DRAFT

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Draft Statement from the Interagency Autism Coordinating Committee regarding scientific, practice and policy implications of changes in the diagnosis criteria for autism spectrum disorder (DSM-5)

The Interagency Autism Coordinating Committee (IACC) is a federal advisory committee, composed of federal and public members, that coordinates efforts and provides advice to the Secretary of Health and Human Services on issues related to Autism Spectrum Disorder (ASD). The committee recognizes the need for diagnostic criteria for autism spectrum disorders (ASD) that reflect current scientific knowledge and progress and define the wide range of symptom expression associated with this disorder. However, it is important to also remember that these criteria are about people who have symptoms that can be helped considerably by services aimed at improving their ability to function in the world. Thus, any revision of the diagnostic criteria must be made with great care and ongoing monitoring so as to not have unintended negative consequences.

Changes in the DSM Criteria

Starting with the DSM-III in 1980, autism was considered one of the Pervasive Developmental Disorders (PDD). In an effort to reflect what has been learned through research and practice since that time, the DSM-5 released in 2013 removed the PDD umbrella label and the accompanying subtypes in favor of a single disorder, Autism Spectrum Disorder (ASD). In addition, ratings of the severity of the impairments caused by the ASD and several clinical specifiers were added. These specifiers provide information about etiology, co-morbidities (e.g. intellectual disability, language delay, medical conditions such as seizures), and pattern of onset. Since ASD continues to be defined by a pattern of developmental and behavioral symptoms, changes to the diagnostic criteria come with potential trade-offs. One goal of the recent revisions was to improve specificity of the ASD diagnosis, i.e. reduce false positive cases; however, concerns exist that this increased specificity may have gone too far in reducing the sensitivity of the ASD diagnosis, i.e. false negative cases. In addition, a new category, Social Communication Disorder (SCD) was added that applies to individuals who exhibit persistent difficulty with verbal and nonverbal communication that cannot be explained by low cognitive ability. Symptoms include difficulty in the acquisition and use of spoken and written language as well as problems with inappropriate responses in conversation.

Implications for research

The changes to the DSM potentially impact those individuals who were considered to have a PDD in the past, and now an ASD in the present. Efforts to improve intervention and understand the etiology of ASD through research have also depended on the diagnostic system to identify people with PDD and ASD. As we move forward with the DSM-5 diagnostic changes, research is also essential to understand the impact of the new classification system. It will be critically important to conduct research to understand whether the new criteria are making a difference in how, when and which people are being diagnosed with ASD, and on our understanding of the etiology of autism; on the reliability of diagnoses using the new criteria and specifiers; on how the new criteria impact prevalence estimates; to develop or modify diagnostics instruments and tools to conform to the new criteria; and on the impacts of the new criteria on service provision for those with ASD. Along these lines, the IACC DSM-5 planning group identified several pressing research questions related to the implementation of the DSM-5 ASD diagnostic criteria.

Who is being identified?

- What is the reliability and validity of DSM-5 ASD diagnoses compared to experienced clinician judgment?
- Do the DSM-5 criteria identify the same individuals who were diagnosed with a DSM-IV PDD? Are certain groups (toddlers, females, those with fewer symptoms) less likely to be diagnosed using DSM-5 criteria?
    - What is the symptom profile of persons who meet one set of diagnostic criteria but not the other?
    - What are the cognitive, demographic, and co-occurring condition profiles of persons who meet one set of diagnostic criteria but not the other?
- How does revision of the DSM-5 impact the number and characteristics of individuals identified with ASD?
    - For instance, increasing the *symptom level* threshold but reducing the *domain level* threshold for toddlers (e.g., Robins et al., 2013).
- What is the reliability and validity of the severity ratings for the two domains: 1) Social Communication and Interaction and 2) Restricted and Repetitive Behaviors and Interests?

- Does the inclusion of severity ratings of at least 1 in each domain (social communication impairment and restricted and repetitive behaviors) correspond to impairment in adaptive functioning that helps distinguish individuals with an Autism Spectrum Disorder from those individuals with features of ASD with or without other conditions?

- Does the removal of the age of three years for symptom onset alter the early identification patterns of children with an ASD?
- How will the DSM-5 criteria impact ASD prevalence estimates? How will trends be evaluated given that current ASD prevalence estimates are based on DSM-IV standards?
- What is the reliability and validity of the Social (Pragmatic) Communication Disorder (SCD) diagnosis? How is SCD distinct from ASD and Pragmatic Language Disorder?
- Will DSM 5 criteria resonate similarly across various underrepresented subgroups – included children from racial-ethnic minorities, females, and adults?

How are people identified with an ASD?

- How will existing screening and diagnostic instruments need to be modified to conform to the DSM-5 criteria (including the existing use of checklists specific to Asperger's)?
    - How will historical and current symptoms be captured, including a reliable way of establishing the presence of restricted and repetitive behaviors?
    - How will assessment tools be adapted to capture a range of strengths and weaknesses, ages, and cultural backgrounds?
    - How will severity ratings and specifiers be assessed and documented reliably?
- How do the DSM 5 criteria change the way clinicians, other health and education professionals, and community members conceptualized and identified ASD (along the lines of the impact of DSM-IV had in broadening the concept of autism to a spectrum including Asperger's)?
- What tools are to be used to assess SCD?

What does it mean to be identified with ASD?

- How does the removal of ASD subtypes affect the culture of individuals with ASD and how they identify, connect, and support one another?
- What are the ways that the severity levels will be used and how will these impact service provision (For example, will Level 1 become "mild ASD" or "Asperger's" and will services take this into account (Level 1, 2, or3 programs)?

- How does the addition of capturing severity levels, co-occurring symptoms (e.g., regression, dietary restrictions), and diagnosable conditions (intellectual disability, language disorder) help inform the management and clinical and etiologic understanding of ASD?
- How does the inclusion of SCD inform and impact treatment techniques and service eligibility?

Implications for practice and policy

There has been concern by many members of the autism community that some individuals who would have previously met criteria for an ASD diagnosis, and would have potentially benefited from ASD-specific services may no longer be diagnosed with ASD under the new system. Clinicians and educators have noted the need for greater clarity regarding how to implement the DSM-5 in real world settings, such as the appropriate use of the specifiers, severity ratings, and intervention recommendations for a child with ASD symptoms who does not meet full criteria for ASD. The IACC identified the following key issues that will be important to consider as DSM-5 is implemented in real-world settings:

- Very little prospective data on the reliability and validity of the new criteria exist for children who are young, individuals from diverse ethnic backgrounds, and adults. Thus, in general, caution is needed when using the DSM-5 criteria to make a diagnosis with these populations until more research is conducted. In particular, clinicians should pay special attention to individuals with obvious ASD symptoms who narrowly missed criteria for ASD based on DSM-5 to ensure that they are not inadvertently denied needed ASD-specific services. For example, a toddler or preschool age child who exhibits significant impairment in social communication and only exhibits one repetitive behavior and no sensory sensitivities will not meet a diagnosis of ASD, but may eventually do so and would likely benefit from early intensive behavioral intervention. Services should be based on need rather than diagnosis; it would not be appropriate for a child to be denied ASD-specific services because he or she does not meet full DSM-5 criteria if a qualified clinician or educator determines that the child could benefit from those services.
- It is important for families, individuals on the spectrum, and practitioners to know that individuals who currently have a diagnosis of ASD based on the DSM-IV system retain an ASD diagnosis for the purposes of qualifying for clinical and educational services. It would not be appropriate for an individual currently receiving ASD services to be denied those services because of a change in the DSM criteria.

- The Social Communication Disorder (SCD) diagnosis is new; virtually nothing is known about its validity and reliability, nor what interventions will be most effective for children with this diagnosis. It is very likely that many children with a diagnosis of SCD will benefit from intervention and other services currently designed for children with ASD. It will be important to evaluate the needs of each individual child and match those needs to the services that are available, including ASD-specific services such as early behavioral intervention, if appropriate. Furthermore, diagnosticians should be aware that the criteria for SCD are similar to those for the social communication domain for ASD, but the SCD criteria capture a greater level of social communication problems, ones that do not develop until 4-5 years of age. As noted in the DSM-5 manual, it would be rare to diagnose SCD in children under age 4 because the kinds of skills that are impaired don't typically emerge until 4-5 years of age. In fact, early intervention, defined as birth to age 3, would not be possible for children with SCD because it's not possible to diagnose SCD that early. It is possible to identify social, language, or autism spectrum disorders in children less than 3 years but not SCD.
- For billing purposes, ICD codes rather than DSM diagnoses are used. Clinicians will have to decide whether to use the ICD PDD-NOS code or the broader ICD PDD code for individuals with a DSM-5 ASD or SCD diagnosis. It will be important for clinicians to develop a rationale and consistent approach in their use of ICD codes for children with an SCD diagnosis until there are more data on the validity of the SCD diagnosis.
- Although Asperger syndrome will no longer be considered a formal DSM diagnosis, it is possible for people with a current DSM-IV diagnosis of Asperger syndrome to request to have a diagnosis of "Asperger syndrome" indicated in their medical/educational record as part of the list of "specifiers." This will facilitate continued research on Asperger syndrome. People who wish to continue to use the Asperger label are encouraged to do so, recognizing that this is no longer a formal DSM diagnosis however. This will allow persons to retain their identity as persons with Asperger syndrome if they choose to do so.
- The IACC recognizes the need for more information for clinicians and educators on use of specifiers and the severity ratings. The clinical specifiers have enormous potential to be used to describe specific subtypes of ASD, including those with limited language function and intellectual disability, known etiologies, history of regression, and medical co-morbidities, such as seizures and GI disorders. However, more systematic and validated methods for determining severity are needed before they can be reliably integrated into clinical diagnostic practice.