aaidd
American Association
on Intellectual and
Developmental Disabilities

May 16, 2012

John Oldham, MD
President, American Psychiatric Association
1000 Wilson Boulevard, Suite 1825
Arlington, VA 22209

RE: DSM-5 Draft Diagnostic Criteria for "Intellectual Developmental Disorder"

Dear Dr. Oldham,

As you may know, the American Association on Intellectual and Developmental Disabilities (AAIDD) is the oldest interdisciplinary professional association concerned with intellectual disability, formerly known as mental retardation. AAIDD has long been the leader in the terminology and classification of the condition now known as "intellectual disability," having published 11 editions of our terminology and classification manual since 1910. Notably to date, the definition offered by the American Psychiatric Association in its Diagnostic and Statistical Manual on Mental Disorders have always been alike in meaning and significance with the AAIDD definition and diagnostic criteria of intellectual disability.

We have been closely following the work of the DSM-5 workgroup on Neurodevelopmental Disorders as it revises the definition and diagnostic criteria for what was previously referred to as "mental retardation." When the DSM-5 draft documents were initially released for review and comment, the AAIDD Board of Directors charged Robert L. Schalock, PhD and Ruth Luckasson, JD (Co-Chairs of the AAIDD Terminology and Classification Committee) with the task of reviewing the draft documents and providing feedback to the APA DSM-5 work group during public comment periods. Commentary was provided on two occasions: May 26, 2011 and December 14, 2011.

AAIDD is ***extremely troubled*** with the direction of the diagnostic criteria for "intellectual developmental disorder" formerly "mental retardation" and the lack of response to the concerns expressed in the two submissions to the DSM-5 work group on the draft criteria. The final draft, despite AAIDD's written feedback and expressed concerns on the criteria and terminology, is unchanged from the initial draft.

We have reviewed carefully the most recent posting of the proposed revision of "Intellectual Developmental Disorder" (updated April, 2012). Below are our ***strongly recommended changes***, along with the rationale for the respective change.

AAIDD Recommendations and Recommendation Rationales

Terminology

Recommendation: We recommend that the term "***intellectual disability***" be used rather than "***intellectual developmental disorder.***"

Rationale: The use of the term "intellectual developmental disorder" is not consistent with the AAIDD position, contemporary practice, and will most foreseeably lead to direct harm to individuals in educational, service, and judicial settings. The term intellectual disability (ID) is the most commonly used term—nationally and internationally—to refer to the condition previously named mental retardation[1]. The term intellectual disability is preferred because it: (a) is consistent with national and international moves to adopt this terminology as a replacement for "mental retardation," (b) better reflects the changed construct of disability promoted by both the World Health Organization's International Classification of Functioning and AAIDD; (c) better aligns with current professional practices that focus on functional behaviors and contextual factors; (d) provides a logical basis for understanding supports provision due to its basis in a social-ecological framework; and (e) is less offensive to people with disabilities (i.e., "disability" is preferred to "disorder"). It is important to note that in October 2010, President Barack Obama signed "Rosa's Law," which replaced the term "mental retardation" with "intellectual disability" in federal education, health, and labor laws, signaling the adoption of "intellectual disability" as the accepted term to replace "mental retardation."

DEFINITION

Recommendation: We recommend the direct alignment of the DSM-5 definition of "***intellectual disability***" with the AAIDD definition of intellectual disability:

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

Rationale: Having the two most authoritative manuals in the country defining "intellectual disability" using different terminology and different definitions would create havoc in the education system, service delivery system, state and federal eligibility determinations, and courts (especially in death penalty cases). Historically, there has been substantive consistency between the APA definition of intellectual disability (formerly mental retardation) and the AAIDD (formerly AAMR) definition. Specifically, the definition of "mental retardation" presented in the 1968, 1980, 1994, and 2000 American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* mirrored those published by AAIDD in comparable years (Table 1.1, pages 8-9, Schalock et al., 2010)[2]. This

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[1] Brown, I. (2007). What is meant by intellectual and developmental disabilities? In I. Brown & M. Percy (Eds.), *A comprehensive guide to intellectual and developmental disabilities* (pp. 3-15). Baltimore, MD: Brookes.
[2] Schalock, R. L. et al. (2010). *Intellectual disability: Definition, classification, and systems of supports (11th edition).* Washington, DC: American Association on Intellectual and Developmental Disabilities.

approximately two standard deviations below the population mean for Criteria to represent the definition generally accepted for "significant deficits," and (c) reporting of the standard error of measurement for the specific instruments used. The instrument's standard error of measurement, which varies by test, subgroup, and age group, is used to quantify the variability inherent in any standardized psychometric instrument and provides the basis for establishing a statistical confidence interval within which the person's true score falls.

Recommendation 3: We recommend that Criterion C be modified so that to meet Criterion C, the condition is manifested during the developmental period, which is generally considered to be before the age of 18 years.

Rationale: The age of onset refers to the age the disability began, and the purpose of this criterion is to distinguish intellectual disability from other forms of disability that may occur later in life. Intellectual disability typically originates close to the time of birth—either during the fetal development, the birth process, or soon after birth. Sometimes, however, especially when the etiology of disability indicates progressive damage (such as malnutrition) or brain damage resulting from an insult, disease, or injury (such as toxin exposure, infection, traumatic brain injury, etc.), the condition may originate later. Thus, while disability does not have to have been formally diagnosed at onset, its origination during the developmental period is crucial to the diagnosis. The proposed lack of specificity in defining the end of the developmental period is fraught with potential for inconsistency in interpretation and application, and is inconsistent with the AAIDD position.
It is our position that age 18 is the best upper limit as: (a) the extension beyond age 18 will change the number of people eligible for diagnosis, impact prevalence rates as the class would include individuals with other cognitive disabilities (e.g., traumatic brain injury, severe persistent mental illness, etc.), and thus substantially changes the inherent construct of the diagnosis; (b) the age 18 as the upper limit is consistent with diagnostic practices in many countries; and (c) such an extension would likely contribute to inaccurate diagnoses among individuals not diagnosed prior 18 as later in life assessments would be unable draw upon such records to determine level of functioning in school. We recognize that when an accurate diagnosis of intellectual disability was not made during the developmental period; however, the adherence to an upper limit of age still allows for a retrospective diagnosis if necessary in some situations (Schalock et al, 2010, pp. 27-28).

SEVERITY GRID

Recommendation: Eliminate the severity grid.

Rationale: We feel strongly that the proposed DSM-5 severity grid does not reflect or represent best practices in the field of intellectual disability. The grid is problematic for the following reasons: (a) it does not address severity of the disability, but merely provides examples of possible adaptive behavior limitations in conceptual, social, and practical adaptive behavior areas; (b) repeats the error found in the proposed definition of substituting adaptive *functioning* for adaptive *behavior*; (c) is internally inconsistent with the proposed APA definition; and (d) represents an old paradigm from the 1980s (Grossman, 1983, Appendix A, p. 203-216)[4].

[4] Grossman, H. (1983). *Classification in mental retardation (8th edition)*. Washington, DC: American Association on Mental Deficiency.

historical consistency in the definition is reflected in current statutes and court opinions that use the commonly accepted definition as a basis for service eligibility, citizenship and legal status, civil and criminal justice, early childhood education, training and employment, income support, and health care (Schalock et al., 2012)[3]. ***It would be disastrous from a public policy and service eligibility perspective should the APA promulgate an inconsistent terminology and definition.***

DIAGNOSTIC CRITERIA

Recommendation 1: We recommend that Criterion A be modified so that to meet Criterion A, a significant limitation in intellectual functioning is considered to be "approximately" 2 standard deviations below the population mean.

Rationale: This level of impairment equates to an IQ score of "about" 70 or less. The DSM has always included the "approximately" because it is clear that tests of intelligence are not infallible and all tests of intelligence have a certain degree of measurement imprecision. It is important that the DSM-5 continue to include language specifically around the issue of measurement error that is generally accepted to be approximately 5 points around an observed score and should thus be applied to the cut point (e.g., a cut-off score of 70 should be considered to represent a range from 65 to 75).

Best practices in the field and the current psychometric literature regarding the diagnosis of intellectual disability require the (a) use of standard deviations to establish the boundaries of intellectual disability and adaptive behavior, (b) establishment of a cutoff criterion of approximately two standard deviations below the population mean to meet Criteria represents the definition generally accepted for "significant deficits," and (c) reporting of the standard error of measurement for the specific instruments used. The instrument's standard error of measurement, which varies by test, subgroup, and age group, is used to quantify the variability inherent in any standardized psychometric instrument and provides the basis for establishing a statistical confidence interval within which the person's true score falls.

Recommendation 2: We recommend that Criterion B be modified so that to meet Criterion B, a significant limitation in adaptive behavior is defined as deficits of approximately 2 or more standard deviations below the population mean in one or more aspects of adaptive behavior, including: conceptual, social, or practical skills.

Rationale: The proposed definition of adaptive behavior as "communication, social participation, functioning at school or at work, or personal independence at home or in community settings" is neither consistent with either the AAIDD position nor with current psychometric literature, and substitutes adaptive *functioning* for adaptive *behaviors*.

As described above, the best practices in the field and the current psychometric literature regarding the diagnosis of intellectual disability require the: (a) use of standard deviations to establish the boundaries of intellectual disability and adaptive behavior, (b) establishment of a cutoff criterion of

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[3] Schalock, R. L., et al. (2012). *Intellectual disability: Definition, classification, and system of supports (11e) - User's Guide.* Washington, DC: American Association on Intellectual and Developmental Disabilities.

We understand that the task of developing the DSM-5 is enormous and that you have hundreds of mental disorders to review, explain, and define. We strongly encourage APA to turn to AAIDD and its definition and diagnostic criteria for "intellectual disability" in its DSM-5. Intellectual disability is our sole focus and our current terminology and classification manual was authored by a nationally and internationally respected interdisciplinary committee of clinicians, educators, and researchers in the field of intellectual disability.

Please do not hesitate to contact us to discuss our recommendations further. We sincerely hope that the DSM-5 will be consistent with current established consensus in the field of intellectual disability.

Respectfully,

Sharon Gomez

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President, AAIDD Board of Directors

Margaret A. Nygren

Margaret A. Nygren, EdD
Executive Director & CEO

cc: David J. Kupfer, MD (DSM-5 Task Force Chair)
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