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Defining intellectual disability: Finally we all agree... almost

Defining and determining intellectual disability.

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It is estimated that approximately 3 million Americans have intellectual disability (Larson, Lakin, Anderson, Kwak Lee, Lee & Anderson, 2001). Previously known as “mental retardation,” the terms used to identify this condition have changed over the years, mainly because of the heavy stigma associated with bearing its label (Tassé & Mehling, in press). The two major diagnostic and classification systems in the U.S., American Association on Intellectual and Developmental Disabilities (AAIDD) and the Diagnostic and Statistical Manual on Mental Disorders (DSM), use the term “intellectual disability” and agree on defining intellectual disability as a developmental condition that is characterized by significant deficits in both intellectual functioning and adaptive behavior, including conceptual, social and practical skills (American Psychiatric Association, 2013; Schalock et al., 2010). There are no universal biomarkers associated with intellectual disability, hence, we rely on a robust clinical evaluation of individual functioning to make a determination of intellectual disability.

Diagnostic Criteria

For the purpose of making an intellectual disability determination, establishing the presence of “significant subaverage” intellectual functioning and adaptive behavior requires clinical judgment (American Psychiatric Association, 2013; Schalock et al., 2010) and a rigorous individualized assessment of the person’s intellectual functioning and adaptive behavior. The generally accepted scientific definition of the term “significant subaverage” is performance that is at least two standard deviations below the average level for the individual’s peers (see: American Psychiatric Association, 2013; Schalock et

al., 2010; Tassé & Grover, 2013). Significant deficits in adaptive behavior are present when the individual presents significant deficits in one or more of: conceptual, social and/or practical skills. Best practice in clinical assessment requires us to consider all sources of measurement error when using and interpreting results obtained from standardized assessment tools and informing our clinical judgment (American Psychiatric Association, 2013; Schalock et al., 2010). It should be noted that “clinical judgment” is not merely one’s professional opinion, but rather is rooted in a high degree of clinical training and expertise and based on a thorough review and analysis of all relevant clinical information (Luckasson & Schalock, 2013).

It is important to remember that intellectual functioning and adaptive behavior are two separate and distinct constructs that complement each other and significant deficits in each is necessary but alone insufficient to meet criteria for a diagnosis of intellectual disability. In fact, both DSM-5 (see: American Psychiatric Association, 2013; p.33) and AAIDD (see: Schalock et al., 2010; p.1) stipulate that intellectual disability is characterized by the presence in significant deficits in “both” intellectual functioning and adaptive behavior.

Deficits in intellectual functioning and adaptive behavior are established by using a combination of established and psychometrically valid standardized assessment tools used in combination with other relevant and complementary clinical evaluations and information (e.g., review of records, qualitative interviews, etc.). Throughout the intellectual disability determination process, clinical judgment plays a critical role.

Developmental Disability

Intellectual disability has long been categorized as a developmental condition with an onset prior to the end of the developmental period. Although U.S. federal law (Developmental Disabilities Act of 2000; PL 106-402) has defined the end of the developmental period to be age 22 years for developmental disabilities, the end of the developmental period for intellectual disability had historically been set at age 18 years (see: Schalock et al., 2010; American Psychiatric Association, 2000). In its most recent revision of the Diagnostic and Statistical Manual for Mental Disorders, the American Psychiatric Association has left the chronological age of cut-off defining the

“developmental period” up to the clinician and their clinical judgement (see: American Psychiatric Association, 2013).

Causes

Intellectual disability is a multifaceted and complex condition that comes in a wide range of clinical presentations but has at least for the past 50+ years been defined by these three long-standing criteria related to the significantly subaverage intellectual functioning, significant subaverage adaptive behavior and the onset of these deficit being during the developmental period. The etiology or risk factors leading to this level of impaired human functioning associated with intellectual disability can originate prenatally (e.g., genetic or chromosomal factors, inborn errors of metabolism, maternal alcohol or drug consumption during pregnancy, etc.), perinatally (e.g., anoxia, infections, trauma, etc.), and/or postnatally (e.g., deprivation, brain injury, exposure to teratogens, etc.). Intellectual disability can be the result of any number of known or unknown genetic cause, neurophysiological or environmental cause, trauma or combination thereof. Establishing the exact etiology associated with intellectual disability is not necessary to establish a formal diagnosis of intellectual disability. Although knowing the cause or causes can be of value to the individual and their family, especially for the purposes of family planning and genetic counseling, it is not needed to make the determination. In fact, it has been estimated that the exact etiology of approximately 40 percent of all cases of intellectual disability is unknown.

Paradigm Shift

Although the AAIDD abandoned some 30 years ago (see: Luckasson et al., 1992) using severity levels to define the condition of intellectual disability, DSM-5 (American Psychiatric Association, 2013) has continued to maintain a system of severity levels for intellectual disability. A major paradigm shift did however occur in this most recent revision of the DSM when APA chose to abandon the use of IQ scores as the determinant of the severity levels of intellectual disability (i.e., mild, moderate, severe and profound). Instead, DSM-5 has proposed using the individual’s adaptive functioning level across conceptual, social and practical skills to guide clinical judgment in determining the severity level of intellectual disability. This clearly signaled the APA’s

desire to discourage the over-reliance on IQ scores and recognition of the greater emphasis that should be placed on the more comprehensive and predictive construct of adaptive behavior.

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