DSM-V Development ASHA Comments Submitted June 2011

The American-Speech-Language-Hearing Association (ASHA) 2011 President Paul R. Rao submitted the following comments on ASHA's behalf related to the anticipated May 2013 publication of the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). Comments were posted on the DSM-5 website: www.dsm5.org.

A 00-01 Intellectual Developmental Disorders

Suggest the inclusion of an assessment of support needs to determine severity of intellectual disability

Rationale In order to determine severity, an assessment of support needs, such as augmentative and alternative communication systems and involvement of communication partners, is also necessary.

A 01 Intellectual or Global Developmental Delay Not Elsewhere Classified

A 02-08 Communication Disorders

A 02 Language Impairment

A. Language impairment (LI) is diagnosed based on language abilities that are below age expectations in one or more language domains; LI is likely to persist into adolescence and adulthood, although the symptoms, domains, and modalities involved may shift with age.

- LI affects acquisition and use of spoken language (sound-, word-, sentence-, and discourse-level comprehension, production, and awareness), written language (reading decoding and comprehension; spelling and written formulation), and other modalities of language (e.g., sign language, *augmentative and alternative communication systems*)).
- LI can affect the domains of vocabulary; grammar; narrative, expository and conversational discourse; and other pragmatic language abilities individually or in any combination.
- Language impairment should be diagnosed based on multiple sources of information, including naturalistic observation and individualized, standardized, culturally and linguistically appropriate psychometric measures.
- A regional, social, or cultural or linguistic variation (e.g., dialect) of language is not an LI.
- LI may occur as a primary impairment or co-exist with other disorders (e.g., **Autism Spectrum Disorder**, **Learning Disorder**, Selective Mutism*).
- B. The difficulties with language result in functional limitations in effective communication, social participation, academic achievement, career opportunities and/or occupational performance, individually or in any combination.
- C. If LI is present, it should be determined whether the criteria are met for Late Language Emergence or Specific Language Impairment, or other related disorders such as Social Communication Disorder or Selective Mutism, in order to formulate appropriate diagnostic testing and treatment plans. LI may be a provisional diagnosis to initiate treatment and further

investigation. LI may be the primary diagnosis if criteria are met for LI but not for any of the other LI diagnostic categories.

- D. Symptoms must be present in early childhood (but may not become fully manifest until speech, language, or communication demands exceed capacities).
- * Selective Mutism may be subsumed under **Social Anxiety Disorder (Social Phobia)** in DSM-5

A 03 Late Language Emergence

A. Late language emergence (LLE) is a delay in language onset with no other diagnosed disabilities or developmental delays in other cognitive or motor domains. LLE is diagnosed when language developmental trajectories are below age expectations for toddlers and preschool children up to 4 or 5 years of age based on age-referenced criteria (e.g., less than 50 words at 24 months, inability to follow verbal instructions, limited use of gestures and sounds to communicate, limited symbolic play, and few word combinations at 30 months). Children with LLE are at risk for Specific Language Impairment, Social Communication Disorder, Autism Spectrum Disorder, Learning Disability, ADHD, Intellectual Disability and other developmental disorders, and therefore need to be identified as toddlers, referred for early intervention, evaluated for more general cognitive problems, and monitored for a change in diagnosis as they approach school age. Late Language Emergence is not due to introduction of a second language. Children who are learning a second language might go through a silent period that can last a few days or a few months. These are typical patterns for second language learners. However, if the child demonstrates other difficulties in the acquisition of language, those difficulties should be evaluated.

A 04 Specific Language Impairment

Recommend the deletion of this category.

Rationale: This is a controversial diagnosis and one that is not available in the vast majority of clinical settings. It is widely used in research, but consensus among language scientists on the robustness and validity of the category has not been reached. Non-verbal IQ is required to make the diagnosis, and this information is not available in many (probably most) clinical settings. It is not best practice to rely on formal testing to make a diagnosis The problems with formal tests are well-known and pervasive. "Culturally and linguistic appropriate measures" are not available for many children who are L2 English learners and speakers of non-standard dialects. Therefore the diagnosis will not apply to many groups of children. In addition, a relatively small number of papers representing a relatively narrow view have been cited to support the proposed categories. The science is not sufficiently advanced, and the controversies have not been laid to rest, surrounding this label. Issues include the fact that nonverbal IQ declines with age (Leonard, L. (1998), Specific Language Impairment, Cambridge, MA: MIT Press), thus rendering the concept of the relation between IQ and language more difficult to understand; the concern with the use of 85 as a cut-off IQ for normal functioning, which is higher than that used for determination of intellectual impairment. Therefore, we respectfully submit to delete this category.

A 05 Social Communication Disorder

A. Social Communication Disorder (SCD) is an impairment of pragmatics and is diagnosed based on difficulty in the social uses of verbal and nonverbal communication in naturalistic contexts, which affects the development of social relationships and discourse comprehension and cannot be explained by low abilities in the domains of word structure and grammar or general cognitive ability. Culture variations may influence nonverbal language in a number of

areas, including eye contact, proximity, and pragmatics (e.g., directness and loudness). Cultural variations should not be considered a social communication disorder.

We find the rationale for separating **social communication impairment** under-developed because language impairment includes pragmatics. Language impairment can affect the domains of vocabulary; grammar; narrative, expository and conversational discourse; and other pragmatic language abilities individually or in any combination. The need for a separate category is not clear. The utility of the diagnosis seems to rest in identifying children with pragmatic language impairments who either do not have the diagnosis of ASD or do not meet the criteria for diagnosis of ASD because this category excludes those diagnosed with ASD. If a child has this label owing to a problem with locating an appropriate professional to appropriately assess ASD, which would seem to prolong a misdiagnosis.

The Language impairment diagnosis specifically states impairment can occur in any realm; the fact that some have found individuals with intact abilities in other realms than pragmatics does not mean those children are not language impaired, which a separate diagnostic category clearly implies. This category appears to be based on a discrepancy between total language ability and social communication ability. This clinical profile is not sufficiently marked to warrant separating it from the primary diagnosis of language impairment.

A 06 Speech Sound Disorder

Speech Sound Disorder

A. Speech sound disorder (SSD) is diagnosed when speech output does not include developmentally expected speech sounds that are appropriate for age and dialect. Symptoms may include errors in speech sound production, errors in speech sound patterns (phonological processes), use, representation, organization, and sequencing. Examples are substitutions of one sound for another (e.g., use of /t/ for target /k/ sound), distortions of sounds, omissions of sounds (e.g., final consonants), sound additions, lack of smooth transitions between sounds, substitutions of front sounds (t,d) for all back sounds (k,g), or deviations of speech prosody.

The difficulties with speech sound production in natural contexts result in functional limitations in effective communication, social participation, academic achievement, career opportunities and/or occupational performance, alone or in any combination.

- B. This is not due to a regional, social, or cultural or linguistic variation (e.g., dialect) of speech production and prosody.
- C. SSD may occur as a primary impairment or concurrent with other disorders, including Language Impairment, cerebral palsy, cleft palate, dysarthria, autism, or childhood apraxia of speech.
- D. Symptoms must be present in early childhood (but may not become fully manifest until speech, language, or communication demands exceed capacities).

A 07 Childhood Onset Fluency Disorder

A. Childhood onset Fluency Disorder, also referred to as stuttering in the U.S or stammering in other countries, is diagnosed when uncontrollable disturbances in the continuity, rate and/or ease of talking are inappropriate for the individual's age and language skills, persist over time, and are characterized by frequent and marked occurrences of one or more of the following:

- 1. sound, syllable, and single-syllable whole word repetitions
- 2. sound prolongations
- 3. blocks at the beginning or in the middle of words
- 4. audible (e.g. um, ah, like) or silent pauses
- 5. circumlocutions (word substitutions to avoid problematic words)
- 6. words produced with an excess of physical tension (e.g., tics, grimacing, extraneous body movements)
- 7. anxiety about symptoms 1-6 leading to avoidance associated with speaking situations.
- B. Cluttering is a fluency disorder characterized by a rapid and/or irregular rate of speech. A person with cluttered speech may show unusual prosody and pausing patterns, often accompanied by increased disfluency that differs from typical stuttering.
- C. The difficulties with speech fluency result in functional limitations in effective communication, social participation, academic performance, career opportunities and/or occupational performance, alone or in any combination.
- D. Exclude dysfluency associated with neurological insult (e.g., stroke, tumor, trauma), conversion reaction and malingering. A fluency disorder may occur as primary or co-exist with other communication disorders or any other disorder not excluded.
- E. Symptoms must be present in early childhood but may not become fully manifest preadolescence.

A 08 Voice Disorder

- A. A voice disorder may occur on a laryngeal level or resonance level and is diagnosed based on abnormal production and/or absence of vocal quality, pitch, loudness, resonance, and/or duration, which usually persists over time and is inappropriate for an individual's age or sex.
- B. The difficulties with voice result in functional limitations in effective communication, social participation, academic performance, career opportunities and/or occupational performance, alone or in any combination.
- C. A voice disorder may occur as primary or co-exist with other communication disorders or any other disorder.
- D. Symptoms may be present in early childhood (but may not become fully manifest until speech, language, or communication at any time over a lifespan).

A 09 Resonance Disorder Suggest:

- A. A resonance disorder is diagnosed based on abnormal acoustic modification of the speech sound wave as it travels through the vocal tract. Resonance disorders include, but are not limited to, hypernasality, hyponasality, and cul-de-sac resonance.
- B. The difficulties with resonance may have a physiological, anatomical, or functional basis.

- C. A resonance disorder may occur as primary or co-exist with other communication disorders or any other disorder.
- D. Symptoms may be present in early childhood (but may not become fully manifest until speech, language, or communication at any time over a lifespan)

Rationale: We have witnessed the effects of misunderstanding the differences between voice and resonance. For example, children with cleft palate, resonance disorder or suspected resonance disorder have been referred for laryngeal evaluations, or for voice therapy rather than a more appropriate type of therapy. Clinicians who receive their cleft palate training in a Voice Disorders class may have some knowledge of the velopharynx, but little to no understanding of the articulation co-morbidities that may occur with resonance disorder.

Classification schemes influence the way we organize thought, perceive normalcy and disorder, and order our research and education programs. If the classification scheme is inaccurate, so too will be our education and research programs.

The DSM is an important clinical tool which has far-reaching effects on clinical care, education, third party reimbursement for care, and research. We feel strongly that failure to make the distinction between voice and resonance now will adversely affect these aspects of our profession in the future

A 09 Autism Spectrum Disorder

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A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays or cultural variations and manifest by all 3 of the following:

- 1. Deficits in social-emotional reciprocity, ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,
- 2. Deficits in communication behaviors used for social interaction, ranging from poorly integrated verbal and nonverbal communication, through abnormalities in eye contact and body language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures
- 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people
- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
 - 1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, monotone or robotic speech, repetitive use of objects, or idiosyncratic phrases).
 - 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).

- 3. Highly restricted, fixated interests that are abnormal in intensity or focus (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
- 4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).
- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed capacities
- D. Symptoms together limit and impair everyday functioning.

A 12-15 Learning Disabilities

A 13 Dyslexia

A 14 Dyscalculia

A 15 Disorder of Written Expression

Concern about definition of learning disorder

Learning disabilities have long been recognized for the linguistic and cognitive processes that underlie academic skills. The proposed DSM V definition of learning disorder focuses only on specific academic disabilities and restricts overlap with the definition of language impairment. However, established national definitions of learning disabilities (e.g., National Joint Committee on Learning Disabilities [NJCLD] and IDEA 2004) recognize language problems as a core deficit of a learning disability. Members of the NJCLD are American Speech-Language-Hearing Association, Association for Higher Education and Disability, Association of Educational Therapists, Council for Learning Disabilities, Division for Communicative Disabilities and Deafness/Council for Exceptional Children, Division of Learning Disabilities/Council for Exceptional Children, International Dyslexia Association, International Reading Association, Learning Ally, Learning Disabilities Association of America, National Association of School Psychologists, and National Center for Learning Disabilities. The proposed definition of learning disorder is incomplete and does not capture the multidimensional aspects of learning disabilities, raising the potential for some individuals to be excluded from the services they need. Such a definition significantly limits and misrepresents the constellation of learning disabilities.

The DSM-V rationale indicates that there are "no previous general criteria for learning disorders." However, the NJCLD definition is widely used and recognized by a range of organizations and practitioners that provide services to individuals with learning disabilities. The NJCLD definition recognizes that learning disabilities are heterogeneous, are intrinsic to the individual, are not limited to academic skills, and can occur across the life span (NJCLD, 1990; NJCLD, 2011).

Recommendations

- The definition of learning disorder should be expanded to include problems related to oral (e.g., listening and speaking) and written language (e.g., reading comprehension, spelling, written expression), and mathematics (e.g., calculation, problem solving)
- Oral language problems and mathematics (instead of arithmetic) should be included in the proposed definition, not just in the rationale for the proposed change.
- The DSM V definition of learning disorder should be consistent with the definition of learning disabilities developed by the NJCLD :

Learning disabilities is a general term that refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the life span. Problems in self-regulatory behaviors, social perception, and social interaction may exist with learning disabilities but do not by themselves constitute a learning disability. Although learning disabilities may occur concomitantly with other handicapping conditions (for example, sensory impairment, mental retardation, serious emotional disturbance), or with extrinsic influences (such as cultural differences, insufficient or inappropriate instruction), they are not the result of those conditions or influences.

and the classification set forth in IDEA 2004 (20 U.S.C. §1401 [30]) that qualifies an individual with learning disabilities to services:

The term 'specific learning disability' means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in the imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations.

Concern about subcategories

As currently proposed in DSM V, the subcategories of learning disorder are too limited and give the impression that the only important areas of learning disorders are the mechanics of reading and arithmetic. The definition of dyslexia is limited to decoding and fluency and does not address other language-based reading disorders.

Recommendations

- Include other language-based reading disorders (e.g., reading comprehension) in the subcategory of learning disorders.
- Maintain the subcategory of disorder of written expression. The references below support the need for this distinct category.

Concern about assessment

The use of standardized measures should not be required. Standardized tests that are reliable, valid, and appropriately normed are not always available, especially for populations such as English language learners.

References

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Neurocognitive Disorders

S 12 - 23 Mild Neurocognitive Disorder

S 16 Mild Neurocognitive Disorder Associated with Traumatic Brain Injury

The definition and description of mild traumatic brain injury (mTBI) in the proposed DSM-V is neither correct nor useful. There is only one sentence that actually addresses mTBI specifically; namely "Major Neurocognitive Disorder rarely results from mild TBI." The rest of this section describes TBI in a general manner and does nothing to help describe the clinical entity of mTBI, which is unique and quite different from major TBI. In the DSM-IV, there is a lot of detail about the variety of symptoms commonly experienced by individuals with mTBI (e.g., becoming fatigued easily, disordered sleep, headache) yet there is nothing under the "Rationale" tab at all so it is entirely unclear why the decision was made to omit this very useful information. It would be much preferable to use the definition provided in the DSM-IV as it actually does define/describe mTBI and also because it includes the following: "The disturbance causes significant impairment in social or occupational functioning and represents a significant decline from a previous level of functioning. In school-age children, the impairment may be manifested by a significant worsening in school or academic performance dating from the trauma." These two points, that mTBI can cause impairments of social and occupational functioning and that it may worsen academic performance in school-aged children, are not included in the proposed DSM-V. Yet, these statements are critical to validating the difficulties individuals with mTBI may experience to educators, healthcare providers, family, and potentially to third party payers and to legal proceedings. Though hard neurologic signs are not always or even typically evident in cases of mTBI, the symptoms and difficulties individuals with mTBI experience can cause significant challenges in social, occupational, and/or academic pursuits and therefore; it seems in alignment with the goals of the DSM to include a description of the major symptoms and challenges commonly faced by individuals with mTBI just as is done for every other disorder listed in the proposed DSM-V.

Under the "Severity" tab, the Glasgow Coma Scale cut-offs for mTBI are provided, which can be helpful in making an initial diagnosis, but is not sufficient for making a definitive diagnosis. If an individual never experiences any difficulties or disturbances after incurring a head injury, then he or she would not be diagnosed with a mTBI. Thus, it is crucial to the purpose of the DSM that the mTBI section include a description of the types of symptoms that would ensue for a person to be diagnosed as having a mTBI. The list provided in the DSM-IV is good but should also include difficulty concentrating as this is probably the most common reason that individuals with mTBI have occupational and/or academic difficulties during the 6 month period following their injury.

In the "Severity" tab, the second to the last sentence has a typo: "Where mild TBI is accompanied <u>my</u> major or progressively deteriorating neurocognitive disorder, additional etiologies such as an associated hemorrhage; comorbid PTSD; or a mood or substance abuse disorder) need to be investigated."

Note: Suggest modification to statement in all

The difficulties with language result in functional limitations in effective communication, social participation, academic achievement, career opportunities and/or occupational performance, individually or in any combination.

Rationale: Communication disorders may also impede an individual's ability to seek out and work in a variety of careers that have heavy demands on language abilities. This might limit their ability not only to perform in these occupations, but to seek out employment in those careers. Intervention goals might assist in opening up new career tracks for these individuals.

Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed capacities).

Rationale: Capacities might not be limited.

A regional, social, or cultural or linguistic variation (e.g., dialect) of language is not an LI.

Rationale: It would be more accurate to indicate that speaking with a dialect is a result of a linguistic variation.