

AAIDD 11th Edition Implementation Committee

To: DSM-V ASD and Developmental Disorders Subgroup, ID Subcommittee

Public Comments Regarding Draft Definition of Intellectual Disability

February 22, 2010

Dear DSM-V ID Subcommittee Members:

The AAIDD (American Association on Intellectual and Developmental Disabilities-formerly The American Association on Mental Retardation) has appreciated the opportunity throughout your deliberation and formulation process to provide input into the DSM-V ID Subcommittee through Dr. Sally Rogers and our liaison person, Dr. Alya Reeve. This collaboration between APA and AAIDD has been valued historically and is reflected in the consistency between the two organization's operational definition of ID (formerly mental retardation) beginning with the 1968 APA Manual and continuing through the 2000 DSM-TR. The APA proposed operational definition of ID is conceptually very consistent with the 2010 AAIDD operational definition with one exception: the proposed criterion of significant deficits in at least two adaptive behavior domains (APA) vs. significant deficits in one or more adaptive behavior domains (AAIDD).

We have read carefully the ID Subcommittee's proposed definition, including the rationale statements. Based on our careful and thoughtful reading and discussion among Committee members, the AAIDD 11th Edition Implementation Committee recommends the following three edits/changes to the proposed revision in order to insure continued alignment of DSM-V and AAIDD operational definitions of ID:

1. To use as the criterion for significant limitations/deficits in adaptive behavior, "performance that is approximately two standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, and practical, or (b) an overall score on a standardized measure of conceptual, social, and practical skills.
2. To insert the word "approximately" before the words "two or more standard deviations" for both criterion a (IQ) and b (adaptive behavior).
3. Insert a statement indicating that a change in terminology (from mental retardation to intellectual disability) does not result in a change in one's eligibility for services and supports.

The following sections of this public response document provide the rationale and justification for each of these three recommended edits/changes. We start by providing the ID Subcommittee with a brief summary of the operational definition of ID presented in the 11th edition of the AAIDD Manual: *Intellectual Disability: Diagnosis,*

Classification, and Systems of Supports that was published in October, 2009. We conclude the document with an offer to work jointly on developing a new classification system in light of the movement away from coding on the basis of IQ levels.

Section I: 2010 AAIDD Operational Definition of Intellectual Disability

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

- The intellectual functioning criterion for a diagnosis of intellectual disability is approximately two standard deviations below the mean, considering the standard error of measurement for the specific assessment instruments used and the strengths and limitations of the instrument.
- In reference to the adaptive behavior criterion for a diagnosis of intellectual disability:
 - Significant limitations in adaptive behavior should be established through the use of standardized measures normed on the general population.
 - On these standardized measures, significant limitations in adaptive behavior are operationally defined as performance that is approximately two standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, or practical, or (b) an overall score on a standardized measure of conceptual, social, or practical skills.

Section II: Rationale for the Recommended Adaptive Behavior Limitations Criterion

The AAIDD 11th Edition Committee (as we are sure with your ID Subcommittee) is aware of the extensive discussion and publications regarding the impact of using different numbers and combinations of domains and standard deviations in the determination of a ‘significant limitation in adaptive behavior.’ Based on our four year study and deliberation process, we formulated the following rationale for using the operational definition given above (performance that is approximately two standard deviations below the mean of either one of the following three types of adaptive behavior: conceptual, social, or practical, or (b) an overall score on a standardized measure of conceptual, social, or practical skills).

1. For a person with ID, adaptive behavior limitations are generalized across the domains of conceptual, social, and practical skills. However, because subscale scores on adaptive behavior measures are moderately correlated, a generalized deficit is assumed even if the score on only one domain meets the operational criterion of being approximately two standard deviations below the mean. A total score of two standard deviations below the mean from an instrument that

measures conceptual, social, and practical skills will also meet the operational definition of a significant limitation in adaptive behavior.

2. Using the criterion of significant limitations in 2 or 3 domains of adaptive behavior (as proposed by the DSM-V Subcommittee) would introduce a new and higher bar into the historically consistent diagnosis of ID, thus creating confusion in the field (because of the incompatible requirements between DSM-V and AAIDD) and significantly increasing the diagnostic risk of ‘false negatives.’ Such an error occurs when a person is actually an individual with ID but is [incorrectly/false] not diagnosed as such. It has been demonstrated repeatedly that individuals with ID who have higher IQ scores can show adaptive skill performance in both practical skills (e.g. activities of daily living) and social skills (in regards to ‘streetwise behavior’ for example) but often demonstrate a marked deficiency in using their skills in a functionally successful way because of a lack of cognitive adaptive skills (the conceptual skills domain). Thus, AAIDD concluded that using significant limitations in one or more adaptive skill areas accurately reflects the science of adaptive behavior assessment and balances the diagnostic risks of ‘false negatives’ and ‘false positives’ (person is incorrectly/false] diagnosed as an individual with ID but actually is not).

Section III: Importance of Inserting “Approximately” In Front Of an IQ Score and an Adaptive Behavior Score

We applaud your statement in the Rationale Section that you are proposing to add rigor to the wording/approach to psychometrics. We have done likewise, especially in the 2002 and 2010 AAIDD Manuals. It has become increasingly clear to us in both our academic and clinical work that measures of human functioning contain error and that a major role of a well trained clinician is to assist others in understanding that any measure of intelligence or adaptive behavior is only an approximation. To underscore the importance of recognizing and using ‘approximately’ in best clinical practices we have stressed throughout the 2010 AAIDD Manual the following.

- To not specify a hard and fast cutoff point/score for meeting the significant limitations criteria for both intelligence and adaptive behavior scores. Rather, one needs to use clinical judgment in interpreting the obtained score in reference to the test’s standard error of measurement, the assessment instrument’s strengths and limitations, and other factors such as practice effects, fatigue effects, and age of the norms used for comparison.
- To address the issues of standard error of measurement and confidence interval in the interpretation of IQ and adaptive behavior scores. In that regard,
 - Standard error of measurement is the variation around the hypothetical ‘true score’ for the person. The standard error of measurement applies only to scores obtained from a standardized test and can be estimated from the standard deviation of the test and a measure of the test’s reliability.

- The standard error of measurement, which varies by test, subgroup, and age group, should be used to establish a statistical confidence interval within which the person's true score falls. For well-standardized measures of general intellectual functioning, the standard error of measurement is approximately 3 to 5 points. Thus, in reference to an IQ score of 70 (which corresponds to the 'cutoff score' of approximately two standard deviations below the mean of the respective assessment instrument) the score of 70 is most accurately understood not as a precise score but a range of confidence with parameters of at least one standard error of measurement (i.e. scores of about 66-74, with 66% probability) or parameters of two standard error of measurement (i.e. scores of about 62-78, 95% probability).
- Reporting the range (i.e. confidence interval) within which the person's true score falls, rather than only a score, underlies both the appropriate use of intellectual and adaptive behavior assessment instruments and best diagnostic practices in the field of intellectual disability. Such reporting must be a part of any decision concerning the diagnosis of ID.

Section IV: A Change in Terminology Does Not Result in a Change in Eligibility

Nationally and internationally the term 'intellectual disability' is replacing the older term 'mental retardation.' As widely accepted, the term ID is the preferred term since it reflects the changed construct of disability, aligns better with current professional practices that focus on functional behaviors and contextual factors, provides a logical basis for individualized supports due to its basis in a social-ecological framework, is less offensive to persons with the disability, and is more consistent with international terminology. However, these advantages should not preclude addressing the concern that may arise when a major change in terminology is implemented: that the change in name may result in a change in one's eligibility for services and supports.

To address this concern, in the 11th addition of the AAIDD Manual we stress two major points. The first is that although the term or name of the condition has changed over time, the three criteria (significant limitations in both intellectual functioning and adaptive behavior and age of onset during the developmental period) have not changed substantially over the last 50 years. The second point is to also stress that this historical consistency supports the trend in the field and the conclusion of the major organizations (such as the President's Committee for People with Intellectual Disabilities) that regardless of the term (intellectual disability or mental retardation) used to name this disability, the same population has been described. More specifically, the term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation in number, kind, level, type, and duration of the disability and the need by people with this disability for individualized services and supports. Furthermore, every individual who is or was eligible for a diagnosis of mental retardation is eligible for a diagnosis of intellectual disability.

Section V: Severity Coding System

Since developing the 1992 AAIDD/AAMR Manual, members of the Terminology and Classification Committee have grappled with developing a classification system that is consistent with current best practices. In 1992, we suggested the need to classify on the basis of the assessed support needs of the persons (which we can now do reliably and validly through the use of standardized support need assessment instruments). In 2002 we suggested that depending on the purpose, the severity of the impairment could be classified according to intensity of support need, adaptive behavior level, and/or intellectual functioning level. In 2010, we have added a further consideration and proposed a multidimensional classification system based on a conceptual framework of human functioning that is consistent with the ICF model proposed by the World Health Organization. The conceptual framework has the following dimensions: intellectual abilities, adaptive behavior, health, participation, context, and intensity of support needs.

Although we realize the time is short in reference to the planned publication in 2013 of the DSM-V, we extend an offer to assist your efforts in developing a system to code on the basis of intensity of support needs and away from coding on the basis of IQ bands. We would be happy to share our endeavors over the last 20 years in this regard.

Conclusion

In conclusion, we hope that the material found in these five sections will be of value to the DSM-V ASD and Developmental Disorders subgroup, ID subcommittee. In summary, we have: (1) summarized the operational definition of ID presented in the 2010 AAIDD Manual: *Intellectual Disability: Diagnosis, Classification, and Systems of Supports*; (2) suggested the use of the following criterion for significant limitations in adaptive behavior: performance that is approximately two standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, and practical, or (b) an overall score on a standardized measure of conceptual, social, and practical skills; (3) suggested the insertion of ‘approximately’ before two or more standard deviations for both criterion a (IQ) and b (adaptive behavior); (4) suggested inserting a statement indicating that a change in terminology (from mental retardation to intellectual disability) does not result in a change in one’s eligibility for services and supports; and (5) offered to work jointly on developing a new coding system in light of the movement away from coding based on IQ level.

We have appreciated the opportunity to provide input to the ID Subcommittee throughout its deliberation and formulation process. We applaud your efforts to date, and having just completed a similar process ourselves as we updated and published the 2010 AAIDD Manual we extend a hand of collegiality and support.

As co-chairs of the AAIDD 11th Edition Implementation Committee Ruth and I would welcome the opportunity to discuss with you any aspect of this document and the continued alignment between APA and AAIDD in reference to the operational definition of ID.

Sincerely,

AAIDD 11th Edition Implementation Committee

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