



Commentary

The evolution of disability language: Choosing terms to describe disability

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ARTICLE INFO

Article history:

Received 12 January 2022

Received in revised form

2 April 2022

Accepted 13 April 2022

ABSTRACT

The use of disability language in academic scholarship has changed significantly over the past several years. Although it would be helpful to have concrete guidelines and rules that could generalize across situations regarding disability terminology, language itself is a phenomenon that evolves and varies over time in response to cultural shifts. People with disabilities have varied preferences about the language they use to describe themselves and what language they prefer to be used to describe them. At the same time, disability researchers, including the current authors, are often given prescriptive guidance by journal editors about the specific disability language they should use (i.e., person-first language). Thus, the tension between approaches to disability language underscores a need for open dialogue about a culturally informed choice of disability language in scholarly publications. Accordingly, this commentary discusses the history and evolution of disability language, explores current trends, and recommends language for academic articles.

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There have been significant changes in the use of disability language in academic scholarship over the past several years.^{1,2} Since language is a phenomenon that evolves over time in response to cultural shifts, it is not advised to establish permanent guidance about the use of disability language.¹ Recent trends suggest that people with disabilities vary in their language preferences, with some preferring person-first language and others preferring identity-first language.² Increasingly, disability researchers, including the current authors, have received requests by journal editors and reviewers to replace identity-first language with person-first language in manuscripts or vice versa.³ Related, several major journal style guides require authors to use person-first language. However, these requests and policies ignore the varying language preferences among disabled people, including disabled researchers. Accordingly, these tensions concerning disability language underscore a need for open dialogue about a culturally informed choice of disability language in scholarly publications.

This commentary discusses the history and evolution of terminology, explores current trends, and makes recommendations for disability language in scholarly writing. To do so, we examine these facets of language from the context of writing and communication in the United States. Ultimately, we recommend academic journals allow for flexibility in using person-first and identity-first disability language. Similarly, journals should focus on ensuring that the language used in their publications does not stigmatize disabled people, including avoiding euphemisms for disability.

The history of societal, economic, and environmental disadvantages has resulted in health disparities for people with disabilities and other marginalized groups. With the goal of public health to improve health outcomes for all populations, it is important to consider the potential impact of terminology on marginalized groups. From language about substance use to body weight, evidence suggests terminology contributes to attitude formation, self-perception, and behaviors.^{4,5} Word choice reflects dominant attitudes, which may further oppress or empower historically excluded groups. Given the potential role of terminology in improving health equity for people with disabilities, discussion about the role of language in shaping our reality and subsequent

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behaviors is merited. Many diverse groups and social movements have attempted to modify terminology to disrupt dominant stigmatizing attitudes.⁵ This can include introducing new terminology or taking back terms previously used in a derogatory fashion and using them as insider slang.⁷ For example, members of LGBTQI + communities moved to take back the terms “gay” and “queer.”⁸ Word choice about disability stems from numerous sources, including socialization, media portrayals, and medical training.⁹ Like the LGBTQI + community, some disabled people have reclaimed previously harmful language, such as adopting the word cripple (often “crip”) as a source of pride.¹⁰ Likewise, mad studies has reclaimed the identifier “mad” to describe individuals with psychiatric disabilities and recognize social understandings of the complex relationship between disabled people and psychiatric services and systems.¹¹ Ultimately, scholars caution that the shortcomings of existing vocabularies should not truncate dialogue around the evolution of language to describe disability.¹¹

Words used socially and in public policy to refer to historically marginalized groups have also evolved. For instance, in 2013, the US Census Bureau dropped the word “Negro” from surveys, leaving “African-American” or “black.”¹² Likewise, differences between the terms “Hispanic” and “Latino” are extremely nuanced and reflect various geographic and sociopolitical differences.^{13,14} “Latinx,” meant to address the intersectionality of gender identity and ethnicity, has recently seen a considerable increase in its usage in social media, advocacy, and academia.¹⁵ “Latinx” has received significant criticism and is far from accepted universally,^{16,17} but it did not yet exist when Comas-Díaz predicted, “names that are appropriate today may be obsolete or even offensive tomorrow” (p. 116).¹⁸ Similarly, the social evolution of language related to disability is also reflected in policy changes. In 2010, Congress passed Rosa’s Law, named after a young girl with Down syndrome whose family sought to have disability represented as diversity rather than the stigmatization associated with outdated terminology, replaced several, but not all, instances of “mental retardation” with “intellectual disability” in US federal law.¹⁹

History of disability terminology

The language used to discuss disability stems from theoretical models, or ways of understanding disability, that have framed disability in the past and through contemporary culture. The oldest model of disability is the moral model, which associates disability with sin or moral failing.²⁰ Terms used to describe disability associated with the moral model include “gimp,” “cripple,” “handicap,” or “imbecile.”²⁰ The terms “cripple” and “lame” are traced back to the early 9th century but were not perceived as stigmatizing until the 17th century, demonstrating that what may be a currently accurate term can change in meaning and impact across time. Another long-established model is the biomedical model of disability, a deficit orientation that situates disability as a problem within the person.²¹ Because this model emphasizes diagnostic categorization and pathology, associated terminology tends to be clinical in nature, such as all-encompassing categorizations such as “the blind” or “the mentally ill.”²² Language stemming from this model can reduce people to their diagnoses or conditions (e.g., “the spastic quadriplegic”).

In the last 50 years, there has been a move away from the biomedical model of disability, reflecting a shift in how disability is perceived. For example, the social model of disability views disability as socially constructed.²³ Thus, according to the social model of disability, the oppression and exclusion that people with disabilities experience are related to environmental factors, cultural attitudes, and social biases that influence how disabled people participate in society, and not merely a result of their

impairments.²³ Moreover, critics of the biomedical model introduced “person-first” language, an approach to disability language that emphasizes distinguishing the person from the disability by referring to those with disabilities first as individuals and then mentioning their disability second and only when needed.²⁴ Eminent rehabilitation psychologist Beatrice Wright championed person-first language in the field of psychology as an effort to reduce stigma and curb the phenomenon of “spread effect,” wherein negative perceptions inherent to impairment would develop into more global negative appraisals of the individual.^{25–27} Wright’s position was that to accentuate their humanity, the person should grammatically be positioned ahead of the disability.²⁶ Subsequently, the phrase “people with disabilities” became widely adopted, including in many disability language guidelines and the 1990 Americans with Disabilities Act.^{6,10} Parent advocate Kathy Snow also championed person-first language among advocacy organizations.²⁸ Thus, for decades, person-first language was promoted not only as a positive approach, but also as the *correct* way to discuss disability.

The diversity or sociopolitical model is built upon the social model’s emphasis on the importance of the environment, including the role of prejudice and discrimination.^{22,29} The diversity model is rooted in civil rights. Thus, from this viewpoint, “a perfect world is not a world without disabilities but a world in which accommodations and services are provided to people with disabilities, and more important, disability is not viewed as inferiority” (p. 35).³⁰ Like the sociopolitical movements of other groups, including feminism, LGBTQI + communities, and people of color, the disability diversity movement has reframed the narrative. Rather than viewing disability as a personal tragedy, the diversity model of disability encourages self-acceptance and the deliberate rejection of shame and internalized ableism. Because the diversity model rejects disability as inferior and promotes disability pride, modern disability rights advocates often elect to use identity-first language, emphasizing disability as central to identity.^{29,31} This is a wider adoption of that of Deaf culture, which has long claimed the term “Deaf” (with a capital D, denoting cultural identity) and rebuffed the label of “persons with deafness”.³¹ It is the responsibility of culturally competent healthcare providers and researchers to remain aware of and sensitive to changes in lexicons used by marginalized groups. This responsibility extends to the language used in scholarly publications.

Re-examination of person-first language

Person-first language places the person before the disability (e.g., “person with autism” or “person with spinal cord injury”). Traditionally, writing and style guidelines, including the Associated Press, the American Psychological Association, the American Medical Association, and the American Speech-Language-Hearing Association, as well as many academic journals, have required person-first language.^{1,32,33} Due to space considerations, person-first terminology often ends up abbreviated. For example, authors often use the term “people with disabilities” initially and then elect to use “PWD” in subsequent sentences throughout a manuscript, making the relationship between person-first language and readers’ perception of disabled people unclear.¹ Adherence to person-first language can also become needlessly cumbersome; for example, having to avoid concise and accurate descriptors such as “amputee.” More importantly, however, some disabled people have questioned the continued importance of separating the individual from the disability, which triggered a re-examination of whether person-first language achieves what it was intended to do.^{1,3}

Notably, research on the efficacy of person-first language has been mixed. For example, one study found that when presented

with a forced choice between identity-first and person-first language, 76% of blind people surveyed preferred identity-first language, with no differences based on age or gender.³⁴ Conversely, another study found that 60% of state employees preferred the phrase “person with a disability”.³⁵ Still, interestingly, 26% of respondents considered “person with a disability” and “disabled person” to be equal terms. Another study measured attitudes concerning disabled people by comparing groups using people-first and disability-first descriptors and did not find any significant differences.³⁶ In contrast, another study found a positive correlation between the use of person-first language and positive intentions toward people with disabilities.³⁷ Interestingly, one study indicated that person-first language was more prevalent in descriptions of disabled children, while identity-first language was used more often to describe disability among those who were incarcerated, fictional characters, and victims, suggesting a perhaps implicit bias that some disabled people are more deserving of person-first language than others.³⁸ Further, in a study where participants were asked to read several passages and divided into two groups, those in the group that did not receive prior information about person-first language did not show any differences in perceived inclusivity between the person-first passages and identity-first passages, while the group that received information beforehand about the intent of person-first language rated the person-first passages as moderately more inclusive.³⁹ Finally, one study found that person-first language was used most frequently to refer to children rather than adults, and to describe children with the most stigmatized disabilities, such as autism and intellectual disabilities.³² While this researcher does not question the good intentions of using person-first language, she points out that by separating the person from the identity, person-first language implicitly indicates that disability is an undesirable characteristic. Thus, person-first language may have inadvertently overcorrected and further stigmatized disability.¹

Some argue that person-first language could even be harmful due to the unintended consequences of separating the person from the disability.⁴⁰ In other words, using person-first language may inadvertently contribute to a fragmented sense of identity, reinforce internalized ableism, and impede positive disability identity formation.^{1,2} According to Botha and colleagues, using person-first language can raise concerns about how disabled people feel when a part of them and their identity is framed as something to be eliminated.⁴¹ Perhaps the most worrisome of these implications is the case of filicide, prejudicially referred to as “altruistic filicide,” wherein a disabled person is killed, most often by a family member, and the defense includes some variation of relieving suffering. These assailants have even singled out disability as the intended victim rather than the person, underscoring the reality that disabilities can only exist within persons and the potential dangers of emphasizing separation.⁴¹

Notably, person-first language is rarely, if ever, used to describe other groups of people. Although terms have changed and preferences have evolved related to other diverse groups, person-first language has not been recommended to refer to members of other marginalized groups. For example, it is not mandated to write people who are women, people who are Jewish, people who are lesbians, or people who are Black. In fact, it would be entirely permissible to describe a Black Jewish lesbian woman as just that.

Identity-first language

Identity-first language, sometimes referred to as disability-first language, places the disability first in phrasing (e.g., “disabled person,” “autistic person,” or “amputee”). As discussed above, an identity-first approach has been used for many years in Deaf

culture but has more recently been adopted by a wider swath of the disability community, particularly those who identify as disability rights advocates. For example, autistic self-advocates, many of whom are scholars, have adopted identity-first language.⁴² Some scholars have posited that abandonment of person-first language and adoption of identity-first language is an unfortunate return to old ways of stigmatizing and objectifying disabled people. However, scholars such as Vivanti argue that identity-first language is “increasingly endorsed as an expression of positive social identity, whereby the language historically used to dehumanize and marginalize a minority group is redeployed as a form of empowerment.”³ In their response, Botha and colleagues argue that identity-first language as it is currently used is not done so in congruence with the medical model of pathology, but rather initiated by much of the disability community themselves in an effort toward autonomy.⁴¹

Indeed, the current adoption of identity-first language is a manifestation of disability pride, consistent with the sociopolitical or diversity model of disability. The difference between identity-first language in its present form and older dehumanizing terminology is that current trends in identity-first language do not describe people as their disability (e.g., “the disabled”) or portray disability as an affliction (e.g., “the cerebral palsied”) but rather use disability as an important identifier, like any other group label (e.g., “disabled people”). This movement allows disability to be one of several individual identifiers; for example, all the current authors identify as disabled women.

Euphemisms and the importance of using the term “disability”

Another concern relating to disability language involves the use of euphemisms, such as “differently abled,” “physically challenged,” or “special needs,” which are ostensibly meant to be less offensive alternatives to the term “disability.”⁴³ These terms were created by nondisabled people, are often endorsed by nondisabled parents of disabled children, and have largely been rejected by the disability community as superficial, infantilizing, and patronizing.² “Special needs” is a particularly popular euphemism, predominantly in the educational system and among nondisabled parents of children with disabilities. The term “special needs” began gaining traction in the 1920s and peaked in the 1990s. Although its use appears to be declining, it is still commonly used today.⁴⁴ Gernsbacher and colleagues’ research indicates that outsiders view people more negatively when described as having “special needs” than when they are described as having a disability or having a certain disability.⁴⁴ The term “special needs” has been rejected by most adults with disabilities, as it connotes segregation and implies special rights as opposed to equal rights.⁴³ Powell argues that “special needs” others disabled people by implying that their needs are different than those of the nondisabled population, contributing to the perception that these needs are optional or burdensome.⁴⁵ In the words of disability activist Lawrence Carter-Long (2017), “a need isn’t special if it’s something everyone else takes for granted.”⁴⁶

Hence, it is essential that researchers use the term “disability” and entirely avoid euphemisms. Indeed, the term “disability” is widely used and universally accepted by leading state and international organizations (e.g., World Health Organization International Classification of Functioning, Disability, and Health; National Institute on Disability and Rehabilitation Research; National Council on Disability). Moreover, the social media campaign #SaytheWord was created by people with disabilities to claim the term and encourage nondisabled people to stop attempting to avoid and replace disability as an identity. Outspoken activism about identity erasure follows on the heels of global movements

like black Lives Matter, which highlights social injustice to illustrate the continued significance of race in the lives of black people. Similarly, disability is an important identity that should not be erased.

Importantly, many people with objective impairments do not identify themselves either as “disabled persons” or “persons with disabilities.” This challenge further complicates using language to describe disability because many people with objective impairments do not self-identify with any disability-related terminology. Societal entanglement of culture, ethnic diversity, poverty, stigma, and ableism contribute to how people with disabilities answer questions about their identity.⁶ The reluctance to identify as having a disability may also be a missed opportunity to reduce disparities since recent research shows that those who both personally identify as disabled and feel connected to the larger disability community experience improved well-being, self-esteem, and quality of life across a wide range of disabilities.^{1,32,47–50}

Conclusion

Disability language has undergone significant evolution in response to cultural changes and advocacy, and the use of person-first or identity-first language can be contentious in the disability community. Person-first language was developed with the good intention of reducing stigma. Yet, as research demonstrates, it is unclear if person-first language works as intended, and its usage may have unintended consequences. Ultimately, decisions about language are personal and may differ based on several factors, including whether disabilities are acquired or congenital, previous experiences with negative and objectifying terminology, and degree of personal disability identity.

The tensions between person-first and identity-first language are also present in academic publishing. For decades, the American Psychological Association (APA) *Style Manual*, used in academic publishing worldwide, instructed writers to use person-first language exclusively.⁵¹ However, the most recent (7th) edition recognizes that both person-first and identity-first approaches to language are designed to respect disabled people and states that authors may use person-first language or identity-first language in scholarly writing.⁵¹ We recommend that other publishing and writing guidelines adopt a similar approach, and allow authors to use either person-first or identity-first language in accord with their preferences and that of the groups they are writing about. Further, the recent APA *Style Manual* urges authors to avoid condescending euphemisms, such as “special needs” and “physically challenged.”⁵¹ We, too, believe that authors must refrain from euphemisms and instead use the term “disability.” At the same time, we recognize that although the language is critical, simply changing how disability is described is inadequate for fully confronting disparities experienced by disabled people. Thus, in addition to questioning and reshaping the words used to describe disability, we must ensure that we are doing so in a way that can have a real impact. To that end, disability researchers must support disabled people as we continue to reclaim and destigmatize language concerning disability while also working with disabled people to achieve health equity and social inclusion.

Funding statement

No funding was used to support this article.

Declaration of competing interest

The authors have no conflicts of interest to report.

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