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The Evolution of Disability Language: Choosing Terms to Describe Disability

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1 **The Evolution of Disability Language: Choosing Terms to Describe Disability**

2 **Abstract**

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

15 **Word count:** 3,034

16

17 There have been significant changes in the use of disability language in academic
18 scholarship over the past several years.¹⁻² Since language is a phenomenon that evolves over time
19 in response to cultural shifts, it is not advised to establish permanent guidance about the use of
20 disability language.¹ Recent trends suggest that people with disabilities vary in their language
21 preferences, with some preferring person-first language and others preferring identity-first
22 language.² Increasingly, disability researchers, including the current authors, have received
23 requests by journal editors and reviewers to replace identity-first language with person-first
24 language in manuscripts or vice versa.³ Related, several major journal style guides require
25 authors to use person-first language. However, these requests and policies ignore the varying
26 language preferences among disabled people, including disabled researchers. Accordingly, these
27 tensions concerning disability language underscores a need for open dialogue about a culturally-
28 informed choice of disability language in scholarly publications. This commentary discusses the
29 history and evolution of terminology, explores current trends, and makes recommendations for
30 disability language in scholarly writing. To do so, we examine these facets of language from a
31 context of writing and communication in the United States. Ultimately, we recommend academic
32 journals allow for flexibility in using person-first and identity-first disability language. Similarly,
33 journals should focus on ensuring that the language used in their publications does not stigmatize
34 disabled people, including avoiding euphemisms for disability.

35 A history of societal, economic, and environmental disadvantages has resulted in health
36 disparities for people with disabilities and other marginalized groups. With the goal of public
37 health to improve health outcomes for all populations, it is important to consider the potential
38 impact of terminology on marginalized groups. From language about substance use to body
39 weight, evidence suggests terminology contributes to attitude formation, self-perception, and

40 behaviors.^{4,5} Word choice reflects dominant attitudes, which may further oppress or empower
41 historically excluded groups. Given the potential role of terminology to improve health equity for
42 people with disabilities, discussion about the role of language in shaping our reality and
43 subsequent behaviors is merited. Many diverse groups and social movements have attempted to
44 modify terminology to disrupt dominant stigmatizing attitudes.⁶ This can include introducing
45 new terminology or taking back terms previously used in a derogatory fashion and using them as
46 insider slang.⁷ For example, members of LGBTQI+ communities moved to take back the terms
47 “gay” and “queer”.⁸ Word choice about disability stems from numerous sources, including
48 socialization, media portrayals, and medical training.⁹ Like the LGBTQI+ community, some
49 disabled people have reclaimed previously harmful language, such as adopting the word cripple
50 (often “crip”) as a source of pride.¹⁰ Likewise, mad studies has reclaimed the identifier “mad” to
51 describe individuals with psychiatric disabilities and recognize social understandings of the
52 complex relationship between disabled people and psychiatric services and systems.¹¹
53 Ultimately, scholars caution that the shortcomings of existing vocabularies should not truncate
54 dialogue around the evolution of language to describe disability.¹¹

55 Words used socially and in public policy to refer to historically marginalized groups have
56 also evolved. For instance, in 2013, the U.S. Census Bureau dropped the word “Negro” from
57 surveys, leaving “African-American” or “Black.”¹² Likewise, differences between the terms
58 “Hispanic” and “Latino” are extremely nuanced and reflect various geographic and sociopolitical
59 differences.^{13,14} “Latinx,” meant to address the intersectionality of gender identity and ethnicity,
60 has recently seen a considerable increase in its usage in social media, advocacy, and academia.¹⁵
61 “Latinx” has received significant criticism and is far from accepted universally,^{16,17} but it did not
62 yet exist when Comas-Diaz predicted, “names that are appropriate today may be obsolete or even

63 offensive tomorrow” (p. 116).¹⁸ Similarly, the social evolution of language related to disability is
64 also reflected in policy changes. In 2010, Congress passed Rosa’s Law, named after a young girl
65 with Down syndrome whose family sought to have disability represented as diversity rather than
66 the stigmatization associated with outdated terminology, replaced several, but not all, instances
67 of “mental retardation” with “intellectual disability” in U.S. federal law.¹⁹

68 **History of Disability Terminology**

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

82 In the last 50 years, there has been a move away from the biomedical model of disability,
83 reflecting a shift in how disability is perceived. For example, the social model of disability views
84 disability as socially constructed.²³ Thus, according to the social model of disability, the

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

100 The diversity or sociopolitical model is built upon the social model’s emphasis on the
101 importance of the environment, including the role of prejudice and discrimination.^{22,29} The
102 diversity model is rooted in civil rights. Thus, from this viewpoint, “a perfect world is not a
103 world without disabilities but a world in which accommodations and services are provided to
104 people with disabilities, and, more important, disability is not viewed as inferiority” (p. 35).³⁰
105 Like the sociopolitical movements of other groups, including feminism, LGBTQI+ communities,
106 and people of color, the disability diversity movement has reframed the narrative. Rather than
107 viewing disability as a personal tragedy, the diversity model of disability encourages self-
108 acceptance and the deliberate rejection of shame and internalized ableism. Because the diversity

109 model rejects disability as inferior and promotes disability pride, modern disability rights
110 advocates often elect to use identity-first language, emphasizing disability as central to
111 identity.^{29,31} This is a wider adoption of that of Deaf culture, who have long claimed the term
112 “Deaf” (with a capital D, denoting cultural identity) and rebuffed the label of “persons with
113 deafness.”³¹ It is a responsibility of culturally-competent health care providers and researchers to
114 remain aware of and sensitive to changes in lexicons used by marginalized groups. This
115 responsibility extends to the language used in scholarly publications.

116 **Re-Examination of Person-First Language**

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

130 Notably, research on the efficacy of person-first language has been mixed. For example,

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

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

166 Notably, person-first language is rarely, if ever, used to describe other groups of people.
167 Although terms have changed and preferences have evolved related to other diverse groups,
168 person-first language has not been recommended to refer to members of other marginalized
169 groups. For example, it is not mandated to write people who are women, people who are Jewish,
170 people who are lesbians, nor people who are Black. In fact, it would be entirely permissible to
171 describe a Black Jewish lesbian woman as just that.

172 **Identity-First Language**

173 Identity-first language, sometimes referred to as disability-first language, places the
174 disability first in phrasing (e.g., “disabled person,” “autistic person” or “amputee”). As discussed
175 above, an identity-first approach has been used for many years in Deaf culture but has more
176 recently been adopted by a wider swath of the disability community, particularly those who

178 scholars, have adopted identity-first language.⁴² Some scholars have posited that abandonment of
179 person-first language and adoption of identity-first language is an unfortunate return to old ways
180 of stigmatizing and objectifying disabled people. However, scholars, such as Vivanti argue that
181 identity-first language is “increasingly endorsed as an expression of positive social identity,
182 whereby the language historically used to dehumanize and marginalize a minority group is
183 redeployed as a form of empowerment.”⁴³ In their response, Botha and colleagues argue that
184 identity-first language as it is currently used is not done so in congruence with the medical model
185 of pathology, but rather initiated by much of the disability community themselves in an effort
186 toward autonomy.⁴¹

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

195 **Euphemisms and the Importance of Using the Term “Disability”**

196 Another concern relating to disability language involves the use of euphemisms, such as
197 “differently abled,” “physically challenged,” or “special needs,” which are ostensibly meant to
198 be less offensive alternatives to the term “disability.”⁴³ These terms were created by nondisabled
199 people, are often endorsed by nondisabled parents of disabled children, and have largely been

201 needs” is a particularly popular euphemism, predominantly in the educational system and among
202 nondisabled parents of children with disabilities. The term “special needs” began gaining traction
203 in the 1920s and peaked in the 1990s. Although its use appears to be declining, it is still
204 commonly used today.⁴⁴ Gernsbacher and colleagues’ research indicates that outsiders view
205 people more negatively when described as having “special needs” than when they are described
206 as having a disability or having a certain disability.⁴⁴ The term “special needs” has been rejected
207 by most adults with disabilities, as it connotes segregation and implies special rights as opposed
208 to equal rights.⁴³ Powell argues that “special needs” *others* disabled people by implying that their
209 needs are different than those of the nondisabled population, contributing to the perception that
210 these needs are optional or burdensome.⁴⁵ In the words of disability activist Lawrence Carter-
211 Long (2017), “a need isn’t special if it’s something everyone else takes for granted”.⁴⁶

212 Hence, it is essential that researchers use the term “disability” and entirely avoid
213 euphemisms. Indeed, the term “disability” is widely used and universally accepted by leading
214 state and international organizations (e.g., World Health Organization International
215 Classification of Functioning, Disability, and Health; National Institute on Disability and
216 Rehabilitation Research; National Council on Disability). Moreover, the social media campaign
217 #SaytheWord was created by people with disabilities to claim the term and encourage
218 nondisabled people to stop attempting to avoid and replace disability as an identity. Outspoken
219 activism about identity erasure follows on the heels of global movements like Black Lives
220 Matter, which highlights social injustice to illustrate the continued significance of race in the
221 lives of Black people. Similarly, disability is an important identity that should not be erased.

222 Importantly, many people with objective impairments do not identify themselves either as
223 “disabled persons” or “persons with disabilities.” This challenge further complicates using

224 language to describe disability because many people with objective impairments do not self-
225 identify with any disability-related terminology. Societal entanglement of culture, ethnic
226 diversity, poverty, stigma, and ableism contribute to how people with disabilities answer
227 questions about their identity.⁶ The reluctance to identify as having a disability may also be a
228 missed opportunity to reduce disparities since recent research shows that those who both
229 personally identify as disabled and feel connected to the larger disability community experience
230 improved well-being, self-esteem, and quality of life across a wide range of disabilities.^{1,32, 48-50}

231 **Conclusion**

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

240 The tensions between person-first and identity-first language are also present in academic
241 publishing. For decades, the American Psychological Association (APA) *Style Manual*, used in
242 academic publishing worldwide, instructed writers to use person-first language exclusively.⁵¹
243 However, the most recent (7th) edition recognizes that both person-first and identity-first
244 approaches to language are designed to respect disabled people and states that authors may use
245 person-first language or identity-first language in scholarly writing.⁵¹ We recommend that other

247 person-first or identity-first language in accord with their preferences and that of the groups they
248 are writing about. Further, the recent *APA Style Manual* urges authors to avoid condescending
249 euphemisms, such as “special needs” and “physically challenged.”⁵¹ We, too, believe that authors
250 must refrain from euphemisms and instead use the term “disability.” At the same time, we
251 recognize that although language is critical, simply changing how disability is described is
252 inadequate for fully confronting disparities experienced by disabled people. Thus, in addition to
253 questioning and reshaping the words used to describe disability, we must ensure that we are
254 doing so in a way that can have a real impact. To that end, disability researchers must support
255 disabled people as we continue to reclaim and destigmatize language concerning disability, while
256 also working with disabled people to achieve health equity and social inclusion.

257

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