Perspectives

The Renaming of *Mental Retardation*: Understanding the Change to the Term *Intellectual Disability*

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Introduction and Overview

There is considerable and intense discussion in the field of intellectual disability/mental retardation about the construct of disability, how intellectual disability fits within the general construct of disability, and the use of the term *intellectual disability* (Glidden, 2006; Greenspan, 2006; MacMillan, Siperstein, & Leffert, 2006; Schalock & Luckasson, 2004; Switzky & Greenspan, 2006b). This discussion is occurring within the context of competing world views of the philosophical and epistemological underpinnings of the conceptions of intellectual disability/mental retardation (Switzky & Greenspan, 2006a).

Increasingly, the term *intellectual disability* is being used instead of *mental retardation*. This transition in terminology is exemplified by organization names (e.g., the American Association on Intellectual and Developmental Disabilities—AAIDD, International Association for the Scientific Study of Intellectual Disabilities, President's Committee for People With Intellectual Disabilities), journal titles, and published research (Parmenter, 2004; Schroeder, Gertz, & Velazquez, 2002). A number of questions have emerged with the increased use of the term *intellectual disability*:

- Why is the term *intellectual disability* currently preferred to *mental retardation*?
- How might the use of the term *intellectual disability* impact the current definition of *mental retardation*?
- How might the use of the term *intellectual disability* affect persons diagnosed or eligible for a diagnosis of mental retardation?

Our purpose in this article is to clarify the shift to the term *intellectual disability*. At the heart of that shift is the understanding that this term 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 of 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.

In addition, in this article we explore why the field is shifting to the term *intellectual disability*. Increased understanding is based on a clear distinction among the *construct* used to describe a phenomenon, the *term* used to name the phenomenon, and the *definition* used to precisely explain the term and establish the term's meaning and boundaries. In this article we represent the first of a planned series of articles by the AAIDD Committee on Terminology and Classification in which we will share our thoughts and ask for input from the field prior to the anticipated publication in 2009/2010 of the 11th edition of the definition, classification, and systems of supports manual (*The Manual*).

Throughout the article we stress that understanding the term *intellectual disability* is enhanced by dialogue and clarity. To that end, the following terms will be used:

- *Construct*: an abstract or general idea that is formed by arranging parts or elements, based on observed phenomena, in the context of a theory. The construct of intellectual disability is contained within the broader construct of disability, aligning and integrating the framework for assessment and intervention of intellectual disability within the broader construct of disability.
- *Name*: the term that is used to refer to a construct (in this case, mental retardation or intellectual

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disability). The name/term should refer to a single entity, permit differentiation from other entities, and improve communication. In addition, the name should adequately represent current knowledge and be robust enough in its operationalization to permit its use for multiple purposes (e.g., defining, diagnosing, classifying).

The Constructs: Disability and Intellectual Disability

Construct of Disability

The current construct of disability is focused on the expression of limitations in individual functioning within a social context and represents a substantial disadvantage to the individual. Disability has its genesis in a health condition that gives rise to impairments in body functions and structures, activity limitations, and participation restrictions within the context of personal and environmental factors.

Construct of Intellectual Disability

The construct of intellectual disability belongs within the general construct of disability. Intellectual disability has evolved to emphasize an ecological perspective that focuses on the person–environment interaction and recognizes that the systematic application of individualized supports can enhance human functioning.

Explanation of the Constructs

The current construct of disability has emerged over the last 2 decades due primarily to an increased understanding of the process of disablement and its amelioration. Major factors in this evolution include (a) the research on the social construction of illness and the extensive impact that societal attitudes, roles, and policies have on the ways that individuals experience health disorders (Aronowitz, 1998); (b) the blurring of the historical distinction between biological and social causes of disability (Institute of Medicine, 1991); and (c) the recognition of the multidimensionality of human functioning (Luckasson et al., 1992, 2002; World Health Organization {WHO}, 2001). Because of these factors, the concept of disability has evolved from a person-centered trait or characteristic (often referred to as a "deficit") to a human phenomenon with its genesis in organic and/or social factors. These organic and social factors give rise to functional limitations that reflect an inability or constraint in both personal functioning and performing roles and tasks expected of an individual within a social environment (De Ploy & Gilson, 2004; Hahn & Hegamin, 2001; Nagi, 1991; Oliver, 1996; Rioux, 1997).

This social–ecological conception of disability is reflected well in current publications of both the American Association on Mental Retardation (AAMR), now the AAIDD, and WHO. In the 2002 *Manual* (Luckasson et al., 2002), *disability* was defined as the expression of limitations in individual functioning within a social context and represents a substantial disadvantage to the individual. Similarly, in the World Health Organization's (2001) *International Classification of Functioning, disability* is described as having its genesis in a health condition (disorder or disease) that gives rise to impairments in body functions and structures, activity limitations, and participation restrictions within the context of personal and environmental factors.

The importance of this evolutionary change in the construct of disability is that intellectual disability is no longer considered entirely an absolute, invariate trait of the person (DeKraai, 2002; Devlieger, Rusch, & Pfeiffer, 2003; Greenspan, 1999). Rather, this social–ecological construct of disability, and intellectual disability, (a) exemplifies the interaction between the person and their environment; (b) focuses on the role that individualized supports can play in enhancing individual functioning; and (c) allows for the pursuit and understanding of "disability identity," whose principles include self-worth, subjective well-being, pride, common cause, policy alternatives, and engagement in political action (Powers, Dinerstein, & Holmes, 2005; Putnam, 2005; Schalock, 2004; Vehmas, 2004).

The Name/Term: *Intellectual Disability*

The term *intellectual disability* is increasingly being used instead of *mental retardation*. Terminology for what is now referred to as intellectual disability has varied historically. Over the last 200 years, terms have included *idiocy, feeblemindedness, mental deficiency, mental disability, mental handicap,* and *mental subnormality* (Goodey, 2005; Mercer, 1992; Schroeder et al., 2002; Stainton, 2001; Trent, 1994; Wright & Digby, 1996).

Luckasson and Reeve (2001) discussed five important factors that need to be considered when selecting a term. First, the term should be specific, refer to a single entity, permit differentiation from

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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 policy makers). 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 for multiple purposes, including defining, diagnosing, classifying, and planning supports. Fifth, it should reflect an essential component of naming a group of people, which is to communicate important values, especially towards the group. This aspect of the naming process (i.e., communicating important values) has generated a great deal of discussion, with many individuals asserting that the term *mental retardation* does not communicate dignity or respect and, in fact, frequently results in the devaluation of such persons (Finlay & Lyons, 2005; Hayden & Nelis, 2002; Rapley, 2004; Snell & Voorhees, 2006).

There is an emerging consensus that not only does the term *intellectual disability* meet these five criteria, but that the term is preferable for a number of reasons. Chief among these are that the term *intellectual disability* (a) reflects the changed construct of disability described by the AAIDD and WHO, (b) aligns better with current professional practices that focus on functional behaviors and contextual factors, (c) provides a logical basis for individualized supports provision due to its basis in a social–ecological framework, (d) is less offensive to persons with the disability, and (e) is more consistent with international terminology.

The Definition

Defining refers to explaining precisely the term and establishing the term's meaning and boundaries. The authoritative definition of *intellectual disability/mental retardation* is that of the AAIDD (previously the AAMR). The definition in the 2002 AAMR *Manual* (Luckasson et al., 2002, p. 1) remains in effect now and for the foreseeable future. This definition is shown here with a minor edit that substitutes the term *intellectual disability* for *mental retardation*:

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.

Assumptions are an explicit part of the definition because they clarify the context from which the definition arises and indicate how the definition must be applied. Thus, the definition of *intellectual disability* cannot stand alone. The following five assumptions are essential to the application of the definition of *intellectual disability*.

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 intellectual disability generally will improve.** (Luckasson et al., 2002, p. 1)

Significant consequences can result from the way a term is defined. As discussed by Gross and Hahn (2004), Luckasson and Reeve (2001), and Stowe, Turnbull, and Sublet (2006), a definition can make someone (a) eligible or ineligible for services; (b) subjected to something or not subjected to it (e.g., involuntary commitment); (c) exempted from something or not exempted (e.g., from the death penalty); (d) included or not included (as to protections against discrimination and equal opportunity); and/or (e) entitled or not entitled (e.g., as to Social Security benefits).

Historical Approaches

Historically, four broad approaches (i.e., social, clinical, intellectual, and dual-criterion) have been used for purposes of definition and classification. Remnants of these four approaches are still evident in current discussions regarding who is (or should be) diagnosed as an individual with an intellectual disability (see, for example, Switzky & Greenspan, 2006a).

Social approach. Historically, persons were defined or identified as having mental retardation because they failed to adapt socially to their environment. Because an emphasis on intelligence and the role of "intelligent people" in society was to come later, the oldest historical definitional approach focused on social behavior and the "natural behavioral prototype" (Doll, 1941; Goodey, 2006; Greenspan, 2006).

Clinical approach. With the rise of the medical model, the definitional focus shifted to one's symp-

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tom complex and clinical syndrome. This approach did not negate the social criterion but gradually shifted towards a more medical model that included an increase in the relative role of organicity, heredity, and pathology and led to a call for segregation (Devlieger et al., 2003).

Intellectual approach. With the emergence of intelligence as a viable construct and the rise of the mental testing movement, the approach changed to an emphasis on intellectual functioning as measured by an intelligence test and reflected in an IQ score. This emphasis led to the emergence of IQ-based statistical norms as a way to both define the group and classify individuals within it (Devlieger, 2003).

Dual-criterion approach. The first formal attempt to systematically use both intellectual functioning and adaptive behavior to define the class was found in the 1959 American Association on Mental Deficiency (AAMD) *Manual* (Heber, 1959), in which *mental retardation* was defined as referring to subaverage general intellectual functioning that originates during the developmental period and is associated with impairments in maturation, learning, and social adjustment. In the 1961 AAMD *Manual* (Heber, 1961), maturation, learning, and social adjustment were folded into a single, largely undefined new term, *adaptive behavior,* that has been used in all subsequent AAMR manuals. The dual-criterion approach also has included age of onset as an accompanying element.

Definitional Consistency

Although the term or name has changed over time, an analysis of the definitions used over the last 50+ years shows that the three essential elements of intellectual disability/mental retardation—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 Appendix A (definition) and Appendix B (age of onset criterion).

Consistency is also reflected in related concepts and definitions not shown in Appendices A and B. For example, Scheerenberger (1983) reported that the major elements (intellectual deficits, problems coping with the demands of everyday life, and onset during the developmental period) common to the current definition were used by professionals in the United States as early as 1900. Similarly, the National Research Council (2002, pp. 1–5) reported that the first formal AAMR/AAIDD definition of the phenomenon was in 1910. This definition defined such persons as being feebleminded, with development arrested at an early age or as evidenced by an inability to manage the demands of daily life or keep up with peers. Analogously, the Individuals With Disabilities Education Act of 2004 defines *mental retardation* as significantly subaverage general intellectual functioning, existing concurrently with deficits in adaptive behavior, and manifesting during the developmental period that adversely affects a child's educational performance.

Construct's Boundaries

Appendix C summarizes how the establishment of boundaries has been operationalized in the AAMR/AAIDD manuals since 1959. Two essential points are evident in these operationalizations. First, the cut-off criterion, based on *SD*s from a population mean, pertained primarily to the IQ element. As of the 2002 AAMR *Manual*, a corresponding cut-off criterion was established for the adaptive behavior element. Second, *SD*s currently are and primarily have been used to establish the boundary of intellectual disability.

The three appendices show clearly how both the definition and its operationalization have remained consistent over time. The minor changes that have occurred reflect three phenomena: (a) advances in understanding of intellectual functioning and adaptive behavior; (b) advances in measurement theory and strategies that permit the use of statistical procedures to control for measurement error (standard error of measurement), practice effects, and normative changes over time; and (c) the essential role of clinical judgment in the administration, scoring, and interpretation of psychometric instruments (Schalock & Luckasson, 2005; Schalock et al., 2007).

This historical consistency supports the trend in the field and the conclusion of the major organizations that regardless of the term used to name this disability, the same population has been described. This conclusion is the same as that drawn by The President's Committee for People With Intellectual Disabilities (2004), which stated,

> The PCPID [President's Committee for People With Intellectual Disabilities] considers the terms mental retardation and intellectual disabilities to be synonymous, covering the same population in number, kind, level, type and duration of the disability, and the need by individuals for specific services and supports. Thus, The American Association on Mental Retardation's definition for "mental retardation" serves as the definition for "intellectual disabilities." (p. 3)

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This conclusion is critical because of the essential role that the term *mental retardation* plays in public policy. For example, in the United States, a diagnosis of mental retardation is commonly used to determine eligibility under state and federal disability programs, such as Individuals With Disabilities Education Act—IDEA(2004), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver. In addition, the term *mental retardation* is also used for citizenship and legal status, civil and criminal justice, early care and education, training and employment, income support, health care, and housing and zoning (Schroeder et al., 2002).

Conclusion

Intellectual disability is the currently preferred term for the disability historically referred to as *mental retardation*, and the authoritative definition and assumptions promulgated by the AAIDD (previously the AAMR) remain the same. 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 of 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.

The fact that the construct of intellectual disability belongs within the general construct of disability helps one understand why the term *intellectual disability* has emerged as a preferred term to replace *mental retardation*. The term *intellectual disability* (a) reflects the changed construct of disability proposed by AAIDD and WHO; (b) aligns better with current professional practices that are focused on functional behaviors and contextual factors; (c) provides a logical basis for individualized supports provision due to its basis in a social–ecological framework; (d) is less offensive to persons with disabilities; and (e) is more consistent with international terminology.

We anticipate that discussions will continue in an attempt to further refine the construct of intellectual disability, improve the reliability of diagnosis, and better understand these aspects of human functioning: the nature of intelligence, adaptive behavior, and disablement. In addition, the field will continue to examine the relationships between people with intellectual disability and other defined groups (such as those with learning disability, developmental disability, and traumatic brain injury); the provision of individualized supports to enhance individual functioning; the impact of the consumer and reform movements on the field; the effects of terminology upon peoples' lives; and the impact of an increased understanding of the biomedical, genetic, and behavioral aspects of the condition (Luckasson, 2003; Schalock & Luckasson, 2004; Switzky & Greenspan, 2006a). At this time and for the foreseeable future, the definition and assumptions of intellectual disability/mental retardation remain those promulgated by AAMR in 2002; the term, however, is changed to *intellectual disability*.

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Appendix A

Historical Definitions of *Mental Retardation* as Formulated by the American Association on Mental Retardation (AAMR) and American Psychiatric Association (APA)

American Association on Mental Retardation:

1959 (Heber): Mental retardation refers to subaverage general intellectual functioning which 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)

1961 (Heber): Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in adaptive behavior. (p. 3)

1973 (Grossman): Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period. (p. 1)

1983 (Grossman): Same as 1973. (p. 1)

1992 (Luckasson et al.): 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)

2002 (Luckasson et al.): 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)

American Psychiatric Association (Diagnostic and Statistical Manuals)

1968 (*DSM–II*): Mental retardation refers to subnormal general intellectual functioning which 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 *DSM–I*.) (p. 14)

1980 (*DSM–III*): 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)

1987 (*DSM–III–R*): 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)

1994 (*DSM–IV*): The essential feature of mental retardation is significantly subaverage general intellectual

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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)

2000 (*DSM–TR*): Same as 1994. (p. 41)

Appendix B

Age of Onset Criterion

Tredgold (1908): A state of mental defect from birth, or from an early age, due to incomplete cerebral development. (p. 2)

Tredgold (1937): A state of incomplete mental development. (p. 4)

Doll (1941): A state of social incompetence, obtained at maturity, or likely to obtain at maturity, resulting from developmental arrest of constitutional origin. (p. 215)

Heber (1959; 1961): . . . which originates during the developmental period (i.e., birth through approximately 16 years). (p. 3)

Grossman (1973): . . . manifested during the developmental period (upper age limit at 18 years). (p. 11)

Grossman (1983): . . . manifested during the developmental period (period of time between conception and the 18th birthday). (p. 1)

Luckasson et al. (1992): Mental retardation manifests before age 18. (p.1)

Luckasson et al. (2002): This disability originates before age 18. (p. 1)

Appendix C

Cut-Off Criteria Associated With Establishing the Condition's Boundaries

Intellectual Functioning Cut-Off Criteria

1959 (Heber): Less than one standard deviation (*SD*) below the population mean of the age group involved on measures of general intellectual functioning. (p. 3)

1961 (Heber): Greater than one *SD* below the population mean. (p. 3)

1973 (Grossman): Two or more *SD*s below the population mean. (p. 11)

1983 (Grossman): IQ of 70 or below on standardized measures of intelligence; upper limit is intended as a guideline and could be extended to 75 or more. (p. 11)

1992 (Luckasson et al.): IQ standard score of approximately 70 to 75 or below based on assessment that includes one or more individually administered general intelligence tests. (p. 5)

2002 (Luckasson et al.): Approximately two *SD*s below the mean, considering the standard error of measurement for the specific assessment instruments used and the instruments' strengths and limitations. (p. 58)

Adaptive Behavior Cut-Off Criteria

2002 (Luckasson et al.): Performance that is at least two *SD*s 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, and practical skills. (p. 76)

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