



Published in final edited form as:

Pediatrics. 2022 April 01; 149(Suppl 4): . doi:10.1542/peds.2020-049437N.

First Do No Harm: Suggestions Regarding Respectful Autism Language

Patrick Dwyer, MA^{a,b}, Jacalyn G Ryan, MA, CPA, CMA^c, Zachary J Williams, BS^{d,e,f,g}, Dena L Gassner, MSW^{h,i}

^aCenter for Mind and Brain, University of California Davis, Davis, California;

^bDepartment of Psychology, University of California Davis, Davis, California;

^cFaculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada;

^dMedical Scientist Training Program, Vanderbilt University School of Medicine, Nashville, Tennessee;

^eDepartment of Hearing and Speech Sciences, Vanderbilt University Medical Center, Nashville, Tennessee;

^fVanderbilt Brain Institute, Vanderbilt University, Nashville, Tennessee;

^gFrist Center for Autism and Innovation, Vanderbilt University, Nashville, Tennessee;

^hSchool of Social Work, Adelphi University, Garden City, New York;

ⁱDepartment of Health Sciences, Towson University, Towson, Maryland

Nationally and internationally, efforts are ongoing to promote diversity, equity, and inclusion in healthcare and other fields. These efforts require consideration of ways in which language and assumptions impact individuals and communities. The autism and disability spheres are no exception. Indeed, the mental health of autistic people is predicted by the degree to which they feel society accepts them as autistic.¹ Thus, we believe discourse that disparages autism could be harmful to autistic people's well-being. Autistic individuals who face further stigma and discrimination due to other intersectional identities might be particularly vulnerable. Unfortunately, autism research and practice have traditionally used disparaging language grounded in the medical model.

Some might object that alternatives to traditional medical model terms are subjective or unscientific. However, we believe traditional terminology is heavily laden with subjective value judgements. For example, the traditional term "disorder" has a decidedly negative connotation. It also implies that individuals' own characteristics are responsible for their

Address correspondence to Patrick Dwyer, MA, 267 Cousteau Place, Davis, CA 95618. psdwyer@ucdavis.edu.

Mr Dwyer contributed to the conception of the commentary and wrote an initial draft of this commentary; Ms Ryan, Mr Williams, and Ms Gassner contributed to the conception of the commentary, and reviewed, revised, and edited the manuscript; and all authors approved the final submitted text and agree to be accountable for all aspects of the work.

CONFLICT OF INTEREST DISCLOSURES: All authors of this commentary receive financial compensation from serving on the Autistic Researcher Review Board of the Autism Intervention Research Network on Physical Health (AIR-P). Mr Williams also serves as a consultant for Roche and a member of the family advisory committee of the Autism Speaks Autism Treatment Network Vanderbilt site.

challenges, and it suggests a need to eliminate this disorder. In contrast, the more nuanced word “disability” allows both individual characteristics and societal or contextual barriers to contribute to challenges. The term disability thus appears to be both more scientifically appropriate and less stigmatizing toward a vulnerable population than disorder.

In Table 1, we list various traditional terms and concepts that we believe are problematic, along with suggested replacements. We also suggest that practitioners and researchers balance a focus on autistic individuals’ challenges with discussion of their strengths and potential. This balanced approach may be especially important for families of young children whose futures may be unclear and a source of considerable anxiety to caregivers.

Furthermore, researchers and practitioners should be aware of an ongoing debate between supporters of identity-first (“autistic person”) and person-first (“person with autism”) language. Many autistic individuals support identity-first language^{2,3} and some fear that person-first language reflects negative attitudes toward autism.⁴ However, others endorse person-first language.^{2,3} The term “person on the autism spectrum” is often the most preferred term among autistic individuals and other stakeholder groups,^{2,3} and this verbiage is typically found to be acceptable by proponents of both person-first and identity-first language. Practitioners should ask about and respect the language preferences of individuals “on the spectrum” who can articulate their views.

Overall, in light of concerns that typically-developing people struggle to understand autistic perspectives,⁵ we urge practitioners and researchers to strive to have empathy for how their language sounds to autistic people. We also suggest it can often be helpful to ask oneself if one would use similar phrasing with other marginalized communities. We feel that there needs to be a shift toward “cultural humility” and willingness to learn from autistic people about autistic identities and how to promote autistic well-being.

Practitioners and researchers interested in a more detailed discussion of appropriate autism terminology should refer to Bottema-Beutel and colleagues.⁶ We provide definitions of neurodiversity terminology (eg, neurodiverse, neurodivergent) in Supplemental Table 2.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

FUNDING:

This study was supported by National Institute of General Medical Sciences grant T32-GM007347 (Z.J.W.), National Institute on Deafness and Other Communication Disorders grant F30-DC019510 (Z.J.W.), and the Nancy Lurie Marks Family Foundation (Z.J.W.). No funding body or source of support had a role in the preparation or decision to publish this article. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health or other sources of support. Funded by the National Institutes of Health (NIH).

REFERENCES

1. Cage E, Di Monaco J, Newell V. Experiences of autism acceptance and mental health in autistic adults. *J Autism Dev Disord.* 2018;48(2):473–484 [PubMed: 29071566]

2. Bury SM, Jellett R, Spoor JR, Hedley D. “It defines who I am” or “it’s something I have”: what language do [autistic] Australian adults [on the autism spectrum] prefer? [published online ahead of print February 28, 2020]. *J Autism Dev Disord*. doi:10.1007/s10803020044253
3. Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*. 2016; 20(4):442–462 [PubMed: 26134030]
4. Sinclair J Why I dislike “person first” language. *Auton Crit J Interdiscip Autism Stud*. 2013;1(2): 2–3
5. Milton DEM. On the ontological status of autism: the “double empathy” problem. *Disabil Soc*. 2012;27(6): 883–887
6. Bottema-Beutel K, Kapp SK, Lester JN, Sasson NJ, Hand BN. Avoiding ableist language: suggestions for autism researchers. *Autism Adulthood*. 2021: 18–29

TABLE 1

Traditional Terms, Concepts, and Ideas, Along With Suggested Alternatives.

Traditional Terms, Concepts, and Ideas	Suggested Alternatives
Disorder	Disability
Autism spectrum disorder	Autism, autism spectrum development, autism spectrum disability
Deficit	Area of challenge, difficulty
Autism symptoms	Autism characteristics, traits, features
Red flags for autism	Signs or indicators of possible autism
Problem behavior or challenging behavior	Distressed behavior, meltdown, more specific description of the behavior (e.g., self-injury, destruction of property)
Restricted interests	Focused, intense interests
Comorbid	Co-occurring
Risk ^a	Likelihood, probability
Risk factor ^a	Predictive factor, predictor, correlate
Healthy controls	Typically-developing or neurotypical (if screened for other diagnoses), non-autistic (if only autism ruled out), or general population (autism not ruled out, group not sampled with regard to autism status) controls
High-functioning or low-functioning autism, severe autism or severity of autism	Descriptions of relevant individual characteristics (eg, autistic person with or without intellectual disability or language impairment)
Prevention of autism; treatments focused on reducing autism symptoms and on promoting recovery, normalization, and “optimal outcomes”	Descriptions of support needs, grounded in specific contexts (as needs vary across contexts)
Rigid, inflexible	Interventions and supports aimed at curing or preventing co-occurring medical problems (not autism itself), at teaching adaptive skills to individuals, at making environments accessible, and at promoting quality of life or well-being or thriving
	Consider: in any particular instance, is it the autistic individual, the environment around them, or both that is or are inflexible?

^aOnly problematic when applied to autism; may be appropriate for many co-occurring conditions.