

Anti-ableist language is fully compatible with high-quality autism research: Response to Singer et al. (2022)

Singer et al. (2022) argue that the current lexical shift within autism research towards more neutral terminology hinders accurate scientific description of the wide range of autistic experiences, particularly within clinical and medical contexts. We disagree with these claims.

Semantic guidelines for referring to disability, gender, race, and ethnicity are established components of research dissemination (e.g., Clauss-Ehlers et al., 2019), and are more, not less, scientifically precise. Recommendations informed by self-advocates are widely recognized as vital tools for mitigating societal biases—reflected and reinforced by language choices—that harm marginalized communities, including disabled individuals (Scully, 2008). Examples include the American Psychological Association’s bias-free and inclusive language guidelines (APA, 2021) and the National Institute of Mental Health’s Stigma and Discrimination Research Toolkit (NIMH, n.d.).

The language guidelines for autism research that Singer et al. object to were developed through diverse collaborations of autistic and non-autistic researchers, clinicians, scholars, and caregivers, informed by decades of intersectional, multidisciplinary autistic and disability rights scholarship. Specific recommendations, such as replacing terms like “risk” and “co-morbid” with the accurate equivalents “likelihood” and “co-occurring” offer a more inclusive alternative to the deficit construals that predominate most published autism research (Botha & Cage, 2022). Practical and inclusive terminology enables discussion of heterogeneity in autism presentation, is less likely to reinforce bias, and is more respectful than terminology with negative connotations. Importantly, these suggestions align with guidance from autistic people designated “profoundly autistic” (Zimmerman, 2022; Whitty 2020) as well as broader autistic preferences (Keating et al., 2022).

In contrast, the terms “required” by Singer et al. (e.g., “profound autism,” “severe,” and “challenging behavior”) are limited in their validity, utility, and specificity, are inconsistently defined, and dehumanizing to many autistic people (Pukki et al. 2022; Kapp, in press). Specific descriptors of cognitive functioning, support needs, or other characteristics of autistic people are more precise and scientifically accurate than ambiguous terms like “profound” and “severe,” which gloss over strengths and the contexts in which impairments can become significantly disabling. Language consistent with existing guidelines can be used to describe differences that are disabling or impairing and their impact. Moreover, Singer et al. mischaracterize the guidelines’ more nuanced engagement with difference and disability as describing “a simple ‘difference’”.

Singer et al. assert that some autism researchers have been denied funding and have experienced heckling at public presentations due to language choices, citing a handful of tweets out of their original context. We do not condone harassment and would hope that feedback is

delivered respectfully and with the intent to educate, not harm. Still, non-autistic people hold nearly all the power in autism research, including funding and publishing decisions. Members of the public have few opportunities to engage with researchers, and open platforms such as social media enable direct engagement between researchers and communities. Autism researchers should expect their work to be consumed and critiqued by the public, including autistic people affected by their research. Such critique is not bullying or weaponization, but feedback that offers autism researchers an opportunity for reflection and dialogue with the wider autistic community they purport to serve. Autism researchers with concerns about how their work will be received should proactively seek guidance and consultation from autistic scholars and self-advocates.

Further, Singer et al. claim that language guidelines “should not be dictated by mostly white, non-Hispanic individuals.” This statement reflects an ignorance of the scholarship of autistic people of color who have contributed to language guidance, including those designated as “profoundly autistic” and their families (McGann, 2021; Malone et al., 2022). These contributions have been made despite the significant barriers and discrimination that contribute to the pervasive underrepresentation of marginalized perspectives in the field. This includes autistic researchers (including minimally or non-speaking), Indigenous and those representing the Global Majority, and others who endure the ongoing and disparate consequences of biased language and research agendas (Jones & Mandell, 2020; Jones, 2022). Tackling this power imbalance and increasing accountability is essential for improving autism research.

Lastly, we extend an invitation for everyone to engage with respectful terminology to create more inclusive, representative, scientifically rigorous, and beneficial research for the entirety of the spectrum.

This letter is authored and co-signed by a diverse group of autistic researchers, scholars, clinicians, and self-advocates with a wide range of clinical presentation and support needs, as well as non-autistic researchers, scholars, clinicians, and loved ones of autistic people.

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