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Overview of Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports (12e)

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Abstract:	Intellectual disability is characterized by significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates during the developmental period, which is defined operationally as before the individual attains age 22. As with previous editions of the AAIDD manual, there are five assumptions that are essential to the application of the definition.

An Overview of *Intellectual Disability*:

Definition, Diagnosis, Classification, and Systems of Supports (12th ed.)

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

AJIDD Guest Editorial

Introduction and Overview

The American Association on Intellectual and Developmental Disabilities (AAIDD) has published terminology and classification manuals since 1921. Their goals over the last 100 years have been consistent: To fulfill the Association's continued responsibility to be the primary repository of intellectual disability-related research and best practices; to publish a scientific definition of intellectual disability (ID) and its assumptions based on research and one that provides a long, stable definitional history; to provide a singular focus on ID and the lives of people with ID and their families; and to communicate professional standards, ethics, and best practices regarding diagnosis, classification, and planning supports. Consistent with these historical goals, the goals of the 12th edition of the AAIDD manual (Schalock et al. 2021) are to: (a) integrate material published in the 11th edition (Schalock et al., 2010) of the AAIDD manual with post-2010 developments and historical markers; (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 intellectual disability based on conceptual models, a clear rationale and purpose, and evidence-based practices; (d) combine current empirical knowledge and best practices into an integrative approach to intellectual disability; and (e) provide practice guidelines that frame best practices, increase understanding, and facilitate precise, valid, and effective decisions, recommendations, and actions.

The content of the 12th edition reflects the transformation that is occurring in the field of intellectual disability. This transformation, which is occurring to various degrees internationally, is characterized by using precise terminology, incorporating a functional and holistic approach to ID, embracing the supports model and evidence-based practices, implementing outcome evaluation, empowering individuals and families, understanding better the multidimensional properties of context, and incorporating an explicit notion of professional responsibility (Schalock et al., in press). As a result of this transformation, the manual contains both modifications of previous concepts and terminology, and the addition of new terms and concepts. These modifications and additions are reflected in the definition of intellectual disability, the evidence-based approach to diagnosis and optional post-diagnosis subgroup classification, the operationalization of systems of supports, and the incorporation of an integrative approach to ID. Throughout the manual, human functioning is viewed from a systems perspective towards understanding human functioning, which includes human functioning dimensions, interactive systems of supports, and human functioning outcomes.

The Manual's Content

Definition of Intellectual Disability

Intellectual disability is characterized by significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates during the developmental period, which is defined operationally as before the individual attains age 22. As with previous editions of the AAIDD manual, there are five assumptions that are essential to the application of the definition.

1. Limitations in present functioning must be considered within the context of community environments typical of the individual's age peers and culture.
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors.
3. Within an individual, limitations often coexist with strengths.
4. An important purpose of describing limitations is to develop a profile of needed supports.
5. With appropriate personalized supports over a sustained period, the life functioning of the person with ID generally will improve.

In reference to the age of onset criterion for a diagnosis of ID, there has been historic consistency that ID originates during the developmental period. Recent scientific research has demonstrated, however, that the developmental period extends longer than previously understood. The age of onset criterion (“...*before the individual attains age 22.*”) found in the 12th edition 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 (Giedd et al., 1999; Jiang & Nardelli, 2016; Mills, Lalonde, Clasen, Giedd, & Blakemore, 2014). As discussed further in the manual, this criterion of “...*before the individual attains age 22*” is also consistent with age 22 in the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act, 2000) and the standards used for a diagnosis of ID by the Social Security Administration (2021).

Diagnosis of Intellectual Disability

A diagnosis of ID requires the presence of significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills, and a verification that the disability originated during the developmental period. Although the three criteria of a diagnosis of ID (significant limitations in both intellectual functioning and adaptive behavior, and age of onset) have remained consistent over time, the 9th-11th editions of the AAIDD manual established greater precision in the diagnostic process. This greater precision required the use of individually administered standardized assessment instruments (first introduced in the 9th edition; Luckasson et al., 1992), the operational definition of significant limitations as an intelligence quotient (IQ) score or adaptive behavior score that is approximately two standard deviations below the population mean (introduced in the 10th edition; Luckasson et al., 2002), and the use of the standard error of measurement to establish a statistical confidence

interval within which a person's true score falls (9th and 10th edition for intellectual functioning; 11th edition for both intellectual functioning and adaptive behavior).

Classification in the Field of Intellectual Disability

Classification in the field of ID is an optional post-diagnosis organizing scheme. As described in the manual, classification involves using an explicit framework and a systematic process to subdivide the group of individuals with intellectual disability into smaller groups based on the established important purpose for the subgrouping. The three major purposes of subgroup classification are to describe (a) the intensity of support needs, (b) the extent of limitations in conceptual, social, and practical adaptive skills, or (c) the extent of limitations in intellectual functioning.

A multidimensional approach to subgroup classification (as reflected in a-c above) was first introduced in the 9th edition of the AAIDD manual. As the field shifted at that time to a more social-ecological model of disability, and with the introduction of the supports paradigm, four levels of classification based on the intensity of needed supports were proposed in the 9th edition (i.e., intermittent, limited, extensive, and pervasive). These levels did not appear in subsequent editions of the manual (although a discussion of "classification by levels of needed supports" did) due to the lack of standardized data on which to establish psychometrically sound classification bands. As described in Chapter 4 of the 12th edition, current standardized scales of supports intensity, yield standard scores that permit a data-based approach to classifying support intensity levels, as was initially proposed in the 9th edition.

Planning Supports

The 9th edition of the AAIDD manual introduced the supports paradigm to the field. Subsequent editions of the manual introduced a supports delivery model and a supports evaluation model (10th edition), as well as a process for assessing, planning, monitoring, and evaluating individual supports; a community health supports model; and a listing of the support needs of persons with ID who have higher IQ scores (11th edition). The 12th edition of the AAIDD manual updates these areas and relates them to the standardized assessment of support needs, the multiple uses of assessed support need information, systems of supports, and the parameters of support evaluation.

Systems of supports are resources and strategies that promote the development and interests of the person and enhance an individual's functioning and personal well-being. Systems of supports are: (a) person-centered, comprehensive, coordinated, and outcome oriented; (b) built on values, facilitating conditions, and support relationships; (c) incorporate choice and personal autonomy, inclusive environments, generic supports, and specialized supports; and (d) integrate and align personal goals, support needs, and valued outcomes.

An Integrative Approach to Intellectual Disability

With the systematic approach presented in the 11th edition of the AAIDD manual in place and referenced in the professional literature and legal decisions, the 12th edition synthesizes the 11th edition with post-2010 developments in the field and presents an integrative approach to ID.

The integrative approach to ID described in the manual combines current knowledge and best practices into a holistic, unified, and systematic approach to defining, diagnosing, classifying, and planning supports for people with ID. The components and associated benefits of an integrative approach to ID include a comprehensive framework, precise terminology, evidence-based practices, clinical judgment standards, an increased understanding of human functioning, and a shared vision of valued outcomes.

Clinical Judgment Guidelines and Standards

The role of clinical judgment in the diagnosis of ID, optional post-diagnosis subgroup classification of people with ID, planning supports for people with ID, and implementing an integrative approach to ID are discussed throughout the manual. Clinical judgment is an essential component of one's professional responsibility, which also includes being knowledgeable in the current evidence-based practices of one's profession, maintaining professional standards, and abiding by a professional code of ethics. Throughout the manual, the term clinical judgment is used to refer to the processes, strategies, and standards that clinicians use to enhance the quality, precision, and validity of their decisions and recommendations. Clinical judgment is defined as 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 environments, analysis of extensive data, and the use of critical thinking skills.

Practice Guidelines

The practice guidelines found at the end of each chapter were critiqued, edited, and validated by a peer-review panel of 32 international experts who served as the 12th Edition Advisory Committee. The basis of these practice guidelines is current research, expert opinion, legal decisions, and peer reviewed publications. The purposes of the Guidelines are to: (a) facilitate best practices regarding the definition, diagnosis, classification, and planning supports for people with ID; (b) provide an integrated approach to disability policy development, implementation, and evaluation; (c) suggest a holistic framework for ID-related research; (d) connect foundational concepts to valued policy; and (e) enhance the functioning and well-being of people with ID.

Glossary

The Glossary, which is found at the end of the manual, provides current literature-based definitions of the major terms and concepts found in the manual and the field. The Glossary provides a common language and understanding of important terms for clinicians, researchers, teachers, policy makers, service/support providers, and people with ID and their families.

Value of the 12th Edition of the AAIDD Manual

The 12th edition incorporates the significant advancements that have occurred in the field over the last two decades. These advancements relate to the increased understanding of ID that comes from the multiple perspectives of ID; the standardized measurement of intellectual functioning and adaptive behavior; the emphasis on the human and legal rights of persons with disabilities, including self-advocacy and consumer empowerment; the application of the

capacities approach to disability and the supports paradigm; the establishment of community-based alternatives and inclusive environments; and the emphasis on evidence-based practices and outcomes evaluation.

This 12th edition has been developed recognizing the diverse interests and needs of those who will read and use the manual. Thus, every effort was made to develop a user-friendly manual that combines theoretical and conceptual material with practical application guidelines for the individuals and groups who will use the manual. In addition, the authors recognize that knowledge is cumulative and emerges from evidence-based information and an active dialog among stakeholders. Both the members of the 12th Edition Advisory Committee and members of the Disability Experience Expert Panel of The Ohio State University contributed significantly to this dialog and consequently to the manual.

The field of ID will continue to evolve based on continuing advancements in the understanding of ID and its amelioration. This 12th edition of the AAIDD manual provides a strong foundation for the field's continuing evolution and for further opportunities for people with ID to create their desired futures. During the field's continued evolution, it is important that AAIDD continue to carry out its definitional responsibilities, as AAIDD is the only professional organization *specifically focused* on ID with the historical engagement, expertise, and resources to accomplish the work.

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