



May 12, 2014

Sujata Bardhan, PhD

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)  
6100 Executive Blvd Room 4B09, MSC 7510  
Bethesda, MD 20892-7510

Dear Dr. Bardhan:

The American Speech-Language-Hearing Association (ASHA) appreciates the opportunity to provide the National Institutes of Health with input regarding the research implications of the changes to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* diagnostic criteria for Autism Spectrum Disorder (ASD).

ASHA is the national professional, scientific, and credentialing association for more than 173,000 members and affiliates who are audiologists, speech-language pathologists, speech, language, and hearing scientists, audiology and speech-language pathology support personnel, and students.

ASHA concurs with the concerns expressed in the statement by the Interagency Autism Coordinating Committee (IACC) that the new DSM-5 diagnostic criteria for ASD might affect access to diagnostic, treatment, and other services and that clinicians need to carefully apply the new diagnostic criteria for ASD in order to ensure that all individuals receive the services they need, regardless of the diagnostic label that is applied. Speech-language pathologists play an integral role in the diagnosis and treatment of individuals with ASD, because deficits in social communication and nonverbal and verbal language are core characteristics of this disorder. Speech-language pathologists are often the first professionals to see a child suspected of having ASD, and DSM-5 should not change the speech-language pathologist's critical role on the diagnostic team.

ASHA's comments regarding DSM-5 changes pertain to (1) the criteria used to diagnose ASD, (2) the need for research on the application of the diagnostic criteria for diverse populations, (3) the need to differentiate Social (Pragmatic) Communication Disorder and ASD, and (4) the value of a crosswalk framework between DSM-IV and DSM-5 criteria for future research.

### **1. Diagnostic Criteria for ASD: Concern About the Lack of Inclusion of *Language Deficits***

ASHA continues to support the elimination of subcategories for ASD due to lack of evidence for discrete categories. However, **ASHA is concerned that the absence of a language component overlooks the importance of language form and content in defining ASD.**

Language delay or lack of spoken language was a diagnostic criterion for ASD in DSM-IV. Its omission in DSM-5 means that children could be misidentified as having either ASD or a language disorder. With the new criteria, clinicians need to make a dual diagnosis of ASD and Language Disorder in order for children to receive all of the interventions that they need.

Spoken language disorders are a hallmark feature of ASD and are often the critical indicators for early identification of ASD. ASD affects all language components to some degree: content (i.e., semantics), form (i.e., phonology, morphology, syntax), and use (i.e., pragmatics, social communication) in all modalities (e.g., oral and sign). The new DSM-5 criteria for ASD, with the omission of a spoken language deficit, could result in an inaccurate description of ASD and result in

a fundamental mischaracterization of ASD that would run counter to an extensive body of research, such as the following major studies:

***Form (Morphology and Syntax)***

Eigsti, I. M., Bennetto, L., & Dadlani, M. B. (2007). Beyond pragmatics: Morphosyntactic development in autism. *Journal of Autism and Developmental Disorders*, 37, 1007–1023.  
Giacomo, A., & Fombonne, C. (1998). Parental recognition of developmental abnormalities in autism. *European Child & Adolescent Psychiatry*, 7, 131–136.  
Prud'hommeaux, E. T., Roark, B., Black, L. M., & van Santen, J. (2000). *Classification of atypical language in autism*. Beaverton, OR: Center for Spoken Language Understanding, Oregon Health & Science University.

***Content (Semantics)***

Mawhood, L., Howlin, P., & Rutter, M. (2000). Autism and developmental receptive language disorder—A comparative follow-up in early adult life. I: Cognitive and language disorders. *Journal of Child Psychology and Psychiatry*, 41, 547–559.  
McDuffie, A., Yoder, P., & Stone, W. (2005). Prelinguistic predictors of vocabulary in young children with autism spectrum disorders. *Journal of Speech, Language, and Hearing Research*, 48, 1080–1097.  
Smith, V., Mirenda, P., & Zaidman-Zait, A. (2007). Predictors of expressive vocabulary growth in children with autism. *Journal of Speech, Language, and Hearing Research*, 50, 149–160.

Indeed, current assessment instruments for ASD are based on verbal and nonverbal aspects of language. Clearly, a language deficit is a defining feature of ASD:

Lord, C., Rutter, M., et al. (2012). *Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)*. Torrance, CA: WPS.  
Rutter, M., & LeCouteur, A., et al. (2003). *Autism Diagnostic Interview, Revised (ADI-R)*. Torrance, CA: WPS.

Some children with ASD demonstrate unaffected early language development, and their problems manifest themselves only with higher-order language tasks (e.g., figurative language, inferencing), whereas other children demonstrate profound language deficits from the onset of the language acquisition process.

Even children with ASD who are verbal do not possess a generative language system (infinite capacity with finite means). They have not internalized the rules for generating novel language forms. Lack of generative language persists over time in children with ASD. In fact, their language acquisition pattern does not follow the typical developmental sequence.

Years of research on assessment and intervention protocols have used a definition of ASD that includes language as a major component. With that component eliminated in DSM-5, it will be difficult to extrapolate research to the newly defined ASD population. This could undermine the reliability, validity, and fidelity of assessment instruments and treatment protocols. Further, the omission of a language deficit as a diagnostic criterion will greatly hinder the ability to appropriately diagnose and treat the population and greatly impact funding. Streams of funding may be diverted imprudently away from treatment and instead go toward the development of new protocols.

### **Recommendation**

ASHA advocates for the inclusion of *language deficit* in subsequent DSM revisions and in any taxonomy defining ASD using wording such as the following:

Persistent deficits in comprehension and expression of language across contexts and modalities (e.g., spoken and manually coded), not accounted for by general developmental delays and manifested as deficits in language form (phonology, morphology, syntax) and language content (semantics), ranging from limited language acquisition to total lack of comprehension and expression of language (as defined in the section on language disorders)

### **Research Questions**

- What percentage of children diagnosed with ASD are reported to have a concomitant language impairment?
- Can existing assessment tools accurately identify individuals with ASD without considering the impact of language?
- Do the severity levels for ASD found in DSM-5 correlate to those of children with ASD diagnosed, with and without, language impairment?

## **2. Diagnostic Criteria as Applied to Diverse Populations**

The lack of attention in DSM-5 to cultural variations in verbal and nonverbal communication could lead to misdiagnosis. For example, nonverbal behaviors vary widely within and across cultures (e.g., sustained eye contact is considered to be rude in some cultures, but is desired in others). It is critical that assessments be culturally and linguistically appropriate.

### **Recommendation**

ASHA recommends that research pertaining to ASD recognize that nonverbal behaviors (e.g., body language, facial expressions, and gestures) vary within and across cultures.

### **Research Questions**

- How are the diagnostic criteria for ASD applied for children from different cultural and linguistic backgrounds?
- How can the diagnostic criteria be sensitive to differences and variances in nonverbal and verbal communication norms across cultures?

## **3. Need to Differentiate Social (Pragmatic) Communication Disorder and ASD**

Clinicians must differentiate between ASD and Social (Pragmatic) Communication Disorder, a diagnostic category new to DSM-5 but not new to speech-language pathology. Speech-language pathologists have a long history of assessing and treating pragmatic language disorders with very good outcomes. If a child has difficulties with social skills, but does not show restricted or repetitive patterns of behavior, the new diagnosis of Social (Pragmatic) Communication Disorder within the domain of Communication Disorder may apply. Distinguishing between ASD and Social (Pragmatic) Communication Disorder is the role of speech-language pathologists and is critical to ensure that individuals receive needed services. Some parents have expressed concern that children—particularly those who are high functioning—may not receive an ASD diagnosis and, consequently, won't qualify for intervention. Though DSM-5 provides guidance on how to distinguish between these two diagnoses, it is likely that mild ASD and severe Social (Pragmatic) Communication Disorder will be hard to distinguish in some cases.

The IACC statement indicates that "...relatively little is known about the validity and reliability of a Social (Pragmatic) Communication diagnosis, nor is it known what interventions will be most effective for children with this diagnosis." ASHA disagrees. Speech-language pathologists have been diagnosing and treating pragmatic language disorders for more than 40 years, and ASHA has published practice guidelines and offered numerous education programs on the topic. In fact, the IACC recognizes the "... large literature on 'pragmatic language disorder,' which shares many features with Social (Pragmatic) Communication." Therefore, clinical practice and research teams can rely on a wealth of research and practice information available from speech-language pathologists related to pragmatics and social communication. ASHA supports the pairing of the term *pragmatics* when *social communication* is used. The pairing of the terms demonstrates that Social (Pragmatic) Communication is not an unknown disorder.

Positive outcomes have resulted for individuals treated by speech-language pathologists for pragmatic/social communication disorders. According to ASHA's National Outcomes Measurement System, gains following speech-language pathology intervention were seen for spoken language comprehension and pragmatics, with 72% and 63% of children achieving one or more levels of progress, respectively. Furthermore, speech-language pathologists routinely provide treatment for those with pragmatic/social communication disorders alone, as well as for patients with neurologically based disorders, such as traumatic brain injury.

Another concern is that the IACC statement suggests that nonverbal communication deficits are limited to social communication. However, definitions of pragmatics typically include verbal and nonverbal communication (see [Components of Social Communication](#)).

Additionally, the DSM-5 manual contains a confusing directive about assigning an ASD diagnosis. The DSM-5 manual notes: "Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder" (DSM-5, 2013, p. 51). As the note makes clear, DSM-IV diagnoses should be retained even with the new DSM-5 criteria. This note appears to say that it is not necessary to re-diagnose patients, unless there is a clinical need (e.g., changes in clinical presentation) and that the new criteria should not be used as a means of excluding individuals from necessary services. However, the note continues with an apparently contradictory statement concerning the need for re-diagnosis: "Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder." This statement could result in more confusion than clarity regarding retention of a previous diagnosis. Again, such language underscores the need for differentiating Social (Pragmatic) Communication Disorder and ASD and ensuring that individuals receive needed services and supports regardless of the diagnostic label.

### **Recommendations**

Clinicians should draw on the large research base in the area of pragmatic language disorders, seek the guidance offered by professional organizations such as ASHA, and avail themselves of the expertise of speech-language pathologists in the diagnosis and treatment of ASD and Social (Pragmatic) Communication Disorder.

### **Research Questions**

- Are there differences in access to intervention for children diagnosed with ASD compared with children diagnosed with Social (Pragmatic) Communication Disorder?

- What do interrater reliability and intrarater reliability findings suggest about the ease and consistency of distinguishing between mild ASD and severe Social (Pragmatic) Communication Disorder?
- What *a priori* criteria should be used to consistently allocate study participants to either the mild ASD or severe Social (Pragmatic) Communication Disorder group to facilitate participant selection and characterization, measurement tool selection and application, data analysis, and interpretation of results?

#### **4. Crosswalk Between DSM-IV and DSM-5**

Standardized guidance on methods and considerations for crosswalking populations between the two DSM versions might be helpful to researchers and clinicians. More specifically, the guidance could facilitate decision-making about which severity level to apply based on each individual's current behavioral characteristics and previous diagnosis (e.g., Asperger's Disorder). Following development and implementation of a crosswalk framework, researchers should conduct both observational and experimental studies designed to elucidate similarities and differences across previously distinct categories to determine if those classifications were moderating factors in the diagnostic accuracy of evaluation tools and the efficacy and effectiveness of interventions.

#### **Recommendation:**

**Develop a crosswalk framework between DSM-IV and DSM-5 diagnostic criteria for ASD, to be published or otherwise shared with the greater research and clinical communities.**

#### **Research Questions:**

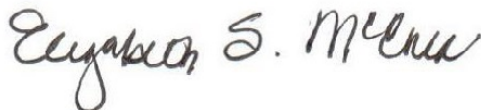
Has the elimination of distinct ASD diagnoses ameliorated, impeded, or made no difference in the selection of appropriate assessments and interventions for individuals with ASD?

How does the elimination of distinct diagnoses impact the understanding various stakeholders (e.g., individuals with ASD, caregivers, spouses, educators, health care providers, policymakers) have of the nature of the disorder, its impact on individuals with ASD, and ways in which symptoms of the disorder are best addressed?

Have any methods been devised to ensure continuity in the classification of individuals with ASD from studies that classified study participants according to the DSM-IV versus the DSM-5?

In light of the changes made to the way in which ASD disorders are categorized, what, if any, implications exist for secondary research analysis?

ASHA would be glad to answer any questions you may have about our recommendations or about the role of speech-language pathologists in the diagnosis and treatment of ASD and Social (Pragmatic) Communication Disorder. Please contact Diane Paul at [dpaul@asha.org](mailto:dpaul@asha.org) for further information or to set up a time to talk.



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