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The use of language in autism research

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The past three decades have seen a major shift in our understanding of the strong links between autism and identity. These developments have called for careful consideration of the language used to describe autism. Here, we briefly discuss some of these deliberations and provide guidance to researchers around language use in autism research.

The history of language used to describe autism

The language used to talk about autism is important. Well-informed use of terminology can empower and support autistic people, while also changing attitudes of the broader community. Although the term ‘autism’ has a long history of clinical use, research over the past three decades has led to a revolution in our understanding of people’s experience of autism and its links to identity [1,2]. These research advances have major implications for the language we use to describe autism.

The term ‘autism’ emerged in the early 20th century through Eugen Bleuler’s observation that some schizophrenic ‘patients’ had withdrawn from social contact and appeared to be living in their own world. Then, in the 1940s, the term was first used to represent children with particular behavioural characteristics. The term was eventually included in the third edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-III)* in 1980. Throughout this time, autism was generally

conceptualised by researchers and clinicians through a medical model lens as being abnormal or atypical and, thus, clinical efforts often focussed on ‘fixing’ or ‘curing’ the autistic person.

Over the past three decades, this medical model stance on autism has been challenged by the neurodiversity and autistic self-advocacy movements, which view autism as a part of the natural spectrum of human diversity and, thus, an inseparable aspect of identity. Aligning with the social model of disability, the neurodiversity paradigm attributes the disabilities associated with autism to the interactions between autistic characteristics and an environment that imposes structural, systemic, and social barriers on autistic people [1,2]. In conceptualising autism as a neurological difference rather than as a disorder, clinical and research efforts are encouraged to focus on creating more inclusive environments and societies to enhance autistic well-being and quality of life.

This evolution in the understanding of autism has also mirrored a transition in the use of language in research contexts. Historically, most autism research has been carried out without input from autistic people [3]. This research has often described autism and autistic people using medicalised, pathologising, and deficit-based language (e.g., disorder, impairment, or cure) and person-first language (e.g., child with autism). This terminology has often formed part of journal formatting requirements, which has sustained and reinforced its use among researchers [4].

The use of these types of terminology has come under sharp criticism by autistic and neurodivergent scholars, who have advocated strongly that such terminology can have negative consequences for how society views and treats autistic people and can even influence how autistic people view themselves [1,5]. Autistic people have the most intimate autism expertise

through their first-hand lived experience [1]. Thus, there is increasingly widespread acknowledgement that the terminology used to refer to autism and autistic people should prioritise the perspectives and preferences of autistic people themselves. These preferences have been explored by several large surveys conducted by researchers and autistic advocates¹ [6–8].

Language use in autism research

The wider autism communities, including clinicians and researchers, have an important role in promoting autistic-preferred language and centralising autistic perspectives. Table 1 provides some practical suggestions for language use in autism research. These have been informed by scholarly research and grey literature from the autism community and were collated by an autistic author (R.M.), and supported by two autism researchers (A.J.O.W. and H.W.). The language recommendations in Table 1 are supported by, and should be considered alongside, other publications that provide lists and discussions of autistic-preferred terminologyⁱⁱ [6–13].

Many of the ‘potentially offensive’ terms within Table 1 portray a medical/deficit-focussed view of autism. These terms imply that there is something ‘wrong’ with the autistic individual, that autistic individuals have to be ‘fixed’ or ‘cured’, and/or that they are inferior in some way to non-autistic people. In line with the neurodiversity movement, autism and being autistic can be celebrated without discrediting the support needs and challenges experienced by autistic people.

Autistic-preferred terms are often more detailed and precise, referring to specific autistic experiences and individuals, providing a more accurate description of the strengths and specific areas in which autistic people may benefit from support to improve their quality of life. Importantly,

Table 1. Practical strategies for replacing potentially offensive terms with autistic-preferred terminology to reduce the stigmatisation, misunderstanding, marginalisation, and exclusion of autistic people

| Potentially offensive | Autistic preferred | Insight and perspectives from the autistic community | Example of preferred language use in research |
|---|---|--|---|
| Autism spectrum disorder (ASD) | Autism, autistic | Disorder is unnecessarily medicalised and reinforces negative discourses that autism is wrong or needs curing | 'Autism is a neurodevelopmental difference...' |
| Person-first language (person with autism) | Identity-first language [autistic (person)] | Identity-first language emphasises autism as inseparable from the person and an integral part of their identity, whereas person-first language suggests a separation between autism and the individual | 'A total of 125 autistic adults participated in the study.' |
| Autism symptoms and impairments | Specific autistic experiences and characteristics | Medical terminology pathologises the characteristics and experiences of autistic people as deficient and abnormal | 'This study recruited autistic participants with a high sensitivity to sensory stimuli.' |
| At risk of autism | May be autistic; increased likelihood of being autistic | Danger-oriented terms (vs. probabilistic terms) imply that autism is a negative (possibly preventable) outcome | 'Children with an increased likelihood of being autistic were also included in the study.' |
| Co-morbidity | Co-occurring | Autism is not a disease, even though it often co-occurs with other neurodivergences or medical conditions | 'Individuals with co-occurring medical conditions were excluded from the study.' |
| Functioning (e.g., high/low functioning) and severity (e.g., mild/moderate/severe) labels | Specific support needs | All autistic people have a range of strengths, skills, challenges, and support needs that can vary over time and in different situations and environments | 'Individuals with sensory and communication support needs.' |
| Cure, treatment, or intervention | Specific support or service | Autism does not need to be cured, treated, or modified. Supports should not be targeted at autism characteristics, although autistic people may benefit from individualised supports | 'The participants were receiving occupational therapy to reduce sensory overload in those with high sensory needs.' |
| Restricted interests and obsessions | Specialised, focussed, or intense interests | Deficit-based terminology pathologises the interests of autistic people rather than celebrating their knowledge | 'The participant had specialised interests in computers and politics.' |
| Normal person | Allistic or non-autistic | Allistic is an empowering term that reframes autism and autistic traits as a difference instead of an abnormality | 'The comparison group included allistic (non-autistic) people.' |

many would argue, these supports should not try to change, or 'intervene' in, autistic ways of being, or target a skill (e.g., eye contact) to 'normalise' the autistic person relative to their peers. For example, clinicians could support the use of augmentative and alternative communication methods, such as a speech-generating device or sign language, rather than focussing solely on allistic speech benchmarks [12]. Supports should also focus on environmental changes and upskilling those around the autistic person to better understand and respond to that person's unique perspective of others and the world around them.

Similar considerations apply to basic research. For example, when modelling the neurobiological basis of co-occurring

conditions and genetic conditions with higher co-occurrence with autism (e.g., Fragile X syndrome), researchers must not conflate these conditions and models with autism itself [12]. Authors should also avoid making statements about 'autistic behaviours' in animal models, because any specific behaviour in animals does not correspond to complex expressions of autism characteristics in humans. It is especially inappropriate to attempt to model 'autism characteristics' in animals with the intention of preventing or curing autism itself.

Views on terminology are highly individual; thus, during personal interactions, the language used should always respect an autistic person's individual preferences.

However, the differing perspectives of autistic individuals should not be used to justify ignoring the preferences shared by most of the autistic community in autism research. For example, while some autistic people express preference for person-first language ('people with autism'), identity-first language (e.g., 'autistic people'; Table 1) has been consistently demonstrated to be preferred by most autistic people [6–8].

Concluding remarks

The terminology preferences of autistic individuals have often been ignored in published autism research, even though these preferences have been clearly demonstrated in several peer-reviewed articles and large community surveys. It is imperative that researchers, journals, and funding

boards promote the terminology preferences of the autistic community and adhere to them, as well as continually interrogate and update their language choices in line with the values of the autistic community. The evolving use of language to describe autism should be also accompanied by a shift in the way autism research is conducted. Specifically, 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 autistic people are integrated throughout the research process [1,4].

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Declaration of interests

H.W. is the clinic lead of the Victoria University of Wellington Autism Clinic and A.J.O.W. is the Director of CliniKids, both of which provide support to autistic individuals. R.M. declares no competing interests.

Resources

ⁱ<https://autisticnotweird.com/autismsurvey/>

ⁱⁱ<https://autismnz.org.nz/autism-new-zealand-terminology-guide/>

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References

- Gillespie-Lynch, K. *et al.* (2017) Whose expertise is it? Evidence for autistic adults as critical autism experts. *Front. Psychol.* 8, 438
- Pellicano, E. and den Houting, J. (2022) Annual research review: shifting from 'normal science' to neurodiversity in autism science. *J. Child Psychol. Psychiatry* 63, 381–396
- den Houting, J. *et al.* (2021) 'I'm not just a guinea pig': academic and community perceptions of participatory autism research. *Autism* 25, 148–163

- Gernsbacher, M.A. (2017) Editorial perspective: the use of person-first language in scholarly writing may accentuate stigma. *J. Child Psychol. Psychiatry* 58, 859–861
- Bury, S.M. *et al.* (2020) 'It defines who I am' or 'It's something I have': what language do [autistic] Australian adults [on the autism spectrum] prefer? *J. Autism Dev. Disord.* Published online February 28, 2020. <https://doi.org/10.1007/s10803-020-04425-3>
- Bottema-Beutel, K. *et al.* (2021) Avoiding ableist language: suggestions for autism researchers. *Autism Adulthood* 3, 18–29
- Kenny, L. *et al.* (2016) Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism* 20, 442–462
- Lei, J. *et al.* (2021) Exploring an e-learning community's response to the language and terminology use in autism from two massive open online courses on autism education and technology use. *Autism* 25, 1349–1367
- Alvares, G.A. *et al.* (2020) The misnomer of 'high functioning autism': intelligence is an imprecise predictor of functional abilities at diagnosis. *Autism* 24, 221–232
- Fletcher-Watson, S. *et al.* (2017) Attitudes of the autism community to early autism research. *Autism* 21, 61–74
- Leadbitter, K. *et al.* (2021) Autistic self-advocacy and the neurodiversity movement: implications for autism early intervention research and practice. *Front. Psychol.* 12, 635690
- Kaplan, B.J. *et al.* (2001) The term comorbidity is of questionable value in reference to developmental disorders: data and theory. *J. Learn. Disabil.* 34, 555–565
- Patten Koenig, K. and Hough Williams, L. (2017) Characterization and utilization of preferred interests: a survey of adults on the autism spectrum. *Occup. Ther. Ment. Health* 33, 129–140