

Twenty Questions and Answers
Regarding the 12th Edition of the AAIDD Manual:
Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports

R. L. Schalock, R. Luckasson, and M. J. Tassé

1. What are the goals of the 12th edition of the AAIDD Manual?

Consistent with AAIDD's historical publishing of Manuals that present the current understanding of the intellectual disability (ID) construct and disseminate best practice guidelines for defining, diagnosing, classifying, and providing supports to people with ID, the goals of the 12th edition of the AAIDD Manual are to:

- (a) integrate material published in the 11th edition with post-2010 developments and historical trends;
- (b) develop a user-friendly Manual that combines the theoretical and conceptual thoroughness of a manual with the practical aspects of a user's guide;
- (c) describe a systematic approach to the diagnosis, optional subgroup classification, and planning of supports for people with ID based on relevant conceptual models, a clear rationale and purpose, and evidence-based practices;
- (d) combine current empirical knowledge and best practices into an integrative approach to ID; and
- (e) provide Practice Guidelines that frame best practices, increase understanding, and facilitate precise, valid, and effective decisions, recommendations, and actions.

2. What is intellectual disability?

ID is a disability characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills. This disability originates during the developmental period, which is defined operationally as before the individual attains age 22.

3. How does the term “mental retardation” compare to the term “intellectual disability”?

Mental retardation is an earlier term for ID. The term ID 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. Mental retardation is an outdated term and is no longer used.

4. What does a diagnosis of intellectual disability require?

A diagnosis of ID requires significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills and origination during the developmental period. The primary purposes of a diagnosis of ID are to accurately capture and communicate the presence of ID in an individual; establish eligibility for relevant benefits, supports,

and services; monitor health and track incidence and prevalence; and study important aspects of ID in peoples' lives.

5. What does the assessment of intellectual functioning and adaptive behavior require?

The assessment of intellectual functioning requires the use of a reliable, valid, and individually administered, comprehensive, and standardized test that is normed on the general population and yields a full-scale IQ score. The assessment of adaptive behavior requires the use of a reliable, valid, and individually administered, comprehensive, and standardized test that is normed on the general population and yields a measure of each of the three adaptive behaviors: conceptual, social, and practical. All test scores should be interpreted considering the 95% confidence interval based on the standard error of measurement for the specific, individually administered test used. Clinical judgment is an important part of the assessment process (see Question #16).

6. What is a retrospective diagnosis of intellectual disability?

A retrospective diagnosis of ID is made after the individual attains age 22, and where the individual did not receive an official diagnosis of ID during the developmental period. For a retrospective diagnosis, the clinician should use multiple sources of information, including a thorough educational, medical, and social history to determine whether significant limitations in intellectual functioning and adaptive behavior were present during the developmental period.

7. What is intellectual functioning?

Intellectual functioning is a term that incorporates the common definitional characteristics of intelligence, the abilities currently assessed by standardized intelligence tests, and the consensus view that intellectual functioning is influenced by other human functioning dimensions and by systems of supports. Thus, intellectual functioning is a broader term than either intelligence or intellectual abilities, but a narrower term than human functioning. In the 12th edition of the AAIDD Manual, full-scale IQ scores are used as a proxy measure for intellectual functioning.

8. What is adaptive behavior?

Adaptive behavior is the collection of conceptual, social, and practical skills that have been learned and are performed by people in their everyday lives. Adaptive behavior is:

- (a) developmental and increases in complexity with age;
- (b) composed of conceptual, social, and practical skills;
- (c) related to the expectations of age and demands of particular contexts;
- (d) assessed on the basis of the individual's typical performance at home, school, work, and leisure, not their maximum performance; and
- (e) assessed in reference to the community setting that is typical for age peers.

9. What is the age of onset?

Age of onset is the third element for a diagnosis of ID, with the other two elements being significant limitations in intellectual functioning and adaptive behavior. This third criterion is essential because it establishes the age-related parameters for determining when ID, as a developmental disorder, originates or is first manifest. Although there is agreement that ID originates during the developmental period, there has been less consistency on the operational definition of the age at which the developmental period ends.

The minor historical inconsistency is due, in part, to the multiple perspectives on development and the developmental period. For example, from an etiological perspective, development is influenced by biochemical, social, behavioral, or educational risk factors that can occur prenatally, perinatally, or postnatally. From a functional perspective, development focuses on the trajectory of adaptive behavior and intellectual functioning. From a cultural perspective, development is influenced by social factors and social roles related to social and family interactions, educational involvement, career development, and assuming adult roles. And from an administrative perspective, the developmental period establishes the age of onset in reference to eligibility for services and supports. Consistent with the 9th-11th editions of the AAIDD Manual, it is acknowledged that some societies may define the developmental period differently, based on their cultural and social norms.

The age of onset criterion “before the individual attains age 22” found in the 12th edition of the AAIDD Manual is based on recent research that has shown that important brain development continues into our 20s. Research using advanced imaging techniques has documented that a number of critical areas of the human brain continue their growth and development into early adulthood, including cortical gray matter volume, corpus callosum, and white matter. As discussed further in the Manual, this criterion “before the individual attains age 22” is also consistent with age 22 in the DD Act of 2000 and the standards used for a diagnosis of ID by the Social Security Administration.

The age of onset during the developmental period is established and documented at the time of the evaluation. The evaluation should include a thorough record review that includes a social, medical, and educational history. The change from age 18, which was the age of onset criterion found in the 9th through 11th editions of the AAIDD Manual, to “before the individual attains age 22” found in the 12th edition of the Manual, (a) should not impact prevalence rates since the vast majority of diagnoses of ID are, and continue to be, made in early childhood; and (b) will enable accurate diagnoses of the small percentage of individuals who are identified nearer the end of the developmental period.

10. What is classification in the field of ID?

Classification is not a diagnosis. Classification in the field of ID is an optional post-diagnosis organizing scheme. The fundamental purpose of classification is to provide a structure for the categorization of various kinds of observations and measures as a way to organize information to better understand a person. Classification is a post-diagnosis scheme that involves the systematic arrangement into subgroups according to a specified purpose and established criteria. Subgroup classification should occur within an explicit framework and systematic process, serve an important purpose, have benefit to the person, be based on relevant information, and provide a better understanding of an individual's needs.

11. What is the explicit framework and systematic process for subgroup classification in ID?

The explicit framework explained in the 12th edition of the AAIDD Manual is based on the three purposes for subgroup classification which are to describe:

- (a) establishing the important purpose for the subgrouping,
- (b) aligning relevant data sets to the subgrouping's purpose,
- (c) describing the data driven procedures used to establish the subgroup classification categories employed, and
- (d) using empirically-based subgroup classification bands to establish the subgroup classification categories.

12. What are systems of supports?

Systems of supports are an interconnected network of resources and strategies that promote the development and interests of a person and enhance an individual's functioning and personal well-being. Systems of supports: (a) are characterized by being person-centered, comprehensive, coordinated, and outcome oriented; and (b) encompass choice and personal autonomy, inclusive environments, generic supports, and specialized supports.

13. What are the four theoretical perspectives on ID that provide a holistic framework for understanding and approaching ID?

The four perspective on ID are biomedical, psychoeducational, sociocultural, and justice. Each perspective contributes to a holistic understanding of ID through major concepts used, perceived locus of the disability, identified risk factors, and related interventions and supports.

14. What role does precise terminology play in understanding and approaching ID?

Precise terminology:

- (a) clarifies ID-related constructs and thus increases precision and validity;
- (b) improves understanding and communication among stakeholders;
- (c) is essential to defining and differentiating among the constructs of disability, intellectual disability, and developmental disability; and
- (d) is necessary to determine prevalence and tracking health status.

15. What are evidence-based practices, and how are they incorporated into the 12th edition of the AAIDD Manual?

Evidence-based practices are based on current best evidence that is obtained from credible sources that used reliable and valid methods derived from a clearly articulated and empirically supported theory or rationale. Evidence-based practices are incorporated into the definition of ID; the assessment of intellectual functioning, adaptive behavior, and support needs; the criteria used to make a diagnosis of ID; subgroup classification bands; the planning of systems of supports; and Practice Guidelines.

16. What is clinical judgment?

Clinical judgment is based on the processes and strategies that clinicians use to enhance the quality, precision, and validity of their decisions and recommendations. Clinical judgment is a special type of judgment that is built on respect for the person, and emerges from the clinician's training and experience, specific knowledge of the person and their context, analysis of extensive data, and use of critical thinking skills. Clinical judgment plays a significant role in diagnosis, classification, planning supports, and an integrative approach to ID.

17. What are clinical judgment standards?

Clinical judgment standards are the specific practices that operationalize clinical judgment.

18. What comprises a multidimensional approach to human functioning?

A multidimensional approach to human functioning encompasses five dimensions: intellectual functioning, adaptive behavior, health, participation, and context. A multidimensional model of human functioning integrates these five dimensions with interactive systems of supports and human functioning outcomes.

19. What are valued outcomes?

Valued outcomes are indicators of enhanced human functioning and personal well-being associated with the five dimensions of human functioning (intellectual functioning, adaptive behavior, health, participation, and context) and the four perspectives on ID (biomedical, psycho-educational, sociocultural, and justice). A shared vision of valued outcomes is developed with the individual with ID using the dimensions of human functioning and the four perspectives on ID.

20. What is professional responsibility in ID?

Professional responsibility includes evidence-based practices, professional ethics, professional standards, and clinical judgment. More specifically, professional responsibility in ID involves using a holistic framework that encompasses the four perspectives on ID; precise terminology to improve communication and facilitate understanding; evidence-based practices to increase the effectiveness of interventions and to enhance personal outcomes; clinical judgment standards to enhance the quality, validity, and relevance of decisions and recommendations; a shared vision of outcomes for people with ID; and placing the person with ID at the center of the service/support delivery system.

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