

THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT Lurie Institute for Disability Policy

# Lurie Institute for Disability Policy Inclusive Language

# Usage Guide

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## **About the Lurie Institute for Disability Policy**

Created in 2007 with a generous gift from the Nancy Lurie Marks Foundation, The Lurie Institute for Disability Policy at Brandeis University's Heller School for Social Policy and Management leads research that helps shape policies, programs, and practices which improve the lives of people with disabilities across the lifespan. To that end, we conduct cross-disciplinary research on real-life issues affecting people with disabilities, including health and health care, parenting, home- and communitybased supports, and more.

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AND MANAGEMENT

## Introduction

Research communications should hew closer to the preferences of people with disabilities and chronic health conditions. The use of language can shape attitudes toward disability and health; in turn, attitudes toward disability and health can also shape the language used to describe it. Our goal, therefore, as researchers and communicators of research, is to use language that affirms the existence, experiences, and rights of people with disabilities. Toward that end, this guide contains concrete suggestions and rationales for making language more respectful.

There are no hard-and-fast rules for using inclusive language, however: Remember that every person with a disability is different. For example, some disability communities, like the autistic, blind, and Deaf Marginalized groups fight over terminology precisely because control over your representation is a form of power. [...] Having the power of naming means framing the terms of discussion. That can be liberating for oppressed groups.

-Sarah Grey, "Euphemism Is Dead"

communities, prefer identity-first language, while others, like people with intellectual disabilities or cerebral palsy, prefer person-first language. People's preferences have a number of sources, including cultural norms, ideas about disability, and personal experiences. *When in doubt, ask!* 

This is a living document; recommendations may change as we continue to learn how to make our language more inclusive.

# Autistic person or person on the autism spectrum

Like the Deaf community, many autistic people prefer *autistic person* to *person with autism* (see person with autism). From Lydia Brown's "Identity-First Language":

Yet, when we say "Autistic person," we recognize, affirm, and validate an individual's identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person — that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something.

#### Blind

Like autistic and Deaf/deaf people, blind people tend to prefer *blind*. Be wary, however, of the metaphor "blind to" (see *Disability as Metaphor*).

# Congenital disabilities or congenital conditions

Prefer to birth defects.

#### **Co-occurring conditions**

This term is more neutral—and easier for people to understand—than "comorbidities."

#### Deaf or deaf

Many deaf (or Deaf) people prefer identity-first language, so use *deaf people* or *Deaf people* rather than *people with deafness*. Capital *Deaf* refers to people in a specific Deaf subculture who often use signed languages to communicate. Lowercase *deaf* is a general term to refer to anyone with significant hearing loss.

#### Hard of hearing

*Hard of hearing* is preferable to "hearing impaired."

#### High or low support needs

More accurate and less demeaning than *highand low-functioning*. "High-functioning" has been used as a synonym for "average or aboveaverage intelligence"; intellectual ability is not the same as the ability to manage activities of daily living.

#### Higher-weight/high weight

Less stigmatizing than "obese" and "obesity."

# Little people, people with dwarfism, or people of short stature

More respectful and less pathologizing than "dwarf."

#### People with cerebral palsy

Like other people with physical disabilities, people with cerebral palsy tend to use personfirst language.

#### People with intellectual disabilities

Members of this community generally prefer people-first language—*people with intellectual disabilities*—over *intellectually disabled people*.

It's similar for specific conditions associated with ID: use *person with Down Syndrome*, not *Down Syndrome person*.

## People with disabilities or disabled people

*People with disabilities* is widely accepted, though some people with disabilities are fine with disabled people, too. s.e. smith has a more exhaustive <u>explanation</u> on *The Daily Dot.* Avoid phrases like "the disabled," "the blind," or "the deaf."

#### Wheelchair user or person in a wheelchair

"Wheelchair user" and "person in a wheelchair" are value-neutral terms that don't insinuate that people are bound or confined to their mobility devices.

### Part 2: Language to Watch 🤚

Changing a phrase — even if it holds the same literal meaning alters the subtle connotations and nuances of the speech, and communicates a different meaning and context than the original phrasing.

—Lydia Brown, "Identity-First Language"

#### Asperger Syndrome/Asperger's

Before the release of the *DSM-5* in 2013, *Asperger Syndrome* was a diagnosis often used to describe autistic people who did not have a speech delay or an intellectual disability. Only use when referring to historical diagnoses, or if a specific person refers to themselves that way. Otherwise, simply say "autistic" or "on the autism spectrum."

#### **Birth defects**

Use *congenital disabilities* or specific conditions (e.g. cleft palate, scoliosis, osteogenesis imperfecta) instead.

#### **Cognitive disabilities**

Refers to any disability that affects thinking, remembering, or planning. These disabilities include the *developmental disabilities* and conditions acquired during adulthood, like traumatic brain injury, acquired seizure disorders, or Alzheimer's and other dementias.

#### Comorbid/Comorbidity

"Co-occurring conditions" is often clearer and more neutral. The connotations of "morbid" may not work for every co-occurring condition.

#### Deficits

Unless you're talking about a government budget, be mindful when using the term "deficit."

#### **Developmental disabilities** See *intellectual and developmental disabilities*.

#### **Disease or disorder**

While conditions like tuberculosis, diabetes, and cancer are rightly called "diseases," using this label for many disabilities like autism and deafness can come across as insulting or condescending. "Disorder" is also under dispute for some conditions, though it is less controversial than "disease." *Condition* or *disability* is preferable to disorder unless you are using a diagnostic label.

#### Diagnostic labels in general

While some diagnostic labels are accepted both by researchers and community members, there are others that are more contentious. See *mental retardation* and *obesity*, for example.

#### **Disability as metaphor**

Be thoughtful about using disabilities or illnesses as metaphors for other ideas. Some of these metaphors include "being *blind* to a problem," "the complaint fell on *deaf ears*," or "political polarization is a *plague* on American civic life."

#### Exceptional

When referring to a disability, just use "disability" or refer to a specific support need. Beware of the term "exceptional" as a euphemism for intellectual disability.

#### Healthy

Examine what you mean by *healthy*. Avoid using "healthy" in contrast with "disabled."

#### IDD

#### See intellectual and developmental disabilities.

#### Impairment

While some disabilities may be considered impairments, those that have an associated community or culture (e.g., Deaf and autistic people) may not want their disabilities called "impairments."

#### Intelligence

Clarify what you mean by "intelligence." Do you mean the general ability to learn, understand information, and recognize patterns, or are you talking about IQ test performance?

If the latter, remember that IQ tests measure only certain components of intelligence, and that many people with disabilities that affect their verbal or motor skills may underperform on these tests. In addition, many of them have a history of racial, gender, and other forms of bias.



# Intellectual and developmental disabilities (IDD)

*Developmental disability* is an umbrella term to refer to cognitive disabilities that occur during childhood and adolescence. These disabilities include intellectual disability, cerebral palsy, fetal alcohol syndrome disorders, fragile X, Down Syndrome, and autism. Intellectual disability is only one kind of DD. There are many people who have a DD who do not have an ID, but all people with ID have a DD. Note that people with intellectual disabilities tend to prefer person-first language.

#### Learning disability

Some British documents say "learning disability" to refer to an intellectual disability. In America, Canada, Australia, and other countries, people use "intellectual disability." In these countries, "learning disability" refers to specific disabilities like dyslexia, dysgraphia, and dyscalculia.

#### Lived experience

While this phrase is common to refer to people with disabilities, it can sometimes come across as euphemistic. "Disabled people" or "people with disabilities" may be clearer.

#### **Mental illness**

Some professionals and self-advocates are shifting toward *psychiatric disability*. Avoid *mental disease*. Also avoid terms like "mental patient" or "mentally ill clients."

#### Normal

*Normal* often sounds like a value judgment. Instead, use *typically developing, non-disabled,* or other value-neutral terms, unless you are using *normal* to refer to other phenomena, like the normal statistical curve.

#### Obesity

While *obese* and *obesity* are diagnostic terms that insurance companies and researchers use, they are often considered stigmatizing and insulting. If you need to refer to the medical label, try "meets criteria for an obesity diagnosis."

Minimize the use of the term when referring to people in general. Avoid referring to "obese patients." In plain-language writing, just say "high weight."

*Note*: Weight stigma is a barrier to receiving responsive health care. This intersects with

racism, classism, and other forms of marginalization: people from marginalized groups are less likely to have access to affordable healthy food options. Stress and anxiety can also cause metabolic problems. The language frequently used to describe the relationship between weight and health is often focused on the individual's "lifestyle problems," rather than systems and processes that affect people's health.

## Person with autism/person with autism spectrum disorder (ASD)

Many autistic people actively dislike *person with autism*. Much of the insistence on *person with autism* comes from non-autistic parents or professionals, not autistic people themselves. In addition, the "disorder" label is firmly situated in a purely medical model; many autistic people use a social model or a combined medical/social model. If you need to refer to a diagnostic category in a paper, say "have an ASD diagnosis" or similar. Don't go overboard and say things like "person with a lived experience of autism spectrum disorder."

#### Person- and identity-first language

There are some patterns—people with physical and intellectual disabilities often prefer personfirst language, while autistic people and people with sensory disabilities (e.g. blind people) often prefer identity-first language. As is already clear, person-first language is a complex issue depending on the condition and the person. Usually, with clear diseases like epilepsy and diabetes, it's always best to use personfirst language: men with diabetes, children with epilepsy. Although some controversy exists about obesity as a disease state, person-first language is also recommended: "man with obesity" is preferred to "obese man."

—Tara Haelle, "Identity-first vs. person-first language is an important distinction"

#### Addict and similar terms

People-first language, like "people with addictions," "people in recovery," and "people with substance use disorder" is preferable. Avoid terms like *addict*, *substance abuse*, *junkie*, and *drug abuse*.

#### **Birth defects**

"Congenital disabilities" is less stigmatizing.

#### Burden

Many publications refer to "the financial burden of raising a child with a disability." Though it's often unintentional, connecting the term "burden" with disability implies that people with disabilities themselves are the burdens.

## Differently abled, handicapable, and other cloying terms

Like "special needs," "differently abled" is an ill-advised euphemism for "disabled." The same applies to "handicapable."

#### Handicap or handicapped

#### Use *disability* instead of *handicap*.

"Handicapped" parking spaces or bathrooms are better referred to as *accessible parking* or *bathrooms*.

#### **Hearing impaired**

*Hard of hearing* is the preferred term.

#### High- and low-functioning

These terms are imprecise; people's skills vary contextually. Someone may have excellent academic skills, but may also struggle with housekeeping and activities of daily living. Refer instead to support needs: *high support needs* instead of *low-functioning*.

#### **Intellectually disabled** Use *people with intellectual disabilities*.

**Intellectual deficiency** Use *intellectual disability*.

#### **Hearing impaired**

The preferred terms are *hard of hearing* or *having hearing loss*.

Mental disability or mental disease Imprecise. Use *cognitive disability*, *developmental disability*, *intellectual disability*, *mental illness*, or *psychiatric disability* depending on the context.

#### Mental retardation or retarded

Formerly a diagnostic label; now widely considered a slur. Use "intellectual disability." If older datasets include this category, add a caveat—mental retardation has not been the standard term in over a decade.

#### Obese

Avoid using phrases like "we had several *obese* people in our sample." See *Obesity* and *Personand Identity-First Language*.

#### Special needs

"Special needs" is a euphemism for "disabled." Just say that people have disabilities or that they are disabled.

## Wheelchair-bound or confined to a wheelchair

Wheelchairs give people the freedom to move around. They're not "bound" to a wheelchair. You can simply say *wheelchair user* or *person who uses a wheelchair*.

#### Suffer from or afflicted with

Avoid saying that people "suffer from" or are "afflicted with" a disability.

## **References and Further Reading**

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The National Center on Disability and Journalism, "Disability Language Style Guide," 2018. URL: <u>https://ncdj.org/style-guide/</u> (Note: While this guide is mostly sound, its advice on autism is not in keeping with the community's preference.)

