Published in final edited form as:

J Autism Dev Disord. 2017 September ; 47(9): 2938–2941. doi:10.1007/s10803-017-3204-3.

Describing function in ASD: Using the DSM-5 and other methods to improve precision

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Letter to the Editor

Use of the term “low-functioning” in the autism spectrum disorder (ASD) literature dates to at least 1969 (Goldfarb, Goldfarb, & Pollack, 1969), and the term “high autistic” was used as early as 1973 (DeMyer et al., 1973). These modifiers were often used to characterize children with ASD on the basis of characteristics not specific to ASD (e.g., IQ, language). A search on this Journal’s website, which like other autism journals lists “high/low functioning” as potential submission classifications, yielded 167 results for “high-functioning” and 49 for “low-functioning” in 2016 alone. Some self-advocates with ASD report that these terms are perceived as pejorative (Ortega, 2009). The scientific problems with use of these terms are also concerning, but are less widely acknowledged. Here, we argue that the imprecision of this terminology hinders scientific progress, and we suggest that we turn to DSM-5 diagnostic criteria that include descriptive specifiers for a more precise, and appropriate, nomenclature.

Across studies, the terms “low-” and “high-functioning” refer to categories based on ratings for a myriad of different behaviors, including cognition (IQ), language, and social-communication. At some point, the terms became so commonplace that the domain of function is often not specified. The level of impairment used to denote “low” or “high” function is often obscured by the casual use of the terms to describe the average or modal presentation of a sample, failing to acknowledge the broad range of abilities actually encompassed by the study participants. Additionally, to categorize an individual as “low-functioning” may obscure strengths (e.g., average cognitive function in minimally verbal individuals; Bal, Katz, Bishop, & Krasileva, 2016), whereas classifying someone as “high-functioning” may underestimate impairments in areas such as daily living skills and supportive needs (e.g., Kenworthy, Case, Harms, Martin, & Wallace, 2010). Inconsistent and poorly defined subgroups make it impossible to carefully compare across studies of so-called “low-” or “high-functioning” individuals.

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“Low-” and “high-functioning” are most often used in research literature to describe the cognitive ability of an individual with ASD. These terms were initially shorthand for an intellectual disability diagnosis (e.g., Freeman, Ritvo, & Schroth, 1984), though the field quickly adopted a more general meaning, frequently using the terms LFASD and HFASD (e.g., McDonald et al., 2015). “Low-” or “high-functioning” sometimes also refers to speech or language level (e.g., DeMyer et al., 1973), though this is often conflated with IQ, as many individuals with little speech receive lower scores on standardized cognitive tests.

The terms have been more rarely used to describe degree of autism symptom severity. That this is relatively uncommon may be related to the limited availability of psychometrically valid dimensional measures of ASD symptom severity (Anagnostou et al., 2015); even scales with content that differs based on language level are influenced by age and cognitive ability (e.g., the Autism Diagnostic Observation Scale (ADOS-2) as described by Gotham, Pickles, & Lord, 2009). The use of HFASD (based on IQ) has historically caused some confusion when conflated with the diagnostic distinction between (DSM-IV-TR) Asperger Disorder and Autistic Disorder. The DSM-IV-TR described clear criteria for Asperger Disorder that did not include reference to the relative reductions in severity of social deficits relative to Autistic Disorder. Nevertheless, some reports indicated less severe social deficits, but no differences in adaptive function, in Asperger Disorder compared to HFASD (Saulnier & Klin, 2007). Findings like these exemplify the confusion in multidimensional aspects of impairment when a “splitting” approach is taken. The need to consider dimensionality in neurodevelopmental disorders, rather than relying on potentially arbitrary behavioral distinctions, has recently been highlighted by the Research Domain Criteria Framework (Casey, Oliveri, & Insel, 2014), and exemplified by the lack of specificity regarding biological factors in relation to IQ, severity, or language subgroups in ASD (Anderson, 2015).

Moving Forward

The obvious solution to lack of specificity in terms is to use more precise language. For example, a study of “low-functioning” individuals who have low IQ and commensurately impaired language scores may instead use the description, “a sample of children with ASD, enriched with children with language impairment and intellectual impairment.” This wording is sourced directly from the DSM-5 ASD diagnostic criteria (American Psychiatric Association, 2013), which contain a potentially useful framework for describing function in ASD. Among the available specifiers are: “With or without accompanying intellectual impairment” and “With or without accompanying language impairment.” However, one reason why implementation of these descriptive terms has lagged is that these terms are not thoroughly operationalized. Proposed frameworks for describing language impairment exist, though they vary from categorical (e.g., minimally verbal versus verbal) to dimensional (e.g., standardized tests). We recommend the use of broad but operationalized terms like few-to-no words, some single words, phrase speech, and fluent speech, consistent with the approach used in assessments like the ADOS-2 (Lord et al., 2012) and recommended as benchmarks for spoken language in ASD (Tager-Flusberg et al., 2009). Importantly, we are not advocating for a particular measure; rather, we propose that researchers should clearly operationalize the terminology they use to describe their sample, as well as the method

implemented to derive that definition, as different approaches may result in different subgroups (Bal et al., 2016).

At first glance, it may seem that intellectual impairment is most simply defined using existing criteria for the diagnosis of intellectual disability. However, we presume that the goal of adding this specifier to the ASD diagnosis was to allow for the clinician to describe additional impairment that does not rise to the level of an intellectual disability diagnosis, or that has a specific profile. In that case, classification may be made at gradations of IQ (e.g., <85, <70, <50, etc.), perhaps separately to reflect an uneven profile (e.g., when nonverbal IQ is stronger/not impaired, but verbal IQ is impaired). To allay confusion, it may be easiest to adopt the conventions used within the DSM-5 intellectual disability diagnostic framework, used here only to describe IQ, regardless of whether the individual qualifies for a diagnosis of intellectual disability. For example, individuals may be described as average nonverbal IQ/borderline verbal IQ or profound nonverbal IQ/profound verbal IQ.

Another promising solution to the problem of “low-” and “high-functioning” is simply to tie the classification to actual function. The World Health Organization has developed an International Classification of Functioning, which focuses on how context affects function and level of disability (see World Health Organization, 2002, 2016b). In this case, “functioning” does not refer to quantification of ability or symptoms, but rather to how those symptoms affect an individual’s age-appropriate ability to respond to the demands of daily life. The presence of significant social-communication symptoms or below-average cognitive abilities does not necessarily confer low function. That these domains are related, but independent, is basic to our conceptualization of mental disorder (symptoms do not constitute disorder unless they are associated with impairment). This phenomenon is commonly observed in individuals with ASD, in whom average cognitive ability frequently co-occurs with impaired adaptive behavior (e.g., Duncan & Bishop, 2015). To be consistent, it would seem that any classification based on *function* should involve the quantification of adaptive behavior. This is consistent with demonstration of impairment, using adaptive behavior, in the diagnostic criteria for intellectual disability (American Psychiatric Association, 2013).

A variety of adaptive behavior measures are currently available, including an updated Vineland Adaptive Behavior Scales (Sparrow, Cicchetti, & Saulnier, 2016) and the Adaptive Behavior Assessment System (Harrison & Oakland, 2003). The Child and Youth versions of the WHO Disability Assessment Schedule 2.0 are under development (see World Health Organization, 2016a) and adult versions are currently available (Andrews, Kemp, Sunderland, Von Korff, & Ustun, 2009). Also under development are Core Sets for ASD within the International Classification of Functioning, Disability and Health (ICF), including a Youth version (ICF-CY) (Bolte et al., 2014). Again, this framework characterizes not only the health condition (ASD), but also participation in activities, environmental factors, and individual factors, including age and other demographic information. Thus, an individual may be described by their abilities and impairments in each area or context. In addition to more precisely measuring function in ASD, the regular use of these instruments would also provide a direct comparison to other psychiatric and developmental disorder populations,

providing opportunities to disentangle the effects of language and cognitive abilities from those of ASD symptoms on function.

Conclusions

The autism spectrum is manifest in a variety of symptom presentations, and comprises the full range of cognitive and language abilities. The development of assessment batteries and paradigms that reflect this diversity, to be used with individuals at varying levels of any of these dimensions, will help us to move away from the need to subgroup participants into categories such as “low-” and “high-functioning.” Until that time, however, researchers will likely continue to find utility in dividing samples on the basis of any number of individual characteristics like IQ, language ability, ASD severity, or adaptive behavior. As scientists, we encourage precision and demand specificity in our use of terminology. Here we urge autism researchers to move away from convenient shorthand and to adopt a more descriptive nomenclature, which we believe is essential to advancing our understanding of ASD in a way that will inform development of targeted interventions and studies of etiology.

Acknowledgments

This work was supported to the NIMH Intramural Research Program. The opinions and assertions contained in this article are the private views of the authors and are not to be considered as official or as reflecting the views of the Department of Health and Human Services, the National Institutes of Health, or the National Institute of Mental Health.

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