COMMENTARY

A full semantic toolbox is essential for autism research and practice to thrive

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Abstract

Individuals diagnosed with autism spectrum disorder (ASD) present with a highly diverse set of challenges, disabilities, impairments and strengths. Recently, it has been suggested that researchers and practitioners avoid using certain words to describe the difficulties and impairments experienced by individuals with ASD to reduce stigma. The proposed limitations on terminology were developed by only a subset of the autism community, and the recommendations are already causing negative consequences that may be harmful to future scientific and clinical endeavors and, ultimately, to people with ASD. No one should have the power to censor language to exclude the observable realities of autism. Scientists and clinicians must be able to use any scientifically accurate terms necessary to describe the wide range of autistic people they study and support, without fear of censure or retribution.

Lay Summary

- Scientists and clinicians must be able to use the vocabulary necessary to describe the wide range of autistic people they study and support without fear of censure or retribution.
- Lists of acceptable terms, written by subsets of the community, threaten inappropriate censorship and erasure of problems experienced by many with autism.
- No one should have the power to censor language to exclude the observable realities of autism. Scientists must have access to a full semantic toolbox to describe research findings and clinical realities.

KEYWORDS

autism spectrum disorder, bias, language, Vocabulary

INTRODUCTION

Individuals diagnosed with autism have a broad range of clinical presentations, all falling under the diagnostic umbrella of autism spectrum disorder (ASD). Recently, some autism community members have urged a dramatic lexical shift concerning ASD—namely, that the field should dispense with language that connotes impairment, pathology or suffering, in favor of "neutral" terminology reflecting an understanding of autism not as a medical issue, but rather as a form of human diversity. Three recent articles suggest avoiding or replacing terms like "disorder," "deficit," "risk," "symptoms," "challenging/problem behavior," "comorbid" and "prevention" to acknowledge ASD as a benign part of the human condition (Bottema-Beutel et al., 2020; Dwyer et al., 2022; Monk et al., 2022). And in many cases, certain words are labeled "ableist" without thought or consideration given to the context in which they are used.

Autism is a spectrum of abilities, disabilities, strengths and challenges, and requires the use of a broad spectrum of descriptors (Lombardo & Mandelli, 2022).

Censorship of certain terms exerts a chilling effect on research and clinical practice, particularly on individuals and their families who experience autism as a life-limiting disorder rather than a divergence or identity. In addition, general terms like "difference" are neither accurate nor precise and cannot clearly capture the realities of people across the spectrum.

While scientific words may at times provoke feelings of social stigmatization in some people, the response should lie in addressing that stigma, not in eliminating fact-based, accurate descriptors in clinical, medical and scientific discourse. Moreover, the words targeted for elimination apply almost exclusively to individuals who are the most severely impacted by autism—individuals who have already been identified as underserved despite their desperate need for meaningful interventions (Lord et al., 2020; Stedman et al., 2019; Thurm et al., 2021). We call for the continued utilization of accurate, scientifically and clinically appropriate terminology in research, advocacy, service delivery and policy across the autism spectrum. It is imperative that clinicians and scientists have at their disposal a comprehensive vocabulary to describe the very different individuals and subpopulations they address. This commentary will not be presenting yet another list of words and alternatives; rather, we hope that scientists and clinicians use the terms they feel best represent the science and the communities and individuals they serve. We also hope that their choice of terms will not be met with attacks or humiliation, either in person or online. In addition, we need to remember that ethnic and cultural factors may influence the choice of words used and that appropriate vocabulary should not be dictated by mostly white, non-Hispanic individuals. This commentary encourages people to use the terms that they feel are most appropriate to describe themselves, their family members, their research subjects and their patients.

McCoy et al. (2020) coined the term "partial representation" to describe situations in which one subset of a population claims to speak for an entire group without consulting all relevant stakeholders—the term "partial" reflects that such advocacy is necessarily both incomplete and biased (McCoy et al., 2020). Legitimate claims of representation, they argue, must reflect input from all factions within a group. Instead of a single set of terms dictated by a fraction of the autism community, clinicians and researchers should remain mindful of the great heterogeneity of the autism spectrum and of their ethical obligation to avoid euphemism in favor of transparent, precise and meaningful language upon which sound medicine and science are predicated. Unfortunately, this partial representation is reflected in previous publications on this topic. For example, the majority of individuals who participated in a survey about language preference were able to use a computer and fill out a survey (Monk et al., 2022), a task impossible for most who are more severely impacted by autism. In addition, some terms,

such as the innocuous phrase "person with autism," were considered offensive and excluded from the list of approved terms, even though ~18% of even the narrow group of participants approved of the term (Monk et al., 2022). To cite a more robust approach, the Els for Autism Foundation, together with The Learning Academy, has widely distributed a survey to a culturally diverse population to identify language preferences among the broad autism community, including outside the United States. We look forward to the results.

We can look to other disorders for context in this debate on autism. In the realm of substance abuse, many in the field have called for terms that accurately reflect the condition and situation of the individual, albeit with warnings against using pejorative language or terms that have been used as insults, such as "crackhead" or "junkie" (Alinsky et al., 2022; Goldberg, 2020). Use of terms such as "substance use disorder" and person-first language such as "person with substance use disorder" is linked to a public health approach that captures the medical malfunction inherent in addiction, while decreasing stigma and increasing help-seeking (Kelly et al., 2015; Volkow et al., 2021).

There are also inherent contradictions in the logic of limiting autism-related terms. For example, while some would argue autism is more of a social construct and that person-first language can perpetuate stigma in autism (Gernsbacher, 2017), others would use that *same* language to destigmatize behavioral impairments with biological underpinnings (Volkow et al., 2021). Likewise, terms like "at risk" or "symptoms" originate in the medical and biological model as part of efforts to explain the pathology of the brain, including structural differences and their roots in genetic deletions and duplications resulting in autism (Andrews et al., 2022; Leppa et al., 2016; Trost et al., 2022). These findings reduce stigma by attributing behaviors and functions to underlying biology instead of personal faults. The intent of using these terms is to describe processes in development which lead to behavioral impairment, and to provide targets for beneficial treatments and interventions. Just as the substance abuse field has, we acknowledge that some words should no longer be used. For example, some medical terms, such as "mental retardation," have been converted to insults like "retard." These are clearly pejorative terms used for the purpose of insulting and dehumanizing others; these terms should not be used and have been universally rejected. But, for example, a decision to use "person with autism" or "autistic person" is a matter of preference, as neither are intended to demean people. In fact, "person with autism" has been embraced by a large proportion of the autism community (Kenny et al., 2016).

There does not need to be a battle between the two viewpoints around autism vocabulary; there is room across the spectrum to acknowledge that autism can be a state of being for some, an impairing condition for others

and somewhere in between for many. Restricting terms used to describe autism will not change the nature of a person's autism nor will it eliminate the impairments and symptoms experienced because of an autism diagnosis. It will not result in clinical benefit for some while reducing any services for anyone else.

"SCIENTIFICALLY ACCURATE" ACROSS THE SPECTRUM

Autism Spectrum Disorder encompasses a wide variety of symptoms, impairments, biological underpinnings, co-occurring conditions, effective interventions, supports and risks (Lord et al., 2020), and there are likely multiple categorizations within the umbrella term (Lombardo & Mandelli, 2022). It is imperative that clinicians and scientists have a comprehensive vocabulary at their disposal to describe with accuracy the very different subpopulations they address. Banning certain words makes accurate scientific descriptions impossible. For example, the word "comorbid" (on the list of disfavored terms) is used to describe a chronic medical or psychiatric condition that is connected with another condition. Conditions such as gastrointestinal (GI) disorders, seizures, ADHD and OCD have been considered "co-morbid" (Bougeard et al., 2021). "Co-occurring" (a suggested alternative) only refers to things that happen at the same time. This may or may not refer to conditions including depression and anxiety, or it may depend on the person rather than the condition. To accurately describe individuals with autism and conditions like ADHD, GI dysfunction, insomnia and seizures, as well as other debilitating conditions, "comorbid" is the accurate term as it conveys the chronic and persistent nature of these problems (Brainstorm et al., 2018; Cross-Disorder Group of the Psychiatric Genomics Consortium. Electronic address & Cross-Disorder Group of the Psychiatric Genomics, 2019). Both co-occurring and comorbid are correct to use under different situations. The scientifically correct term should always be used.

While terms like "differences," "traits" and "characteristics" may be appropriate to describe some individuals in certain contexts, autism is *defined* by the American Psychiatric Association in its *Diagnostic and Statistical Manual 5.0* as a "mental disorder" involving clinically significant impairments in the social communication domain and restricted behaviors. These measurable behavioral features are associated with lifetime functional impairment around daily functioning, learning, communication and social interaction, and are not mere "differences" (Lord et al., 2022). Indeed, they often have profound impacts on communication, cognition and social interaction, and include dangerous life-threatening behaviors including aggression, self-injury, elopement, property destruction and pica. Describing head-banging so intense and frequent that it results in concussions or

habitual elopement into hazardous traffic as mere traits trivializes some of the life-threatening realities of ASD. Government funding for diagnostics, treatments, support and programs is driven by the direct expression of need. If autism is a mere "difference," we risk a future where policymakers are blinded to the dysfunctions and impairments that underlie service needs, while researchers turn away from seeking causes of and treatments for ASD.

Given our increasing awareness of the heterogeneity in autism etiology, neurobiology, treatment and outcomes, it seems increasingly likely that ASD will at some point be divided into an array of different conditions, each with their own risk factors, pathways and treatments, but for now, instead of narrowing the terminology available to researchers, we need a linguistic toolbox that grows more expansive and precise with each discovery that emerges from the broad range of medical specialties, including genetics, psychiatry, developmental pediatrics, neuroscience, gastroenterology, neurology and others. A diverse range of terms that accurately and comprehensively describe the phenomena under investigation across all contexts and experiences of ASD is essential for the advancement of science and medicine (Roman-Urrestarazu et al., 2022).

CONSEQUENCES OF RESTRICTIONS

The authors of previous articles on this topic describe their proposed vocabulary as "suggested" and say it should not apply to disabling conditions that cause suffering, but to the autism itself. This distinction has not been clearly made in the autism literature and has been misinterpreted by readers of these articles as mandates. There is no nuance or context applied to the determination of appropriate terminology. We see no reason to carve out a pure, pathology-free "autism" when we can find nothing in the diagnostic literature describing it. Further, while we appreciate the intention of reducing stigma, the list of terms suggested to be eliminated has unfortunately already been weaponized against scientists and against family members who do not consider autism a simple "difference." The list of restricted terms has been used to insult, bully and demean those who use the terms (Alice, 2022; Blaber, 2022; Carley, 2022; Donnelly, 2022; Lutz, 2021; Michael, 2022; Natri, 2022; Shakes & Cashin, 2020; Witch, 2022). Ironically, the intention to narrow permissible language to promote inclusivity is having the opposite effect, and the community is becoming more polarized. These are just a few examples of the real abuse that individuals who choose to use terms like "disorder" and "protective effect" have endured.

In addition, access to vital research grants has been compromised due to a misunderstanding that applications must use certain preferred terminology. For example, students and early-career investigators, observing

regular attacks on researchers whose language and work do not fit the neurodiversity paradigm, are expressing hesitation about remaining in the field of autism research and have shared grave concerns about presenting autism findings at public conferences for fear of retribution and retaliation. There are reports of scientists being attacked at meetings for making presentations that include certain words, for example, "risk," at an epidemiology meeting where "risk" is a scientific term that is not meant to stigmatize. Reviewers for scientific journals have at times demanded the use of neutral terms in research papers, potentially derailing important research from being published. The question of "correct" language has been used to argue for a lower score on grants that come in for review, without regard for the context of the research project. The inevitable downstream effect of this self-censorship and external censorship will be the diminishment of interest in the field and further exclusion of research focused on profound autism, where symptoms and outcomes require the use of words like "severe," "problematic" or "challenging."

An additional, and also pragmatic, argument for maintaining scientific terminology is the need for consistent use of terms that support searching the literature for papers on key topics. There has been a growing importance of systematic reviews and meta-analyses in the field, and continued research depends on scientists being able to access all relevant published papers on topics that use common scientific terms.

We urge the autism community to continue to ask families and individuals what terms they need and prefer to describe themselves, and to accept the use of a broad array of scientific terminology in scientific journals. Scientists should not feel the need to censor their language for fear of judgment or retribution. The push for neutral language robs the scientific community of the ability to describe, with accuracy, the day-to-day realities of life of people with autism, particularly those with profound autism. No one should have the power to limit language to exclude the observable realities of autism. Scientists, clinicians and scientists need access to the full semantic toolbox to describe the multiple realities of autism and make progress toward understanding patient experiences and needs, the various underlying causes and the future for meaningful treatments.

DISCLOSURE

The authors are all mothers of individuals on the spectrum. Three have children with what can be described as profound autism, and another cares for a daughter who is autistic and in a mainstreamed learning environment.

DATA AVAILABILITY STATEMENT

The data that support the findings will be available at https://www.autismsciencefoundation.org following an embargo from the date of publication to allow for commercialization of research findings.

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