DRAFT

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Statement from the Interagency Autism Coordinating Committee Regarding Scientific, Practice and Policy Implications of Changes in the Diagnostic 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 all efforts within the Department of Health and Human Services (HHS) concerning autism spectrum disorder (ASD). The committee recognizes the need for diagnostic criteria for ASD that reflect current scientific knowledge and progress and define the wide range of symptom expression associated with this disorder. It was the goal of the Neurodevelopmental (ND) Workgroup for the Fifth Edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) to meet these standards. The DSM-5 criteria were published in May 2013 (APA 2013). Although the DSM-5 diagnostic criteria are intended primarily for use by clinicians and researchers in their diagnostic assessments, the IACC is aware that it is important to also remember that these the criteria also have a direct impact on people who have the disorders and their families, and their ability to assess symptoms and obtain services that can help them optimize their health, well-being and quality of life. Any revision of the diagnostic criteria must be made with great care so as to not have the unintended consequence of reducing critical services aimed at improving the ability of persons with autism. In this statement, the IACC describes a range of research, practice, and policy implications that arise as a result of the changes in the DSM criteria which deserve consideration as the DSM-5 is implemented in research, clinical, and educational settings.

Changes in the DSM Criteria

Starting with the DSM-III in 1980, autism was categorized as a 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 category and the accompanying subtypes (autistic disorder, Asperger disorder, Childhood disintegrative disorder and Pervasive Developmental Disorder – Not Otherwise Specified) with a single disorder, Autism Spectrum Disorder (ASD). The DSM-5 criteria place greater emphasis on the two core symptom domains of ASD (social communication and restrictive, repetitive behaviors), and no longer consider verbal abilities as a diagnostic feature. Other changes included

adding ratings of the severity of the two symptom domains and several clinical specifiers. 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. For example, removing a specific age cut-off for diagnosis was intended to improve the sensitivity of the DSM-IV criteria (which had required symptom onset by age 3 years). By DSM-5's more inclusive criterion, "Symptoms must be present in the early developmental period but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life" may reduce diagnostic specificity by expanding the list of differential diagnoses that must be considered. The inclusion of historical information also may have unintended consequences on sensitivity and specificity.

Another major change in DSM-5 was the addition of a new diagnosis category, Social Communication Disorder (SCD) which applies to individuals who exhibit persistent difficulty with the social use of verbal and nonverbal communication that cannot be explained by low cognitive ability. The symptoms of SCD have significant overlap with those of the ASD social communication domain, but the two disorders are considered to be unique and separate from each other. The distinction is clarified in the DSM-5 criteria, which note that ASD must be ruled out before a diagnosis of SCD can be considered. However, there is limited published information on SCD with a research basis primarily in the condition previously studied as Pragmatic Language Disorder (PLD). While SCD includes PLD, there is much to learn about the definition, measurement, scope, reliability, and validity of SCD as a diagnosed condition.

Implications for research

As we move forward with the DSM-5 diagnostic changes, research is essential to understand the impact of the new classification system on individuals who were diagnosed with a subtype of PDD in the past or with ASD in the current system. In addition, research on autism etiology and intervention is dependent on the classification system used to define the individuals included in studies and any impact of changing this system needs to be understood. 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; and impact of the new criteria on prevalence estimates. Efforts are needed to develop or modify diagnostics instruments and tools to conform to the new criteria, and to assess the impacts of the new criteria on service provision for those with ASD. Along these lines, the IACC has 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-TR autistic disorder, Asperger's disorder, or PDD-NOS (particularly those individuals who had subthreshold symptoms)?
    - Do the DSM-5 criteria improve diagnosis for groups who were previously reported to be under-recognized (minorities, females, toddlers, older adolescents and adults)?
    - What is the symptom profile of individuals 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?
- 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?
    - Do the severity ratings improve assessment of impairments in adaptive functioning and thus, help distinguish individuals with an ASD from those individuals with subthreshold symptoms or other disorders and conditions (e.g., ADHD, social phobia, intellectual disability, and others)?
- Does the removal of the symptom onset prior to the age of three years have an impact on diagnostic applications? For example, are more adolescents eligible for a DSM-5 diagnosis? Does the phrase "early developmental period" (Criterion D) provide sufficient coverage for toddlers and facilitate early identification of young children with 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 the combined DSM-IV-TR diagnoses of autistic disorder, Asperger's disorder, and PDD-NOS?

- What is the reliability and validity of the Social (Pragmatic) Communication Disorder (SCD) diagnostic criteria? What are the key features that distinguish SCD distinct from ASD?

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)? What new measures are required for screening and diagnostic assessment?
    - How will historical and current symptoms be captured, including assessment of the individual's lifetime history of symptoms?
    - How will assessment tools be adapted to capture the range of symptoms and developmental stages (toddlers, preschool, school-aged, adolescents, young and older adults)? What tools are needed to address differences in clinical presentation related to gender or cultural backgrounds?
    - What tools are needed to provide "individualized" diagnoses that specify no only the severity of the core symptom domains, but also an individual's strengths and weaknesses, co-occurring conditions and challenges?
    - 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, community members, and researchers conceptualize and identify ASD How are the DSM-5 criteria being applied in educational and other service systems? Although special education eligibility is based on educational need, how are state and local education authorities' procedures affected by the DSM-5 changes and addition of new conditions like SCD?
- What tools are to be used to assess SCD and how are these assessments related to first ruling out ASD?

What does it mean to be identified with ASD?

- How does the removal of specific ASD-related diagnoses (particularly, Asperger's disorder) 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 to describe the social communication and RRB domains? Do the severity levels have an impact on service eligibility or provision?
- How does the addition of specifiers for severity levels, age and pattern or onset, etiologic factors, and co-occurring symptoms conditions (e.g., intellectual disability, language disorder,

medical disorders) help inform the clinical management of ASD? Do the specifiers have an impact on our clinical and etiologic understanding of ASD? Are research findings published on individuals identified with DSM-IV criteria comparable to those using DSM-5 criteria? How will existing research datasets be integrated with DSM-5-based datasets?

- What is the impact of the DSM-5 diagnostic changes on service provision to individuals with isolated social communication deficits who may have met PDD-NOS criteria by DSM-IV-TR standards, but meet SCD criteria by DSM-5 standards? Is eligibility for ASD services increased, decreased, or unchanged? Are therapeutic interventions designed for ASD effective for addressing symptoms of SCD, or are new interventions required?

Implications for practice and policy

The DSM-5 criteria are likely to have a tremendous impact on assessment and diagnosis of ASD in a variety of settings. At this early stage, it isn't possible to know how the DSM-5 criteria will compare against the previous standards set by the DSM-IV. Researchers have begun to address these questions, as well as to assess the diagnostic utility, reliability and validity of the DSM-5 criteria. While we wait for those studies to produce results, clinicians will be using the DSM-5 criteria to diagnose individuals of different ages, developmental stages and cultural backgrounds. In addition to gaining familiarity with the new diagnostic criteria, professionals will need to learn how to use the diagnostic specifiers, including the severity ratings for the two core domains. The IACC identified the following key issues that will be important to consider as DSM-5 is implemented in real-world settings:

- There is concern that the new severity ratings might be inappropriately used to prescribe services. Although in the future reliable and valid tools for rating symptom severity that could meaningfully guide decisions regarding service need may become available, at this time, use of the severity ratings to determine type and level of services would not be appropriate.
- 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. 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.

- Clinical observation and some research suggest that some children who have ASD may not manifest the full range of ASD symptoms before three years of age. For example, a toddler who eventually will qualify for an ASD diagnosis based on DSM-5 criteria may exhibit a significant impairment in social communication and only exhibits one repetitive behavior and no sensory sensitivities. This toddler will not meet a diagnosis of ASD but would likely benefit from early intensive behavioral intervention. It would be appropriate for a child who is less than three who shows clear autism symptoms (e.g. significant impairments in social communication or restricted, repetitive behaviors) but does not meet full criteria for ASD to be given a provisional diagnosis of ASD and an opportunity to benefit from ASD-specific early intervention services. A diagnosis of ASD or a provisional diagnosis of ASD should be considered a disability that qualifies a child for early intervention services.
- If the initial diagnosis is being made with DSM-5 criteria, clinicians are encouraged to consider the full range of symptom severity described in the text for ASD. Although the criteria include a few symptom examples, these are not exhaustive and the sections on "Diagnostic Features" and "Development and Course" (pp 53-55 of DSM-5) include a more complete description of the clinical features at various ages and developmental stages. The comprehensive listing is provided to ensure that less common presentations are considered, and to ensure that all individuals who might benefit from ASD-specific services will receive them. In particular, clinicians should pay special attention to individuals with obvious ASD symptoms who don't meet DSM-5 criteria for an ASD diagnosis. In those cases, obtaining a more complete lifetime symptom history may reveal sensory sensitivities were present in early childhood, or that the individual had difficulties with transitions (bedtimes, leaving for school, etc.) and an inflexible adherence to bedtime or bath routines. As mentioned above, in young children, the evolving nature of ASD may make it difficult for them to receive an ASD diagnosis because symptoms aren't yet present in both core domains. Clinicians should consider the larger context of the child's presentation, keeping in mind that therapeutic interventions and provision of services should be based on need rather than diagnosis. 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. Individuals who currently have a diagnosis of ASD are not required to

be "re-diagnosed" with the new system in order to qualify for ASD services. The DSM-5 criteria contain the following note: "Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified (PDD-NOS) should be given the diagnosis of autism spectrum disorder (ASD)." As the note makes clear, DSM-IV diagnoses should be retained even after DSM-5 has replaced DSM-IV as the diagnostic standard. The manual explicitly states that there is no need to "rediagnose" 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 (p. 51 of DSM-5).

- In DSM-IV, there were very broad domain diagnostic criteria for PDD-NOS and it included a wide variety of clinical presentations, including autistic symptoms that didn't fully meet criteria for one of the defined disorders, "subthreshold" symptoms, and "atypical autism" which was defined by the presence of only deficits in reciprocal social interactions, or restrictive, repetitive behaviors (e.g., stereotypies associated with intellectual disability could meet this criterion). Although it was appropriate to include these atypical cases in the broad umbrella of a DSM-IV pervasive developmental disorder (PDD), the divergent cases don't fit within the autism spectrum and are unlikely to meet DSM-5 criteria for ASD. However, as stipulated in DSM-5, it is expected that all individuals with a "well-established DSM-IV diagnosis of PDD-NOS" will retain the diagnosis.
- The Social Communication Disorder (SCD) diagnosis is new. Compared to a diagnosis of ASD, relatively little is known about the validity and reliability of a SCD diagnosis, nor is it known what interventions will be most effective for children with this diagnosis. Although the SCD diagnosis is new, there is a large literature on "pragmatic language disorder", which shares many features with SCD. Pragmatic language disorder is defined by deficits in the social use of verbal communication; in SCD, the addition of nonverbal communication deficits provides a more comprehensive picture of the impairments in social communication. SCD also overlaps with the social communication deficit of ASD. It is very likely that individuals many children with a diagnosis of SCD will benefit from interventions and other services that are useful in addressing the social communication/reciprocity deficits of currently designed for children with ASD. Until specific treatment guidelines are developed for SCD, it will be important to evaluate the needs of each individual child and to match those needs to available services and therapeutic interventions.

- While the symptoms of SCD overlap with some symptoms of ASD, the two disorders are meant to describe separate conditions. SCD is categorized as a communication disorder, and is not considered to be part of the autism spectrum. It is important for clinicians to note that the symptoms which constitute SCD criteria capture symptoms typically not present until 4 – 5 years of age (or later). As noted in the DSM-5 manual, it would be rare to diagnose SCD in children under age 4 yrs. Therefore, SCD is not likely to be useful as a diagnostic justification for early intervention. However, under DSM-5 it remains 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. The DSM manual provides information regarding how the new DSM-5 diagnoses should be mapped onto the ICD codes. Although Asperger syndrome will no longer be considered a formal DSM diagnosis, people who wish to continue to use the Asperger label are encouraged to do so. This will allow them to retain their identity as persons with Asperger syndrome. In DSM-5, the verbal and intellectual abilities which distinguished Asperger syndrome from autistic disorder in DSM-IV are indicated by use of specifiers. Thus, the DSM-5 equivalent to Asperger disorder is: ASD without intellectual or language impairments.
- It should be noted that some states limit access to certain services by people with an Asperger syndrome diagnosis, but will provide them to people with an ASD diagnosis. • The IACC recognizes the need for more information for clinicians and educators on use of the diagnostic specifiers and the severity ratings. The clinical specifiers have enormous potential to be used to individualize diagnoses, and to describe specific subtypes of ASD, including those with limited language function, and severe intellectual disability, known etiologies, late onset age or history of developmental regression, and medical co-morbidities, such as seizures and GI disorders. For the first time, etiologic relationships can be indicated as part of a DSM-5 diagnosis, by utilizing the specifier, “Associated with known medical or genetic condition or environmental factor”. The severity specifiers are another aid to individualizing the ASD diagnoses, but provide only a general guide to rating symptom severity. The IACC encourages the development of valid and reliable measures that can aid in the clinical assessment of symptom severity across the lifespan and various cultural backgrounds.