

Guidelines for inclusive language in autism research

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In the decades since the "clinical" definitions of autism in the 1980s, many have been advocating to understand autism as a normal part of the neurodiversity spectrum rather than as a "problem" to be "fixed." Still, in



the research literature, autism is often described using medical or pathologizing language. To make autism research less harmful to the autistic community, researchers publishing in the journal *Trends in Neurosciences* on September 29 lay out a data-driven guide for how scientists and researchers should talk about autism in their work.

"The evolution in the understanding of <u>autism</u> has also mirrored a transition in the use of language in research contexts," write the authors. "Historically, most <u>autism research</u> has been carried out without input from autistic people. This research has often described autism and autistic people using medicalized, pathologizing, and deficit-based language (e.g., disorder, impairment, cure) and person-first language (e.g., child with autism)."

The paper was authored by Ruth Monk, an autistic researcher at University of Auckland in New Zealand; Andrew Whitehouse, an autism researcher at the Telethon Kids Institute and professor at The University of Western Australia; and Hannah Waddington, a senior lecturer in <u>educational psychology</u> at Victoria University of Wellington, New Zealand.

The authors offer a table of potentially offensive language and preferred alternatives, compiled from several large surveys of autistic community members.

For example, "<u>autism spectrum disorder</u>" should be replaced with "autism"; "person with autism" replaced with "autistic person"; "normal" replaced with "allistic" or "non-autistic"; and "co-morbidity" with "cooccurring."

"Autistic people have the most intimate autism expertise through their first-hand lived experience," the authors write. "Thus, there is increasingly widespread acknowledgement that the terminology used to



refer to autism and autistic people should prioritize the perspectives and preferences of autistic people themselves. These preferences been explored by several large surveys conducted by researchers and autistic advocates."

The authors also advocate for a shift in the way autism research is conducted. "Specifically," they write, "the increasing use of participatory and co-produced research aims to reduce power imbalance between the researcher and the autistic community and to ensure that <u>autistic people</u> are involved throughout the <u>research process</u>."

More information: The use of language in autism research, *Trends in Neurosciences* (2022). DOI: 10.1016/j.tins.2022.08.009, www.cell.com/trends/neuroscien ... 0166-2236(22)00166-7

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