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Abstract
This article focuses on the power of naming, defining, diagnosing, classifying, and planning supports for people with intellectual disability. The article summarizes current thinking regarding these five functions, states the essential question addressed by the respective function, and provides an overview of the high stakes involved for people with intellectual disability, their families, and the field of intellectual disability.

Key Words: classifying; defining; diagnosing; intellectual disability; naming

Introduction and Overview
We are living in a transformation era in which we see changes across the political and social spectrum, human service organizations and systems, and educational and professional practices. The field of intellectual disability (ID) is a part of this transformation. In 2010, the American Association on Intellectual and Developmental Disabilities (AAIDD) published its most recent (11th) edition of their definition, classification, and systems of supports manual (Schalock, Borthwick-Duffy, Bradley, et al., 2010), followed in 2012 by the User’s Guide to accompany the manual (Schalock, Luckasson, Bradley, et al., 2012). Both texts reflect current best practices regarding naming, defining, diagnosing, classifying, and planning supports for persons with ID. As noted recently, the American Psychiatric Association (APA) plans to publish the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM–5) in 2013 after 5 years of extended study and discussions around intellectual and closely related developmental disabilities. Similarly, the World Health Organization (WHO) is currently preparing for the publication of the International Classification of Diseases, 11th edition—(ICD–11), which has involved international work and study groups to address the felt need to update the ICD–10 (WHO, 1999), and the International Classification of Functioning, Disability and Health (ICF; WHO, 2001). In addition to these activities, jurisdictions throughout the world are grappling with terminology, diagnostic criteria, classification schema, and entitlement issues.

Each of the aforementioned efforts has required—and will continue to require—high stakes discussions in which all relevant stakeholders participate. That discourse should be based on a thorough understanding of where we are now and the infusion of future thinking and future-oriented mental models to guide where we need to go in regard to implementing best practices in the field of ID.

The purpose of this article, the first of two articles by the authors in this Special Issue, is to summarize current best thinking regarding terminology in the field, the definition of ID, how best to diagnose those persons who potentially have ID, how to implement a classification system that incorporates those factors impacting human functioning, and current best practices regarding planning supports for people with ID. As part of our discussion of each of these five functions, we state the essential question asked in regard to the respective function and indicate what is at stake regarding that function for people with ID, their families, and the ID field.

Naming
The essential question in naming is, “How will the status be known, and what words will attach to the
individual and people close to the person?” The term intellectual disability is increasingly being used internationally in public policies, in service delivery systems, and within the research community because the term is preferable over those used previously. Over the last 200 years, for example, terms used to name the condition have included idiocy, feeble-mindedness, mental deficiency, mental retardation, mental disability, mental handicap, and mental subnormality (Brown & Radford, 2007; Schalock, Luckasson, Shogren, et al., 2007).

Luckasson and Reeve (2001) discussed five important factors that need to be considered when a naming term is selected. First, the term should be specific, refer to a single entity, permit differentiation from other entities, and enhance communication. Second, it must be used consistently by different stakeholder groups (e.g., individuals, families, schools, clinicians, lawyers, physicians, professional organizations, researchers, and policymakers). Third, the term must adequately represent current knowledge and be able to incorporate new knowledge as scientific advances occur. Fourth, it should be robust enough in its operationalization to permit its use within multiple purposes, including defining, diagnosing, classifying, and planning supports. Fifth, it should enhance an essential component of naming a group of people, which is to communicate important values, especially toward the group. There is an emerging consensus that the term intellectual disability meets these five criteria (Schalock & Luckasson, 2005; Schalock et al., 2007).

Defining
The essential question in defining is, “What group will be ‘in’ for protections and benefits, and what group will be ‘out’ of the category?” Today we distinguish between operational and constitutive definitions of ID. An operational definition focuses on the operations with which a construct such as ID can be observed and measured. The operational definition of ID is used to diagnose a person and thus addresses the question of who is “in” and who is “out” of the category. In distinction, a constitutive definition defines the construct of ID and thus helps both to clarify the theoretical underpinnings of the construct and to provide a framework for policies and practices.

Operational Definition of Intellectual Disability
Based on a review of the international literature (Brown, 2007; Brown & Radford, 2007; Schalock, 2010), the most commonly used operational definition of ID is the one promulgated by AAIDD. According to this operational definition, “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” (Schalock et al., 2010, p. 1).

Although the term or name has changed over time, an analysis (Schalock et al., 2007, 2010; Schroeder, Gertz, & Velazquez, 2002) of the U.S.-based definitions used over the last 50 or more years by AAIDD and APA shows that the three essential elements of ID—limitations in intellectual functioning, behavioral limitations in adapting to environmental demands, and early age of onset—have not changed substantially. A summary of this analysis is presented in Table 1 (history of definition) and Table 2 (age of onset).

Constitutive Definition of Intellectual Disability
The construct of ID belongs within the general construct of disability or the expression of limitations in individual functioning that represents a substantial disadvantage to the individual within a social context. The current social–ecological conception of disability has emerged over the last two decades as our understanding has increased regarding the process of disablement and its amelioration. Major factors contribute to this increased understanding. First, research on the social construction of illness has demonstrated the extensive impact that societal attitudes, roles, and policies have on the ways that individuals experience health disorders (Aronowitz, 1998). Second, the historical distinction between biological and social causes of disability has blurred. Third, scholars and clinicians have begun to recognize the multidimensionality of human functioning. As a consequence of these factors, the concept of disability has evolved from a person-centered trait or characteristic (often referred to as a “deficit”) to a constellation of functional limitations that reflect an inability or constraint in both personal functioning and performance of socially expected roles and tasks.
<table>
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<tr>
<th>Source</th>
<th>Definition</th>
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<tr>
<td>1959 (Heber)</td>
<td>Mental retardation refers to subaverage general intellectual functioning that originates during the developmental period and is associated with impairment in one or more of the following: (1) maturation, (2) learning, (3) social adjustment. (p. 3)</td>
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<td>1961 (Heber)</td>
<td>Mental retardation refers to subaverage general intellectual functioning that originates during the developmental period and is associated with impairment in adaptive behavior. (p. 3)</td>
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<td>1973 (Grossman)</td>
<td>Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period. (p. 1)</td>
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<td>1983 (Grossman)</td>
<td>Same as 1973 (p. 1)</td>
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<td>1992 (Luckasson, Coulter, Polloway, et al.)</td>
<td>Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18. (p. 1)</td>
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<td>2002 (Luckasson, Borthwick-Duffy, Buntinx, et al.)</td>
<td>Mental retardation is a disability 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. (p. 1)</td>
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<td>2010 (Schalock et al.)</td>
<td>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. (p. 1)</td>
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<td>1968 (DSM–II)</td>
<td>Mental retardation refers to subnormal general intellectual functioning that originates during the developmental period and is associated with impairment of either learning and social adjustment or maturation, or both. (These disorders were classified under “chronic brain syndrome with mental deficiency” and “mental deficiency” in <em>DSM–I</em>; APA, 1952.) (p. 14)</td>
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<td>1980 (DSM–III)</td>
<td>The essential features are (1) significantly subaverage general intellectual functioning, (2) resulting in, or associated with, deficits or impairments in adaptive behavior, (3) with onset before the age of 18. (p. 36)</td>
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<td>1987 (DSM–III–R)</td>
<td>The essential features of this disorder are (1) significantly subaverage general intellectual functioning, accompanied by (2) significant deficits or impairments in adaptive functioning, with (3) onset before age of 18. (p. 28)</td>
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<td>1994 (DSM–IV)</td>
<td>The essential feature of mental retardation is significantly subaverage general intellectual functioning (Criterion A) that is accompanied by significant limitations in adaptive functioning in at least two of the following skill areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety (Criterion B). The onset must occur before age 18 years (Criterion C). Mental retardation has many different etiologies and may be seen as a final common pathway of various pathological processes that affect the functioning of the central nervous system. (p. 39)</td>
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<td>2000 (DSM–IV–TR)</td>
<td>Same as 1994 (p. 41)</td>
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This shift is consistent with broader social changes, including the personal empowerment and self-determination movement, a stronger emphasis on personal rights and desired personal outcomes, and an awareness of the effects of discrimination and marginalization on persons with a disability (Oliver, 1996; Rioux, 1997; Schalock, 2004).

Because of this evolutionary change in the construct of disability, ID is no longer considered an absolute, invariant trait of the person. Rather, the social–ecological conception of ID emphasizes the interaction between the person and the environment, focuses on the role that individualized supports can play in enhancing individual functioning, and allows for the pursuit and understanding of “disability identity,” the principles of which include self-worth, subjective well-being, pride, common cause, policy alternatives, and engagement in political action. These changes are apparent in the constitutive definition of ID, which defines the construct in relation to other constructs that reflect the impact of the social–ecological model of disability. According to this model, ID is a state of human functioning that manifests across multiple dimensions in relation to environmental demands (Luckasson & Schalock, 2012).

Thus, a constitutive definition of ID defines the phenomenon in terms of limitations in human functioning, emphasizes an understanding of disability consistent with an ecological and multidimensional perspective, and recognizes the significant role that individualized supports play in improving human functioning. Such a constitutive definition of ID is advantageous in that it recognizes ID as biologically and socially complex, it captures the essential characteristics of affected individuals, it establishes an ecological framework for supports provision, and it provides a solid conceptual basis upon which to differentiate among persons with other developmental disabilities (Wehmeyer, Buntinx, Coulter, et al., 2008).

### Diagnosing

The essential question one asks in diagnosis is, “What assessment steps are required for identifying individuals?” According to the operational definition of ID presented earlier in the article, the diagnosis of ID is based on three criteria: significant limitations in intellectual functioning; significant limitations in adaptive behavior as expressed in cognitive, social, and practical adaptive skills; and age of onset prior to age 18. Each of the first two criteria (significant limitations in intellectual functioning and adaptive behavior) is defined in terms of cutoff scores and interpreted in reference to a statistical confidence interval (Schalock et al., 2010, 2012). More specifically, the “significant limitations in intellectual functioning” criterion for a diagnosis of ID is an intelligence quotient (IQ)
score that is approximately 2 standard deviations below the population mean, considering the standard error of measurement (SEM) for the specific instruments used and the instruments’ strengths and limitations. This criterion has been used widely since 1973 (Schalock et al., 2007, 2010). Analogously, the “significant limitations in adaptive behavior” criterion for a diagnosis is performance that is approximately 2 standard deviations below the mean of either (a) a measure of conceptual, social, or practical adaptive behavior or (b) an overall score on a standardized measure of conceptual, social, and practical skills. As with the intellectual functioning criterion, the assessment instrument’s SEM must be considered when the individual’s obtained score is interpreted.

The results of any psychometric assessment need to be evaluated in terms of the accuracy of the instrument used. Obtained scores are subject to variability as a function of varied sources of error, including variations in test performance, examiner’s behavior, cooperation of the test taker, and other personal and environmental factors. The SEM, which varies by test, subgroup, and age group, is used to quantify this variability and provide the basis for establishing a statistical confidence interval around the obtained score within which the person’s true score falls. From the properties of the normal curve, a range of statistical confidence can be established with parameters of at least 1 SEM (66% probability) or parameters of 2 SEM (95% probability).

### Classifying

The essential question asked in classifying is, “How is the total group that was defined as ‘in’ now subdivided on the basis of criteria that are relevant to a specified purpose of subdividing?” All classification systems provide organized categorization schemes that guide decisions about funding, research, and provision of services/supports, as well as communication about selected characteristics of people and their environments. Three of the most widely used classification systems in the field of ID are the ICD–9–CM (MediCode, 1998), the ICD–10 (WHO, 1993), and the DSM–IV (APA, 2000). All three systems subclassify individuals with ID into a coded system primarily on the basis of full-scale IQ score bands.

As the field of ID moves increasingly to an ecological focus and a supports paradigm, policies and practices are emerging that require a broader, multidimensional classification approach. Individuals are, for example, most likely to be grouped for reimbursement and funding on the basis of weighted combinations of factors that might include assessed support needs, adaptive behavior, health status, and/or context (e.g., residential platform and geographical location). In addition, current research methods focus more heavily than did those of the past on multidimensional predictors of human functioning and desired personal outcomes. Finally, the field is moving toward recommending and implementing individualized supports based on the pattern and intensity of assessed needs across human functioning dimensions and life activity areas. As a result of these changes in policies and practices, multidimensional classification frameworks are emerging. One such framework, which is consistent with both the AAIDD system (Schalock et al., 2010) and the ICF model (WHO, 2001), is presented in Table 3.

### Planning Supports

The essential question asked in planning supports is, “What approach does one take to improve human functioning?” Public policies and organization and system practices toward people with ID have focused over the last 30 years on their inclusion and participation in society (Shogren, Bradley, Gomez, et al., 2009). This movement, which is reflected in programs related to supported employment, supported living, and inclusive education, has been augmented by the supports paradigm that provides the framework for planning supports. Since the mid-1980s, the supports paradigm has led to the following three significant changes in policies and practices regarding persons with ID: (a) It has brought together the related practices of person-centered planning, personal growth and development opportunities, community inclusion, self-determination, and empowerment; (b) the judicious application of systems of support has allowed organizations to evaluate the impact of individualized supports on enhanced human functioning and personal outcomes; and (c) the assessed pattern and intensity of a person’s support needs can be used for individual, agency, and systems planning.

Since the mid-1980s we have seen significant progress in our conceptualization and measurement of the support needs of people with ID; the way we think about what systems of supports entail;
the process we use to develop, monitor, and evaluate the individual’s support plan; and a clearer focus on what the desired outcomes should be in an individual supports planning process. Basic to this progress has been a clear understanding of the following terms and concepts (Schalock & Verdugo, 2012; Thompson, Bradley, Buntinx, et al., 2009):

- **Supports:** Resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and enhance individual functioning.
- **Support needs:** A psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning.
- **Systems of support:** The planned and integrated use of individualized support strategies and resources that encompass the multiple aspects of human performance in multiple settings. Systems of support involve maximizing natural resources, employing assistive and information technology, providing educational opportunities to develop new skills and knowledge, employing assistive technology, providing incentives, building on personal strengths, and accessing professional services.
- **Systems of support model:** A model that provides a structure or framework for an organization to provide individualized supports that enhance human performance and personal outcomes.
- **Individual support plan:** A logical, sequential, and transparent process for developing, implementing, monitoring, and evaluating the use of best practice support strategies to enhance personal outcomes.

### Conclusion and Transition to Part II

In conclusion, each of the five functions discussed in this article—naming, defining, diagnosing, classifying, and planning supports—involves high stakes for people with intellectual disability, their families, and the ID field. In naming, the high stakes involve personal identity, stigma or value for individuals and their families, and whether individuals are separated from society or included in the mainstream of life. In defining, the high stakes include eligibility for services, government and economic commitment, and a framework for distinguishing between the operational and the constitutive definition of ID. In diagnosing, the high stakes involve fairness and accuracy, individualized decision making, and efficiency. In
classifying, the high stakes involve improved understanding of the person, a rational linkage of subgroup characteristics to important actions (such as research, funding, supports planning, outcomes evaluation, and societal priorities), fairness, and the equitable distributions of resources. In planning supports, the high stakes involve the functioning of a citizen or family; the responsibilities of a society to enhance the personal well-being of its citizenry; attention to personal goals and assessment of the person's support needs; and the deliberated alignment of needs, resources, and desired outcomes.

Because of the high stakes involved, we should address these five functions not on the basis of an academic discussion or exercise, but rather on the basis of a high stakes discourse in which all stakeholders participate. In Part II, we present a number of timely recommendations to facilitate the high-stakes discourse, inform the debate, and provide a solid basis for making critical decisions.

**References**


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