose. Because of bias in our health care system, it can be harder for many people to get accurate diagnoses, including people of color, women, transgender or nonbinary people, and people at a higher weight. Also, getting a diagnosis for tricky-to-identify conditions often means seeing multiple specialists, which can be complicated — and very expensive. And for many people, especially in rural areas, it can be hard to even find a specialist close to home.

For some people, self-diagnosis can be a stepping stone to a formal diagnosis. Others may choose not to pursue a diagnosis because having that "label" on their medical record could lead to discrimination. For example, some U.S. states have passed laws that restrict access to gender-affirming care for people with specific diagnoses. Until and unless medical discrimination becomes a thing of the past, self-diagnosis will continue to fill unmet needs. If we don't acknowledge that reality, we risk alienating people who may already feel unheard.

So how can health communicators approach self-diagnosis without alienating our audiences? We have some ideas:

- **Meet people where they are.** Acknowledge common barriers to diagnosis like bias in the health care system, long wait times, and expensive assessments.
- **Stick to the facts.** If you're addressing misinformation, focus on sharing reliable info and avoid commenting on people's personal experiences.
- Share guidance to help people advocate for themselves at the doctor's office.
- **Explain the benefits and risks of pursuing a formal diagnosis** so readers can make an informed decision based on their own situation.
- Suggest ways to make diagnosis more affordable, like sliding scale providers or organizations that provide funding for people seeking a diagnosis.
- **Recommend specialists who have experience working with your audience,** like doctors who specialize in diagnosing learning disabilities in adults, for example.
- **Clarify who qualifies for services.** If your organization provides services for people with specific health conditions, note if people need a formal diagnosis to qualify.

If we come to the conversation with empathy, we can build trust and empower our audiences to make informed decisions about seeking a diagnosis.

Helpful Resources

Websites

- <u>10 Principles of Disability Justice by</u> <u>Sins Invalid</u>
- Ableism 101
- ADA 30 In Color
- American Public Health Association (APHA): Addressing Intellectual and Developmental Disabilities as a Health Equity Imperative
- <u>APHA: Disability and Health Resources</u>
- The Americans with Disabilities Act (ADA)
- <u>Autistic Women and Nonbinary Network</u>
- Disability Justice Audit Tool
- Introducing the Human Rights Model of Disability
- Invisible Disability Project
- Longmore Institute on Disability
- <u>United Nations (UN): Disability Inclusive</u>
 <u>Language Guidelines</u>

Books

- Demystifying Disability: What to Know, What to Say, and How to Be an Ally by Emily Ladau
- Care Work: Dreaming Disability Justice and The Future Is Disabled by Leah Lakshmi Piepzna-Samarasinha
- Disability Visibility: First-Person Stories from the Twenty-First Century, edited by Alice Wong
- We're Not Broken: Changing the Autism Conversation by Eric Garcia
- The Pretty One by Keah Brown

Social Media Accounts³

- <u>Disability:IN</u>
- <u>Diversability</u>®
- Keah Brown
- <u>Shane Burcaw</u>
- <u>Annie Elainey</u>
- Emily Ladau
- Morenike Giwa Onaiwu
- Ludmila Praslova
- <u>Alice Wong</u>

³ The opinions expressed on these accounts are those of the account owners and do not necessarily reflect the views of CommunicateHealth.

Acknowledgements

At CommunicateHealth, we believe inclusive communication starts with humility. That's how we always try to approach our publications, and this one is no exception. Again, we know that there's no one-size-fits-all approach to writing for or about any audience. But we're happy to contribute this resource to the ongoing conversation about respectful, inclusive communication with people who have disabilities. And we hope it will prove helpful to our fellow health communicators.

On a related note, please share any feedback you have about this playbook! We're always interested in your thoughts on how we can improve our resources. After all, you're our audience.

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