

Terminology guidance

Autism: The International Journal of Research and Practice

All authors who publish in *Autism* should use language that is respectful to autistic people, their families, and caregivers when communicating their research findings. We have developed this terminology guide to support authors in doing so.

This guide is not a prescriptive checklist that authors must follow. Instead, it is designed to encourage authors to engage deeply with the literature on this topic (see below) in order to understand the views of autistic people, to be sensitive and respectful of their preferences in the language used to describe them, and to make decisions that ensure their writing is grounded in deep-seated respect.

In what follows, we present some key debates / discussions in the field for authors to consider.

Person-first or identity-first language

The use of person-first versus identity-first language has been subject to much debate, with autistic people, researchers, professionals, and parents often differing on the language they use to describe autism. Many published and unpublished surveys show that autistic people prefer identity first language (“autistic person”) to person-first language (“person with autism”) (Bury et al., 2020; Kenny et al., 2016; Lei, Jones & Brosnan, 2021; <https://autisticnotweird.com/2018survey/>). While there is not a definitive consensus on the preferred language of autistic people (Vivanti, 2020), there is clear consensus on the least preferred language: “person with autism” or “person with autism spectrum disorder/condition” (Botha et al., 2021; Bury et al., 2020; Bradshaw et al., 2021; Kapp et al., 2013; Kenny et al., 2016; Lei et al., 2021).

These studies have limitations, including constraints of survey design, participant selection bias, and a lack of inclusion of autistic people who are unable to respond for themselves (Kapp et al., 2013; Kenny et al., 2016; Bury et al., 2020; Lei et al., 2021; <https://ollibean.com/person-attitude-trumps-language/>). However, there are other compelling points when considering the most appropriate language to use.

While often touted as a means of reducing stigma toward autistic people, person-first language may actually have the opposite effect (Bottema-Beutel et al., 2021). Non-autistic people, as well as those with less stigmatized conditions (e.g., deafness) are commonly described using identity-first language, whereas individuals with highly stigmatized or pathological conditions (e.g., cancer) are often described using person-first language (Botha et al., 2021; Gernsbacher, 2017). This discrepancy can lead to perceptions that autism is inherently negative. Both research (Botha et al., 2020) and the words of autistic self-advocates (Sinclair, 1999) show that many autistic people elect to use identity-first language as a means of shedding these negative associations and accepting their autism as a central part of their personhood.

Ultimately, we expect authors to closely consider the language they use to describe autistic participants taking part in their research, and in the world at large. Language choices should be informed by the critical autism studies literature, and not only follow the model of published papers in clinical or psychology journals. Where possible, the preferences of any

autistic people actively involved in the research should inform terminology choices (Gillespie-Lynch, et al., 2017). Needless to say, in one-to-one settings, the personal preference of the individual being addressed should always be respected.

Functioning labels

Labels such as “high functioning”, “low functioning” or “severe” autism have often been used in an attempt to describe the abilities of autistic people and characterise research participant groups. These ambiguous – and often misleading – terms fail to acknowledge the complexity of autistic abilities, which extend beyond intellectual capabilities, and which may vary over time and context (see Alvares et al., 2020).

Authors should use precise clinical characteristics to describe their sample - e.g., referring to their cognitive or verbal abilities, their support needs, or specifying the presence of intellectual disability where relevant.

“At risk” of autism

The term “at risk” of autism is often used in investigations into the earliest signs of autism in infants, however “at risk” has negative connotations, and an international online survey has suggested that this term is disliked by many people with personal/professional connections to autism (Fletcher-Watson et al., 2017). The term “at increased likelihood” of autism has been proposed as a neutral alternative.

Comparison groups

In studies that compare autistic groups with other (e.g., non-autistic) groups, writers should refer to these groups as “comparison” groups, not “control” groups. The exception to this is in the context of an intervention study, where the “control” group refers to a comparison group that has not been assigned to receive an intervention.

Authors often make assumptions about the characteristics of non-autistic participants, referring to comparison groups as “normal/typically-developing” or “neurotypical”. Participants are rarely screened for anything apart from autism, and thus may be otherwise neurodivergent or have a health condition; therefore “non-autistic” or “without autism” may be more accurate (Boucher & Bowler, 2008).

Non-preferred language

Whilst our terminology guidance is not intended to be prescriptive, there are terms that are universally considered to be offensive/inappropriate when referring to autistic people and we would not expect to see these featured in research articles published in our journal.

- Framing autism as a burden, which people “suffer from”, “are victims of”, or “are living with”.
- Referring to autism as a disease/illness.
- Using derogatory terms such as “retarded”, “mentally handicapped” or “backward”.
- Using value-laden terms such as ‘deficit’ and ‘disorder’, which suggest that difficulties experienced by autistic people are due to them being “broken” in some way (Kenny et al., 2016; Ryan & Runswick-Cole, 2009, Bottema-Beutel et al., 2021). While “Autism Spectrum Disorder(s)” is a diagnostic label and in some cases may be

the most relevant way to refer to a group, we ask you to be selective using this term and instead consider whether “Autism” or “Autism Spectrum Condition(s)” would be viable alternatives.

Anything else?

Note that terminology preferences may differ internationally (most published academic research on this topic is from the UK or USA). It is important that decisions on language take into account relevant cultural and linguistic contexts.

This guide has been developed based on research publications and the perspectives of the autistic community. We strongly encourage all authors to consider these perspectives in their writing and be respectful of the preferences of autistic community. A selection of useful and thought-provoking writing is included at the end of this guide.

References

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Also see:

<https://autisticnotweird.com/2018survey/>

<https://ollibean.com/person-attitude-trumps-language/>

Useful links

A plea to the autism community, from one of your own. Available at <https://autisticnotweird.com/plea/>

Person-First Attitude Trumps Language by Judy Endow. Available at <https://ollibean.com/person-attitude-trumps-language/>

Why I dislike ‘person-first’ language by Jim Sinclair. Available at http://web.archive.org/web/20090210190652/http://web.syr.edu/~jisincla/person_first.htm

The sound of stigma: a journey across the rope bridge. #AutismAcceptance <https://soniaboue.wordpress.com/2017/03/27/the-sound-of-stigma-a-journey-across-the-rope-bridge-autismacceptance/#comments>

Avoiding Ableist Language: Suggestions for Autism Researchers. Available at <https://www.liebertpub.com/doi/10.1089/aut.2020.0014>

