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The contemporary view of intellectual and developmental disabilities: Implications for psychologists

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Abstract

Background: The field of intellectual and developmental disabilities (IDD) is currently experiencing a significant transformation that encompasses an integrated approach, especially regarding shared aspects such as a focus on the human and legal rights, the eligibility for services and supports, and an emphasis on individualized supports provided within inclusive community-based environments. Accompanying this transformation is the increased need of precision in both the operational definitions of IDD-related constructs, and the terminology used to describe the respective construct. **Method:** The specialized literature was revised, and previous works on the subject by the authors were updated. **Results:** This article provides psychologists with the current definition of intellectual disability, operational definitions of intellectual disability and developmental disabilities constructs and associated terminology, and the parameters of an integrated approach to disability. **Conclusions:** Implications for psychologists who are involved in diagnosis, classification, and planning supports for persons with intellectual or developmental disability are discussed.

Keywords: Disability constructs, disability terminology, integrated approach to intellectual disability and developmental disabilities.

Resumen

La visión contemporánea de las discapacidades intelectuales y del desarrollo: implicaciones para psicólogos. **Antecedentes:** el campo de la discapacidad intelectual y del desarrollo (DID) experimenta en la actualidad una significativa transformación que implica un enfoque integrado, especialmente en lo que se refiere a aspectos compartidos como el enfoque en los derechos humanos y legales, la elegibilidad para recibir servicios y apoyos, y el énfasis en los apoyos individualizados proporcionados en entornos comunitarios inclusivos. Esta transformación se acompaña de una creciente necesidad de precisión en cuanto las definiciones operativas de los constructos relacionados con la DID y la terminología utilizada para describir cada uno de ellos. **Método:** se ha revisado la literatura especializada y se han actualizado los trabajos previos de los autores sobre el tema. **Resultados:** este artículo proporciona a los psicólogos la definición actual de la discapacidad intelectual, las definiciones operativas de los constructos de discapacidad intelectual y discapacidades del desarrollo, así como de la terminología asociada, y los parámetros de un enfoque integrado de la discapacidad. **Conclusiones:** se discuten las implicaciones para los psicólogos involucrados en el diagnóstico, la clasificación y la planificación de apoyos a personas con discapacidad intelectual o del desarrollo.

Palabras clave: constructos de discapacidad, terminología de discapacidad, enfoque integrador de las discapacidades intelectual y del desarrollo.

Psychologists are involved in the diagnosis, classification, and planning supports for persons with intellectual disability (ID) and closely related developmental disabilities (DD). The field of intellectual and developmental disabilities (IDD) is currently experiencing a significant transformation. This transformation encompasses an increasingly integrated approach to IDD, especially regarding shared aspects such as limitations in human functioning (i.e., disability), a focus on the human and legal rights of persons with a disability, the eligibility for services and supports based on significant functional limitations in major life activity areas, and an emphasis on individualized supports provided within inclusive community-based environments. Accompanying this transformation is the increased precision in both the operational definitions of IDD-related constructs, and the terminology used to describe the respective construct (Luckasson & Schalock, 2013; Schalock & Luckasson, in press; Schalock, Luckasson, Tassé, & Verdugo, 2018; Schalock & Verdugo, 2012). The reader is encouraged to study Tables 1 and 2 prior to reading the article to fully understand the operational definitions and associated terminology for each of these constructs.

The purpose of this article is to provide psychologists with the current definitions of intellectual disability, operational definitions of intellectual and developmental disabilities constructs, and the parameters of an integrated approach to disability. The article also discusses the implications of the above to psychologists who are involved in the diagnosis, classification, and/or planning supports to persons with IDD.

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Current definitions of intellectual disability

There are currently three closely aligned definitions of intellectual disability (ID). The authoritative definition is that of the American Association on Intellectual and Developmental Disabilities (AAIDD). The AAIDD definition is that, "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 before age 18" (Schalock et al., 2010, p. 1). Closely aligned with this definition is that proposed in DSM-5 by the American Psychiatric Association (APA, 2013) which is that "intellectual disability (intellectual developmental disorder) is a disorder with onset during the developmental period that includes both intellectual and adaptive behavior deficits in conceptual, social, and practical domains" (p. 33). The third definition is found in ICD-11 (World Health Organization, 2018), which is that, "disorders of intellectual development are a group of etiologically diverse conditions originating during the developmental period characterized by significantly below average intellectual functioning and adaptive behavior that are approximately two or more standard deviations below the mean (approximately less than the 2.3rd percentile), based on appropriately normed, individually administered standardized tests. Where appropriately normed and standardized tests are not available, diagnosis of disorders of intellectual development requires greater reliance on clinical judgment based on appropriate assessment of comparable behavioural indicators."

Although the wording used in the definition of ID has changed somewhat over the last 50+ years, *what has not changed* in these definitions is the emphasis on significant deficits in intellectual functioning and adaptive behavior, age of onset during the developmental period, and the correlational and not causative relation between intellectual functioning and adaptive behavior (Tassé, Luckasson, & Schalock, 2016). *What has changed* in these definitions and their application are: (a) terminology that has evolved from mental deficiency and mental retardation to intellectual disability; (b) an increasing acceptance of the equal weight given to adaptive behavior and intellectual functioning in the diagnosis of ID; (c) a better understanding of the factor structure of adaptive behavior (i.e., conceptual, social, and practical adaptive skills); (d) the use of the 95% confidence interval to establish the range of scores within which the individual's true score falls; and (e) an increased use of a subclassification system based on the person's needs for supports rather than the individual's intelligence quotient (IQ) level. These changes reflect a better understanding of intelligence and adaptive behavior; advances in the conceptualization and measurement of intellectual functioning and adaptive behavior; advances in understanding measurement error and score interpretation; and the expanded use of the definition as a basis for supports planning and subgroup classification (Schalock & Luckasson, in press; Tassé et al., 2016).

Operational definitions of IDD-related constructs and associated terminology

Operational definitions

A construct is an abstract or general idea based on observed phenomena and formed by arranging parts or elements (Schalock et al., 2010). An operational definition explains a construct and establishes its meaning and boundaries. The terminology used in reference to the respective construct is determined by its operational definition. Since this article focuses on the constructs of disability, intellectual disability, developmental disability, developmental disabilities, and intellectual and developmental disabilities, it is important to psychologists to understand the similarities and differences among these constructs. Based on the work of Schalock and Luckasson (in press), operational definitions of each are presented in Table 1.

The operational definitions presented in Table 1 allow for the better understanding of both the similarities and overlapping nature among IDD-related constructs. As reflected in the operational definitions, similarities involve defining the construct in terms of significant functional limitations, and focusing on the multidimensionality of human functioning. As also noted, the constructs of intellectual disability and developmental disabilities overlap. Thus, some but not all people who meet the criteria for developmental disability are considered to have intellectual disability. However, intellectual disability and developmental disabilities are not completely overlapping constructs; the construct of developmental disabilities

Table 1
Operational definitions of disability-related constructs

Disability-related construct	Operational definition
Disability	A significant functional limitation that: (a) reflects an inability or constraint in both personal functioning and the performance of socially expected roles and tasks; (b) represents a substantial disadvantage to the individual; (c) is influenced by contextual variables, and (d) can be mitigated (i.e., reduced or alleviated) through interventions and supports, or by reducing barriers that preclude opportunities, equity, and inclusion (Luckasson & Schalock, 2013)
Intellectual Disability (ID)	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 (Schalock et al., 2010, p. 1)
Developmental Disability (DD)	A severe, chronic disability of an individual that: (a) is attributable to a mental or physical impairment or a combination of mental and physical impairments; (b) is manifest before the individual attains age 22; (c) is likely to continue indefinitely; (d) results in substantial functional limitations in 3 or more major life activity areas; and (e) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, and other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated (DD Act, Sec. 102. (8)(A))
Developmental Disabilities (DDs)	A term used to refer to "a group of conditions due to an impairment in physical, learning, language, or behavior areas. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime" (CDC, 2018)
Intellectual and Developmental Disabilities (IDD)	The broader, combined field of intellectual disability and developmental disabilities

also includes people with physical disorders (such as cerebral palsy or spina bifida) and other disorders that emerge during the developmental period, such as those with Fetal Alcohol Disorder and Autism Spectrum Disorder who do not have co-occurring ID (AAIDD, 2018; Brown, Wehmeyer, & Shogren, 2017; Centers for Disease Control and Prevention [CDC], 2018; National Institute of Health [NIH], 2018; Williams, Wheeler, Linder, & Jacobs, 2017).

Associated terminology

There is confusion in the IDD field about what precise term or term combination should be used in particular circumstances. This confusion is reflected in the plethora of terms and term combinations currently found in the literature and in statutes. Examples include "people with IDD", "ID/DD", "IDD", "ID-DD", "conditions similar to or related to mental retardation (now intellectual disability)", "conditions similar to one of these conditions", "pervasive developmental disorder", and "children and adults with intellectual and developmental disabilities."

Selecting the correct terminology to use regarding a specific construct should be based on each construct's operational definition, and the circumstances in which the construct is used. The need to use correct terminology is paramount. Matching the terminology to the construct is essential for valid clinical decisions and recommendations, establishing eligibility criteria for services and supports, conducting research, communicating across disciplines, and implementing an integrated approach to IDD. Terminology consistent with the operational definitions presented in Table 1 is provided in Table 2. The table also includes examples of the term's use.

The operational definitions of IDD-related constructs presented in Table 1, and the terminology associated with each construct presented in Table 2, make significant contributions to clear thinking, the use of more precise terminology, and an integrated approach to IDD. Specifically, their use will enhance valid clinical decisions and recommendations; facilitate the establishment of eligibility criteria for services and supports; provide objective, measurable variables for research studies; and improve productive communication across disciplines and professionals within support teams. In addition, the understanding of the similarities, differences, and overlapping nature of the constructs of intellectual disability (ID) and developmental disabilities (DD) will foster an integrated approach to disability policy development, implementation, and evaluation. Finally, the recognition of the relation of intellectual disability and developmental disabilities to the construct of disability anchors these two constructs within the construct of disability, which internationally is considered to be the expression of limitations in individual functioning within a social context and represents a substantial disadvantage to the person. This anchoring will facilitate cross-national communication and help to establish standardized international terminology (Luckasson & Schalock, 2013).

The parameters of an integrated approach to disability

There are currently four perspectives that explain IDD. Each perspective explores the impacts of various factors influencing

Table 2
Terminology consistent with the construct's operational definition

Construct	How to use terminology that is consistent with the construct and its operational definition	Examples of the term's use
Disability	As a broad, generalized label for individuals who exhibit significant functional limitations that cause a substantial disadvantage to the person	■ A person with a disability (e.g., "I have a disability") ■ A bounded field of study, policy development, service/ support provision, or research (e.g., the field of disability)
Intellectual disability (ID)	As a diagnosis or label given to individuals who meet the criteria of significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills, and is manifest before age 18	■ A person with intellectual disability (e.g., "I have ID") ■ A bounded field of study, policy development, service/ support provision, or research (e.g., the field of intellectual disability)
Developmental disability (DD)	As a label based on a diagnosis or for those individuals who meet the criteria of severe, chronic disability as specified in Sec.102. (8)(A) of the DD Act of 2000 (see Table 1)	■ -A person with a developmental disability (e.g. "I have a developmental disability"; "I have autism"; "I have Down syndrome") ■ A specialized field of study bounded by a precise etiology or similar support needs ■ A bounded field of study, policy development, service/ supports provision, or research (e.g. autism spectrum disorder, Down syndrome)
Developmental disabilities (DDs)	As a broad, non-categorical label for a chronic disability manifest before age 22 but limited to persons with a specific diagnosis OR for those whose disability (manifest before age 22) results in substantial functional limitations in three or more major life activity areas and who require long-term services and supports	■ "Individuals with developmental disabilities" ■ A bounded field of study, policy development, service/ support provision, or research (e.g., the field of developmental disabilities) ■ An administrative definition (e.g., "Five percent of our state has developmental disabilities and 80% are receiving services and supports")
Intellectual and developmental disabilities (IDD)	As a broader, combined field of intellectual disability and developmental disabilities	■ Persons with intellectual and developmental disabilities ■ Children and adults with intellectual and developmental disabilities ■ A bounded field of study, policy development, services/ supports provision, or research (e.g. the field of IDD) ■ Organization names and journal titles where the focus is on both ID and DDs (e.g. AAIDD, Journal of Intellectual and Developmental Disabilities, American Journal of Intellectual and Developmental Disabilities

IDD, provides the basis for interventions and supports, and organizes relevant information into a usable form for increased understanding and as a basis for better recommendations and decisions. As described by Schalock, Luckasson, Tassé, and Verdugo (2018), these four perspectives approach IDD from a biomedical, psycho-educational, sociocultural, or justice perspective.

- The *biomedical perspective* emphasizes genetic and physiological factors that result in IDD.
- The *psychoeducational perspective* emphasizes intellectual, psychological/behavioral, and learning limitations associated with IDD.
- The *sociocultural perspective* emphasizes the interaction between people and the environments through which social meaning of IDD develops from society's common beliefs, behaviors, language, and events around people with IDD and the responses of individuals to the interaction.
- The *justice perspective* emphasizes that all individuals, including those with a diagnosis of ID or DD, have the same human and legal rights.

Although each of these four perspectives currently serves and will continue to serve important purposes, individually they do not explain the complexity of IDD, nor do they individually provide an integrated approach to understand IDD and guide efforts to mitigate its impact. The integrated approach to IDD described in this article involves four parameters: the locus of disability, risk factors leading to disability, systems of supports, and an explicit and systematic process for subgroup classification. Key aspects of each are described next.

Locus of disability

The essential concept underlying this parameter is the multidimensionality of human functioning. A multidimensional approach reflects the interactive nature of disability and the significant role that personal and contextual factors play in the expression of genes and brain development, the dynamic and reciprocal engagement among intellectual functioning, adaptive behavior, health, one's context and participation, and the size and complexity of the discrepancy between personal competence and environmental demands. This multidimensional approach to human functioning also incorporates the presumed causes of disability, such as gene-environmental interaction, brain development, health, functional limitations, societal conditions and arrangements, and government structures.

Risk factors leading to disability

The risk factors leading to disability can be integrated into types of risk factors and timing of risk factors. Types of risk factors include (a) biochemical factors related to biologic processes such as genetic disorders or poor nutrition, (b) neural or brain development disorders, (c) social factors related to social and family skills and interactions, (d) behavioral factors related to potentially causal behaviors such as dangerous (injurious) activities or parental substance abuse, and (e) educational factors related to the availability of learning opportunities and supports that promote intellectual development and the development of adaptive skills. Additionally, risk factors are related to societal attitudes, impoverished or segregated environments, social inequality, injustice, discrimination, or denial of rights.

The timing of risk factors involves those that occur during the prenatal, perinatal, or post-natal period. Prenatal factors include chromosomal disorders, poverty, parental drug use, or lack of preparation for parenthood. Perinatal factors include birth injury, lack of access to prenatal care, parental rejection of caretaking, or lack of knowledge about interventions and supports. Postnatal factors include traumatic brain injury, impaired child-caregiver interactions, child abuse and neglect, or delayed diagnosis.

Systems of supports

Supports are defined as resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and enhance that person's functioning (Thompson et al., 2009). Systems of supports involve choice and personal autonomy, inclusive environments, generic supports, and specialized supports.

- *Choice and personal autonomy* involves opportunities to make choices and exercise self-determination, and recognition as a person before the law, enjoying the legal capacity on an equal basis with individuals who do not have a disability. Choice and personal autonomy is facilitated through supported decision making.
- *Inclusive environments* are those that provide access to resources, information, and relationships, encourage growth and development and support people, and accommodate psychological needs related to autonomy, competence, and relatedness. Examples include supported employment, supported living, supported/inclusive education, and aging in place.
- *Generic supports* are those that are widely available to the general population, including natural supports, technology, prosthetics, life-long education, reasonable accommodation, dignity and respect, and personal strengths/assets (Lombardi, Claes, & Schalock, 2018).
- *Specialized supports* are professionally-based strategies and therapies (e.g. educational, medical, psychological, occupational therapy, physical therapy, speech therapy, psychiatric, nursing).

Subgroup classification framework and process

Classification is not a diagnosis. Classification is an optional post-diagnosis organizing process that provides an organized scheme for the categorization of various kinds of observations and measures as a way to organize information to better understand a person's needs. Classification involves the systematic arrangement into subgroups according to established criteria. Subgroup classification has to occur within an explicit framework and systematic process, serve an important purpose, be based on relevant information, be used to better understand the individual's needs, and focus on the person's functioning rather than on the severity of the individual's disability (Schalock & Luckasson, 2015).

An *explicit subgroup classification framework* is built around three primary purposes for subgroup classification. These are to

describe the intensity of support needs, the extent of limitations in intellectual functioning, and the extent of limitations in conceptual, social, and practical adaptive skills. For each purpose, the *systematic process for subgroup classification* involves: (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.

Using this framework and these components allows psychologists to align the subgroup classification of support needs to best practices. For example, for supports planning, the pattern and intensity of assessed support needs obtained from the administration of a standardized support needs scale can be used. If it is necessary to classify the intensity of the individual's support needs, the categories of intermittent, limited, extensive, or pervasive can be used, with their subgroup classification bands established on the basis of percentile scores that reflect the intensity of support needs. When the purpose of subgroup classification is to describe the extent of limitations in conceptual, social, and practical adaptive behavior skills, adaptive behavior scores obtained from a reliable, valid, individually administered, comprehensive standardized test that yields adaptive behavior scores in each of the following three adaptive behavior domains of conceptual, social, and practical can be used. Although being used less, when the purpose of subgroup classification is to describe the extent of limitations in intellectual functioning IQ scores obtained from a reliable, valid, individually administered, comprehensive standardized test that yields a full-scale IQ score can be used.

There are numerous advantages for implementing an integrated approach to IDD. Chief among these are that an integrated approach to IDD: (a) sensitizes individuals to the interactive nature of human functioning dimensions, systems of supports, and human functioning outcomes (Luckasson & Schalock, 2013); (b) causes clinicians to realize that they should do more than just diagnose and/or classify individuals with ID; rather, clinicians need to align the clinical functions of diagnosis, classification, and planning supports (Schalock & Luckasson, 2014); (c) provides a better understanding of the complexity of IDD, the specific risk factors associated with its manifestation, and effective prevention and mitigation strategies; (d) provides a holistic framework for policy development and best practices, including wrap-around interventions and supports that integrate traditional interventions with strength-based support strategies; and (e) encourages the use of subgroup classification systems that are purposeful and benefit the individual (Schalock, Luckasson et al., 2018).

Relevance to psychologists

The transformation that is occurring in the field of IDD is having a significant impact on psychologists and their involvement in diagnosis, classification, and planning supports to persons with an intellectual or developmental disability. As discussed in this article, for precise and accurate decisions and recommendations, it is critical for psychologist to: (a) assure that the required criteria for a diagnosis of ID or DD are met; (b) understand IDD related constructs and use precise terminology associated with each construct; (c) recognize the different perspectives that explain ID and DD; (d) use best practices in terms of providing systems of supports; and (e) approach subgroup classification as an optional post-diagnosis organizing scheme that is based on an explicit subgroup classification framework.

In conclusion, it is important that psychologists recognize that intellectual disability and closely related developmental disabilities are more than a biomedical dysfunction or a psychoeducational impairment that can be mitigated through interventions and supports. Although a person's functioning generally will improve when the proper supports are in place (Schalock et al., 2010), intellectual disability and related developmental disabilities are life-long conditions. These disabilities are also social constructs that are based on the interactions of people and their environments, the human and legal rights operating within those environments, and the roles people with IDD and their families play within society. Thus, psychologists need to go beyond their own single perspective, and incorporate the contributions of other perspectives on IDD. When this is done, an integrated approach to IDD will ultimately enhance a wider range of valued outcomes for the individual.

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