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Introduction

The nature and definition of intellectual deficits have been debated since the beginnings of the classification of mental disorders. The terminology has changed at least ten times in the past century. Moreover, because people with intellectual deficits are often undervalued in society, scientific terms describing them have been used disparagingly. Consequently, classification systems must contend with stigma and seek to introduce non-pejorative terminology. Currently, the emphasis in classification is placed either on the underlying neurodevelopmental disorder (Author APA, 2013) and resulting deficits in adaptive reasoning and functioning in academic, social, or practical settings or on disability, functional deficits, and the identification of needed supports (Schalock et al., 2010; Schalock, 2011).

Esquirol (1845) referred to intellectual deficits overall as conditions of incomplete mental development based on known (or unknown) bio-

logical or environmental causes. From this perspective, Intellectual Disability (ID) or Intellectual Developmental Disorder (IDD) can be considered first and foremost as a failure of cognitive progression that occurs during the developmental period. Failure in cognitive progression during development impacts adaptive reasoning and may result in deficits in functioning and disability. The link between developmental deficits in general mental functioning and resulting difficulties in adaptive reasoning and functioning is emphasized in DSM-5, but these elements were not specifically linked in DSM-IV-TR or in the AAIDD definition and often are considered as independent criteria, often referred to as prong one and two of the definition.

Unlike the USA, the World Health Organization (WHO) has two classifications, the International Classification of Diseases (ICD) and the International Classification of Functioning (ICF). Like the ICD, the DSM-5 definition focuses on health conditions and makes clear that it is a classification of disorders by using the designation intellectual disability (intellectual developmental disorder) while the AAIDD description focuses on human functioning. The AAIDD states in its manual, seeking to clarify their approach, that its focus is on the disability construct like that of the ICF. The AAIDD focuses on the interaction of the person with their environment, and rather than emphasizing an underlying person-centered neurobiological deficit, its focus is on the social

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interface between a person and the environment. The AAIDD emphasizes that, without adequate environmental supports, the extent of functional disability can worsen. The differences in classification systems have led to confusion in the field because ID (IDD) is treated as a developmental “disorder,” in DSM-5 an etiologically based condition specified by neurobiological criteria (Author APA, DSM-5), and in the USA also as a “disability” (Schalock et al., 2010) by AAIDD, typically specified by IQ criteria that are statistically determined and linked to support services.

Another difference is in how severity is dealt with in the DSM and AAIDD approaches. For example, when classified as neurodevelopmental disorders (a new grouping in DSM-5 introduced to parallel neurocognitive disorders (e.g., Alzheimer’s disease) with onset later in life), neurodevelopmental syndromes raise issues in classification regarding the role of intelligence scores and adaptive behavior in establishing severity. DSM-5 addresses this issue by continuing to require standardized intelligence testing but eliminating IQ cutoff points in defining severity. Severity is determined based on adaptive functioning in everyday life. Instead of a severity classification, the AAIDD focuses instead on listing the extent of environmental supports needed for different degrees of severity.

Because there is tremendous variability in the degree of severity (globally and in the intensity of impairments and needed supports) characterizing individuals within the broad category on ID (IDD), who have various neurobiological etiologies, it is difficult to generalize about people with ID (IDD); they do not strongly resemble each other because there is considerable variability in their neurocognitive profiles. The majority of those identified are mildly intellectually impaired. In the past, mildly intellectually impaired was presumed to represent the lower end of the normal distribution of intelligence or to be linked to sociocultural/familial variables. Previously, it had been proposed that there were two groups: a pathological group and sociocultural/familial group (Lewis, 1933; Penrose, 1938; Zigler, 1967). Sociocultural factors include low

parental IQ, adverse social risk factors, lack of environmental stimulation, and social deprivation. Those with “pathological” forms fell in the severe range (IQ less than 50) and the mild forms with higher IQ scores. Severity is important in determining services. However, the two-group approach is overly restrictive because intellectual functioning is believed to be polygenetic for most who score in the mild range and do not have identified syndromes (Butcher et al., 2005; Kaufman, Ayub, & Vincent, 2010). In addition families with sociocultural adversity may have family members who are mildly and/or severely affected (Broman, Nichols, Shaughnessy, & Kennedy, 1987).

Many people with ID (IDD), even those with known brain-based syndromes, may fall in the upper end of the ID (IDD) spectrum (IQ in the 60s or low 70s). People with known neurogenetic causes such as fragile X syndrome can vary in ability from severe to mild. Moreover, despite being disabled, not everyone with an identified neurogenetic or neurodevelopmental disorder actually qualifies for the status of ID (IDD). This is because higher-functioning individuals with a known neurogenetic/neurodevelopmental syndrome may fail to meet statistically devised criteria (IQ ceilings) specified for the diagnosis of ID (IDD); however, they do meet adaptive functioning criteria generally because of atypical brain development. Overall, insufficient attention has been paid to developmental neurobiology during the life cycle in the mildly impaired group. Long-standing stereotypes held by laypeople and even many mental health professionals are grounded in beliefs about more severe manifestations of ID (IDD) without consideration of the full range of deficits. Because the implications of the differences between disorder and disability are not sufficiently emphasized in the USA, the implications of these approaches will be developed further in this chapter and serve as the unifying framework for much of its content.

This chapter will review historical landmarks, diagnosis and classification, and issues that arise about the current classifications. It will discuss the nature of ID (IDD) and will trace the history of recognition and services for people with intellectual

deficits moving from early descriptions to early interventions and to the current focus on empowerment and self-determination.

Historical Landmarks

The earliest reference to intellectual disability (intellectual developmental disorder) may be from ancient Egyptian medicine in the Papyrus Ebers (1552 BCE) (Bryan, 1974). Yet despite recognition since antiquity, there is little evidence available to suggest early medical interest. Still references in the various religious traditions suggest and indicate that people who were affected were to be treated with kindness. Despite such positive admonishment, infanticide was practiced in Greek and Roman cultures, and trephining was utilized in Europe and Central and South America as an intervention, probably based on beliefs that evil spirits might be released. People diagnosed with ID (IDD) may have been slaves in some cultures or chosen for court jesters in others. Thus, historically, attitudes ranged from humane concern to ostracism and abuse. In some countries, those affected were viewed as harmless innocents and allowed to wander at will. In England, Henry II promulgated legislation to make them wards of the king to provide for their protection (Harris, 2006).

At the end of the eighteenth century, with rising respect for the individual at the time of the French and American Revolutions, the rights of not only mentally ill, blind, and deaf people but also those with an ID (IDD) were beginning to be acknowledged (Kanner, 1964). Jean Marc Gaspard Itard, ignoring the opinion of the experts of his time, invested 5 years (1801–1806) seeking to teach and habilitate Victor, the wild boy of Aveyron (Lane, 1976), with support from the French Academy of Sciences that followed his interventions. Despite Victor making limited progress, the methods Itard established were acknowledged as highly meritorious by the French Academy of Sciences. Gradually the effort to educate people with an ID (IDD) spread, first to Switzerland and later in other parts of Europe and the USA. Interest in ID (IDD) was

stimulated by Rousseau's positive philosophy regarding prospects for human development. Pestalozzi and the encyclopedists promulgated this philosophy. Moreover, Itard's success encouraged Edouard Seguin to develop treatment programs for persons with ID (IDD).

Amentia or idiocy had been thought to be a homogeneous category. Both "idiocy," a designation for ID (IDD), and "insanity," a designation for mentally ill, were regarded as homogeneous entities. In 1845, in his treatise on mental maladies, Esquirol divided ID (IDD) into two levels, idiot and imbecile. He proposed that in the idiot, intellectual and moral faculties did not develop, writing "Incapable of attention, they cannot control their senses. They hear but do not understand; they see but do not regard. Having no ideas, and thinking not, they have nothing to desire..." (Esquirol, 1845, p. 467). The imbecile was near normal in their intellectual faculties yet would never attain normal knowledge for age, normal educational level, or normal social relations (Scheerenberger, 1983). Seguin in 1846 accepted these two categories and added to them feeble-mindedness and superficial retardation (Scheerenberger, 1983).

Soon afterward in 1850, early medical attention to cretinism resulted in a periodical publication, *Observations on Cretinism*. Griesinger (1876) noted that even though everyone diagnosed with cretinism was developmentally retarded, not every developmentally retarded person was a cretin (Scheerenberger, 1983). Thus he insisted that ID (IDD) is a heterogeneous category (meta-category) and not a single entity. Previously no distinctions had been made between etiologies of ID (IDD). The next distinctions were made by John L.H. Down in his classical paper, "Observations on an Ethnic Classification of Idiots" (Down, 1866), that addresses heterogeneity and Desire-Magloire Bourneville in his description of tuberous sclerosis in 1880 (Scheerenberger, 1983). An era began to find more clearly defined disorders, commonly named after their discoverers.

With the recognition that ID (IDD) was not a homogeneous category, the way was paved to distinguish specific conditions that differed in

both pathology and etiology that were characterized by intellectual deficits. Degenerative diseases were recognized such as Tay–Sachs disease. These findings established the view that ID/DD is caused by brain pathology and is not curable and raised questions about the possibility of any medical habilitation. With no medical treatment, educators provided amelioration.

Attention soon turned to intelligence testing and to the heredity of disorders of intellectual development. The most important people involved in early IQ testing are Francis Galton (Galton, 1869, 1883) and Alfred Binet and Theodore Simon (1911). Galton was a cousin of Charles Darwin whose theory of natural selection suggests that there is inherited variation among members of a species transmitted from one generation to the next. Galton sought to establish the hereditary basis of differences in ability and was first to see the importance of the twin method in investigations of intelligence.

In 1905, two French physicians, Alfred Binet and Theodore Simon (Binet & Simon, 1911), introduced psychometric tests. With the advent of compulsory primary education, Binet was charged by the French Ministry of Public Instruction to find a reliable method to find children who were unable to profit from instruction in normal schools (Mackintosh, 2011). Because the tests were considered objective and scientific, they were widely accepted. Binet and Simon wrote: “It seems to us that there is a fundamental faculty in intelligence, any alternation or lack of which is of the utmost importance for practical life. This is judgment, otherwise known as common sense, practical good sense, initiative, and the ability to adapt oneself to circumstance. To judge well, to comprehend well, these are the essential ingredients of intelligence” (Binet & Simon, 1911 quoted by Mackintosh, 2011). Their focus is on the ability to cope in everyday life. Binet sought norms for age and made comparisons among children of the same age to establish a mental age. The next steps in intelligence testing were taken in the USA. Henry Goddard, director of the Vineland Training School, in New Jersey, translated Binet’s tests. He found that these tests were a reliable means to assess

intelligence by evaluating 400 residents of the Vineland Training School and afterward administering these tests to 2000 typically developing children (Goddard, 1911). By 1916, Goddard had distributed 22,000 copies of the Binet and Simon paper (Mackintosh, 2011). Goddard added a third designation, moron, to the long-standing usage of idiot and imbecile.

It was Lewis Terman at Stanford University who made the greatest early advances in test development (Terman, 1916). His Stanford–Binet test was a revision of Binet’s 1908 and 1911 tests with 40 new items along with his changes in other items. This resulted in six test items for each age. Terman tested around 1000 children ages 4–14 years to establish his norms. All participants were of similar social status. Terman adopted a previously published intelligence quotient, or IQ, based on mental age divided by chronological times 100. Thus the average child would have an IQ of 100 and a 6-year-old child with a mental age of 7 would have an IQ of 133. Subsequently, group tests were devised to test large numbers of people and used in the First World War in the USA by a team led by Robert Yerkes (Yaokum & Yerkes, 1920). Because these tests were so widely administered, the American public became more aware of intelligence testing.

Goddard, Terman, and Yerkes adopted the view that intelligence was highly heritable as Galton earlier had claimed. His interest in hereditary led Galton to propose the term eugenics to refer to the science of improving adaptability by selective breeding. Eugenics was noted to take into account influences that may “give the more suitable races or strains of blood a better chance of prevailing...” (Mackintosh, 2011 p. 19). People with ID (IDD) were thought to be incurable and by some to be morally and socially deviant and a menace to society. This led Goddard to seek to document the relationship between ID (IDD) and antisocial behavior in a family study of the *Kallikaks* that consisted of two family lineages with the same father; one lineage was socially prominent and the other filled with members with antisocial behavior and intellectual deficits. Goddard’s *The Kallikaks* sought to

determine whether ID (IDD) and antisocial behavior were genetically rather than socially transmitted by neglect, poverty, and mistreatment by following these two lineages. Goddard's (1912) description of the Kallikaks described persons in the ID (IDD) lineage as a menace with increased criminality and drug abuse. Moreover, this lineage was determined to be the genetic source of more retarded persons in each new generation. The eugenics movement used this Kallikaks study as evidence of danger to society characterizing their "moral imbecility," indiscriminate sexual behavior, and excessive procreation. Eugenic considerations resulted in the placement of persons ID (IDD) in institutions and in sterilization programs. Such views increased the institutionalized population in the USA and led to the sad, long-lasting sterilization programs in the USA and in Europe, most tragically culminating in involuntary euthanasia programs in Nazi Germany.

Despite the misuse of science in negative eugenic experiments, productive research into the causes of ID (IDD) continued. The earliest preventive intervention for a neurodevelopmental syndrome resulted from Ivar Asbjörn Følling's (1888–1973) discovery in 1934 that phenylketonuria (PKU) is a metabolic disorder that could be reversed and treated by a restriction diet (Harris, 2006). The identification of biochemically based ID (IDD) syndromes made clear that such research was a legitimate endeavor in the biological sciences (Hagerman & Hendren, 2014).

The early discoveries led to national programs that bring medicine, education, psychology, sociology, genetics, and the various specialties together into special federally funded university-affiliated centers to find treatments. Currently, academic medicine is actively involved with other specialties, community organizations, and parent groups to investigate the etiology of neurodevelopmental syndromes, find therapeutic interventions, and establish habilitation and prevention programs. Advances in the developmental neurosciences, developmental psychology, developmental psychopathology, phenomenology and classification, family, behavior, and drug

treatments have led to a renewed and ongoing commitment to persons with intellectual developmental disorders.

Terminology for Intellectual Disability (Intellectual Developmental Disorder)

Terminologies and Criteria Used in the Twentieth Century

The use of early diagnostic terms such as idiocy, imbecility, moronity, and mental subnormality persisted in diagnostic manuals in the first half of the twentieth century (1921, 1933, 1941, 1952, 1957, 1959). Major change came in 1961 when the American Association on Mental Retardation (AAMR) introduced the term "mental retardation" to replace earlier terms that had become pejorative. The 1961 definition was the first definition that provided objective criteria and test scores for measurement, and it introduced dual criteria for intelligence and adaptive behavior. It was the first classification to be nearly universally adopted (Greenspan & Switzky, 2006a). The 1961 definition was "Mental retardation refers to subaverage general intellectual functioning which originates in the developmental period and is associated with impairment in adaptive behavior." Subaverage was defined as more than one standard deviation from the population mean and operationally defined as a score of 84 or less on a standardized psychometric test. The developmental period was defined up to the age of 16. Severity levels of intelligence were numbered 1–5 (borderline, mild, moderate, severe, profound) corresponding to standard deviations from the population mean. Adaptive functioning was subcategorized as levels 1–4 (mild, moderate, severe, profound).

The manual was revised again in 1973. Because one standard deviation from the population mean was found to be overly inclusive and resulted in the over-assignment of minority students to special education and because the adaptive behavior criteria were widely ignored, the wording was changed from subaverage to

“significantly subaverage” and the IQ cutoff point changed to two standard deviations from the population mean. Impairment in adaptive functioning was defined as “concurrent with deficits in adaptive behavior.” The developmental age range was increased to 18 years.

The next revision in 1983 was significant in adding the IQ’s standard measurement error (typically five points) to the definition. Severity ratings based on standard deviations from the population mean were maintained but the actual numbers were now spelled out (e.g., mild 50–55 to approximately 70, moderate 35–40 to 50–55, etc.). The importance of clinical judgment was emphasized in the 1983 definition. Emphasis was added in regard to the importance of the impact of social milieus in facilitating or impeding intelligence. An important goal was to keep the classification system congruent with the American Psychiatric Association’s diagnostic manual (DSM-III 1980) and the ICD of the World Health Organization.

The 1992 AAMR definition represented a paradigm shift that sought to take into account differences in service models and to provide greater emphasis on self-advocacy and on the disability construct. It makes the philosophy of the AAMR clearer regarding the model of mental retardation preferred by the organization that mental retardation should be viewed as a state rather than a trait. The 1992 AAMR manual states that “mental retardation refers to a particular state of functioning that begins in childhood in which limitations in intelligence coexist with related limitations in adaptive skills” (Luckasson et al., 1992, p. 9). It notes that mental retardation is neither a mental disorder nor a medical disorder. The focus on the disability construct is clarified by stating that mental retardation is not an absolute trait expressed solely by an individual but an expressed interaction between the affected person and the environment (Luckasson et al., 1992, p. 9). The intelligence criterion is a score of 70–75 or below on a standardized intelligence test. Major 1992 changes were to extend adaptive behavior to ten specific adaptive skill (not behavior) areas and to require significant disabilities in two or more adaptive skill areas in the definition.

Subclasses of mild to profound were replaced with four-level subclassification systems of intensities and patterns of supports (intermittent, limited, extensive, and pervasive). Finally, a multidimensional approach to classification was introduced with 4 dimensions (intellectual functioning and adaptive skills; psychological/emotional considerations; biomedical, social, behavioral, and education factors; and environmental considerations). The age of onset remained below the age of 18 years. Spitz (2006) in a critique of the 1992 definition points out that the AAMR does not discuss familial (hereditary) mental retardation and does not acknowledge polygenetic contributions to the mild level.

The 1992 AAMR diagnostic manual created some dissatisfaction within the psychological community, for two reasons: (a) the attempt to eliminate subcategories and replace them with support need profiles and (b) a shift from a 70 to a 75 IQ ceiling. This dissatisfaction was expressed most concretely in an attempt by Division 33 of the American Psychological Association to put forth its own diagnostic document, which was published in 1996 (Jacobson & Mulick, 1996). This manual consisted of two parts: (a) a brief definitional section and (b) a longer section with chapters by distinguished authors (who had no input into the definition) on various topics related to mental retardation. The manual section essentially was a return to the definition in use by AAMR before its 1992 manual. The document led the AAMR to revise its manuals to bring back the possibility of severity subcategories (as options) in subsequent manuals and to move away from an IQ ceiling of 75 and adopt IQ “70–75” range based on test standard error.

During the twentieth century, the American Psychiatric Association (APA) essentially followed the lead of the AAMR in DSM-III (1980) maintaining compatibility between the classifications. In DSM-IV, the definition remained compatible between the classifications, but DSM-IV maintained the earlier levels of severity with the same IQ cutoffs as before and continued with the DSM multiaxial classification rather than adopting the AAMR multidimensional approach. Moreover, in a classification of disorders, unlike

the AAMR, the American Psychiatric Association views ID (IDD) as a trait that may be heritable. It is a trait that may result from a variety of neurogenetic developmental disorders and poly-genetic inheritance.

Terminologies and Criteria Introduced in the Twenty-First Century

In the twenty-first century, the AAMR updated its 1992 definition and description in 2002 by specifically stating that mental retardation is a disability to emphasize its severity and to align its position with that of the WHO's International Classification of Functioning (ICF). It emphasized that there are significant limitations in both intellectual functioning and adaptive behavior. Previous definitions noted concurrent limitations in adaptive behavior but now each was placed on equal footing. It introduced a tripartite model of adaptive behavior by emphasizing adaptive skills in conceptual, social, and practical domains. It added a fifth dimension of human participation, interactions, and social roles.

In 2007, the American Association on Mental Retardation (AAMR) changed its name to the American Association on Intellectual and Developmental Disabilities (AAIDD) and in 2010 published its most recent update to its manual. It clearly places intellectual disability, the new naming it proposes, as being solidly placed in the broader construct of disability noting that intellectual disability is no longer viewed as an invariant trait of a person. The focus instead is on a social–ecological construct of the person interacting with his or her environment. It highlights the principles of self-worth, well-being, and self-determination emphasized within the disability movement. It continues the focus of its earlier classifications of supports needed to help each person reach their potential. The accompanying manual text includes a chapter on etiology that draws attention to the multifactorial nature of etiology. It recognizes that the traditional two-group approach (biological and cultural familial) is focused on multiple risk factors that may be

present for both of these categories. Those with severe known neurogenetic disorders and others with nonsyndromic milder presentations (and potentially polygenetic inheritance) may both be impacted by environmental risk factors that affect functioning. Still, fundamentally, the AAIDD's classification focus is mainly on functioning, adaptive behavior, and support needs that are consistent with the conceptual model proposed by the ICF and not that of the WHO's International Classification of Diseases (ICD).

The adoption of the disability construct (consistent with the ICF) by the AAIDD and its decision to introduce intellectual disability as the new term for mental retardation gained momentum in the context of the revision of the two major classifications of mental disorders: the ICD-10 and the American Psychiatric Association (APA)'s Diagnostic and Statistical Manual of Mental Disorders (DSM).

If disorders of intellectual development were defined as disabilities and not as health conditions, they would not be included in the ICD. They would only be classified using codes from the ICF. However, it is the ICD rather than the ICF that is primarily used by the 194 WHO member countries to provide health care to their citizens. ICD categories, including those related to intellectual development, are used to designate which people are eligible for specific health care, educational, and social services. Thus removal from the list of ICD health conditions could have impact on national and global health statistics and on the service availability (Bertelli, Harris, & Salvador-Carulla, 2016).

The World Psychiatric Association's section on Psychiatry of Intellectual Disability solution was to indeed consider disorders of intellectual developmental to be health conditions in the International Classification of Diseases (ICD) viewing them as "a syndromic grouping or meta-syndrome analogous to the construct of dementia, which is characterized by a deficit in cognitive functioning prior to the acquisition of skills through learning." They note that the intensity of the intellectual deficit interferes in a significant way with an individual's normal functioning and results in limitations in activities and restriction

in participation (disabilities) as described in the International Classification of Functioning (Salvador-Carulla et al., 2011).

These deliberations assumed importance in the USA with the revision of the American Psychiatric Association's diagnostic manual, DSM-5. It is the *official* classification for mental disorders in the USA and by international agreement shares diagnostic codes with the ICD. For DSM-5, there was liaison with the WHO ICD-11 committee to assure harmonization of the two classifications. The ICD-11 committee at the time that DSM-5 was being finalized used the term intellectual developmental disorder (the newest draft uses disorders of intellectual development). To harmonize the naming and to make clear that the DSM-5 definition was on disorder, the final naming in DSM-5 is intellectual disability (intellectual developmental disorder) or ID (IDD). The term intellectual developmental disorder in parenthesis is listed to make clear that the DSM-5 focus is on disorder and not the disability construct preferred by AAIDD and the ICF. Moreover, the term intellectual disability is used in the scientific literature in the USA for both the disorder construct and the disability construct.

The DSM-5 definition is a major revision from DSM-IV-TR. The DSM-IV criteria were similar to the 1992 AAMR definition in requiring significantly subaverage intellectual functioning and concurrent deficits in present adaptive functioning in 2 of 11 designated areas, among them communication, self-care, social/interpersonal skills, functional academic skills, and self-direction. However, it went further in designating an IQ of approximately 70 or below on an individually administered IQ test in the body of the definition. In DSM-IV-TR, mental retardation was listed in the multiaxial system on Axis II separating it from other developmental disorders with the expectation that this placement would lead to its regular assessment.

DSM-5 introduces a new category, *neurodevelopmental disorders*, not used in DSM-IV-TR to make it clear that intellectual and other developmental disorders are neurodevelopmental problems in brain functioning. *Neurodevelopmental disorders* parallel neurocognitive disorders of

late-life onset (e.g., Alzheimer's disease) as disorders of brain functioning in DSM-5. DSM-5 eliminates the term mental retardation that was used in DSM-IV-TR and eliminates the multiaxial classification that had placed mental retardation on Axis II. The new term that replaces mental retardation in DSM-5 is intellectual disability (intellectual developmental disorder) and provides new disorder diagnostic criteria thus aligning it with all the other mental disorders in the classification. As noted earlier, "disorder" is placed in parenthesis to make clear that the focus in DSM-5 is on a disorder of neurodevelopment of the brain. It is classified as a brain-based disorder. Additional specifier codes are used to indicate specific causative syndromes such as fragile X syndrome.

The term "intellectual disability" is retained in DSM-5 because this term is commonly used to obtain services and this term is used in federal legislation (PL 111-256) for service determination. Both DSM-5 and AAIDD provide similar definitions for intellectual disability in the body of the definition. However, as noted earlier, the AAIDD makes clear in their manual (2011) that, like the WHO's International Classification of Functioning (ICF), it is based on the disability construct rather than the disorder construct.

The DSM-5, for the first time, includes a definition of intelligence in Criterion A (Harris, 2013; 2014a). This inclusion is a major clarification meant to make clear how intellectual deficits are defined and their relationship to adaptive functioning. These criteria are based on a consensus definition of intelligence accepted by the APA and AAIDD (Gottfredson, 1997). Defining intellectual deficits is important to assure their assessment in both clinical (psychiatric interview) and psychometric (IQ and neuropsychological testing) evaluations. This is a departure from the DSM-IV-TR classification that does not delineate intellectual deficits in its definition. Unlike the earlier DSM classifications, DSM-5 does not refer specifically to an IQ number in the definition nor does it refer to IQ in Table 1 (severity levels on pp. 34–36 in DSM-5). Instead it lists intellectual deficits in reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience.

These deficits must be confirmed by *both* clinical assessment and individualized standardized intelligence testing to make a diagnosis.

Importantly, DSM-5 (unlike DSM-IV-TR) clarifies that the first two criteria, A and B, are interrelated. DSM-5 specifies that adaptive functioning (Criteria B) is an outcome of intellectual deficits (Criteria A). DSM-IV-TR has been interpreted by the courts as having 2 prongs—prong 1 in DSM-IV-TR is based on statistically derived IQ test numbers and levels and prong 2 defines deficits in adaptive functioning that impact adaptation in the community. Because Criteria A and B are interrelated in DSM-5, they should be considered together rather than as prong 1 and 2 and understood as linked. By defining intellectual deficits as deficits in reasoning, problem solving, and planning, DSM-5 links the first and second criteria. Thus, rather than distinct elements, they are interrelated ones and both must be considered together to make a diagnosis.

Specifically, in this neurodevelopmental disorder, intellectual deficits result in *problems in adaptive reasoning* leading to deficits in adaptive functioning in academic, social, and practical. Thus, in DSM-5, the severity of the disorder (mild, moderate, severe, profound) is NOT based on IQ score. It is based on the severity of the adaptive functioning in conceptual, social, and practical domains as noted in Table 1 in DSM-5.

The medical community recognizes that the IQ test is imprecise even though it is of considerable significance. When IQ scores (taking into account the standard error of measurement) are used to assess a defendant's eligibility for the death penalty, it is important that the courts view test scores with the same skepticism with those who do design and use the tests because an IQ test score represents a range rather than a fixed number. Moreover, in regard to the IQ test, DSM-5 states that the use of a battery of neuropsychological tests that measure discrete intellectual functions such as verbal comprehension, executive functions, and memory provides a better description of a person's overall cognitive abilities than an IQ test alone. As noted in the explanatory text to DSM-5 on page 37: "in some instances if adaptive deficits are severe then one

can meet criteria based on those adaptive deficits even if the IQ is in the 70s." Thus DSM-5 shifts the emphasis in diagnosis when determining the severity to focus on adaptive functioning and reasoning and makes clear that Criterion A and B are interrelated. As stated in the DSM-5 text, "IQ tests scores are approximations of conceptual functioning but may be insufficient to assess reasoning in real-life situations and mastery of practical tasks" (DSM-5, p. 37). Thus the critical issue is adaptive reasoning in the three domains described in DSM-5 (conceptual, social, and practical).

The third criterion is onset of deficits in the developmental period. In the explanatory text, the developmental period is discussed in the section on *developmental course*. Here information is provided that recognition of deficits in adaptive functioning is recognized in early life and persists throughout life. ID (IDD) is not simply a development delay but a long-term chronic disorder of functioning. Thus any assessment of adaptive functioning must take into account early developmental history and make reference to school records, testing, and reports.

Finally, individuals with ID (IDD) diagnoses are at increased risk of co-occurring mental disorders that further impacts their adaptive functioning. Such diagnoses occur in up to a third of individuals in published studies and include the full range of psychiatric disorders such as attention deficit disorder, schizophrenia, major depression, and bipolar disorder. The co-occurrence of mental disorders further impact adaptive functioning (Harris, 2014b).

History and Limitations of the IQ Statistic

Adoption of the Deviation IQ Method

The first widely used intelligence test, devised in France by Binet and Simon in the first decade of the twentieth century and imported to the USA by Goddard and Terman, chose to use a measure of mental age (MA). This was determined by establishing mean scores for all subjects in a standardization sample. The tested individual

was compared to a norm table and his or her MA is established identifying the comparable age mean. Thus, if a 15-year-old subject scored at the mean level of a 10-year-old, he or she would have a chronological age (CA) of 15 and a MA of ten.

The invention of the intelligence quotient (IQ) in the 1930s by the German psychologist William Stern had major implications for the diagnosis of ID (IDD). Initially, IQ was calculated by use of the “ratio method” that entailed dividing CA into MA and multiplying the result by 100. Using the previous example, if a youth of 15 had a MA of ten, he would have an IQ of 67 ($10/15 = 0.67 \times 100 = 67$). If the same youth at age 15 had a MA of 15, this IQ would be 100 ($15/15 = 1.0 \times 100 = 100$). Thus, the convention was established that an average IQ equals 100.

An obvious problem with the ratio method is that, at some point in adolescence, growth in MA ceases to increase very much, while CA increases at a steady pace. In diagnosing ID (IDD), the use of MA resulted in many false positives. For example, a 20-year-old with a MA of 14 would have an IQ of 70 and falsely be identified as defective. Fourteen is the age at which MA growth begins to reach an asymptote, so the person in question would actually have a relatively normal intelligence.

The solution to this problem was a change introduced in the 1960s to move from the ratio method to the “deviation IQ” method. In this method, the norming sample (typically only a few thousand subjects) would be divided up into small age blocks, and statistics would be calculated separately for each age block. The basic statistic is a “z-score” that indicates the distance an individual falls from the mean for that sample in a number of standard deviation units. The zero point in the z-distribution is arbitrarily set at 100, which means that 50 % of the distribution falls above or below 100. Individual scores are then calculated based on number of z-scores from the age-block mean (thus, a score of minus 1.5 means that the individual’s IQ score falls one-and-a-half standard deviation units below the mean). Just as the z-score of zero is arbitrarily set at 100, a z-score of 1 is arbitrarily set at 15. Thus a z-score of minus one would equate to an IQ score of 85,

while a z-score of minus two would equate to an IQ score of 70. As the distribution of z-scores follows the very well-defined “normal” (bell-shaped) curve, with a severe drop-off to the right or left after minus one or plus one z, an IQ score of 75 places one at the fifth percentile, an IQ score of 70 at the second percentile, and an IQ score of 55 at a tiny fraction of the first percentile.

Thus, the IQ standard deviation (SD) units were used not only to define the upper level of the ID (IDD) population but also to devise subclassification categories (mild, moderate, etc.). Interestingly, in the 1961 AAMR manual, there was so little emphasis on IQ standard deviation-based subcategories that they are to be found only in a single footnote in a table. That changed dramatically in later years, where subcategories were entrenched. Because subcategories were so well established, the removal of IQ-based subcategories based on discontinuous standard deviation units by the AAMR in its 1992 manual and replacing them with a continuous index intensity of support needs caused the American Psychological Association (Jacobson & Mulick, 1996) to publish its own manual as mentioned earlier. This decision was successful and the AAMR reversed its decision agreeing that IQ SD-defined subcategories were important. In the long run, the effort to restore IQ-based subcategories failed when DSM-5 decided that subcategories should be based on the degree of adaptive deficits and not on the degree of IQ deficit.

An advantage of the deviation method is that one can reliably locate where an individual falls in relation to the norming sample of people of approximately the same age. Still, there are a profusion of problems that inhere in the heavy reliance on IQ scores, particularly the full-scale (overall summary) statistic that is its most widely used index. Three of these problems are (a) problems with norms, (b) problems with content coverage, and (c) problems with use (particularly reification).

Problems with Norms

Because performance on an IQ test derives its meaning from where it places someone in the

distribution of scores in a standardization sample, a score is valid only if the test developers used adequate methods to constitute the normative sample and statistically analyze the results properly. That is not always the case. For example, the developers of the WAIS-III, in compensating for the WAIS-R's "tree stump" (floor effect) problem caused by too few low-functioning standardization subjects (if a tree stump took the WAIS-R, it would have received a full-scale IQ in the 40s), overcompensated by recruiting too many low-functioning subjects for their new test edition. As a result, the WAIS-III overstated IQ by over two points (Flynn, 2007). That a new IQ test (such as the RIAS) correlates well with older tests (people who do well or poorly on one also do well or poorly on the other) does not mean that they produce the same results (the RIAS results, especially nonverbal ones, are significantly higher). While consistent differences can sometimes be addressed through a correction of the resulting score, one cannot fix, or even interpret, a score obtained from a test that is incorrectly constructed, as was the case with the Mexican Spanish-language version of the WAIS-III (Suen & Greenspan, 2009).

A common source of IQ score invalidity is termed the *Flynn effect* (Flynn, 1987, 2007) and refers to the fact that, on newer IQ tests (e.g., the WAIS-IV), subjects produce lower scores than on its earlier edition (e.g., the WAIS-III). The reason is not because a subject has gotten less intelligent in the intervening years but because the population from which standardization sample is drawn has scored higher on some subscales (especially the nonverbal ones). This is established when tests are being constructed, as a subsample of the standardization sample is given both the old and new test in counterbalanced order. Subjects uniformly do worse on the new test, by an average of three full-scale points per decade of norm obsolescence. In high-stakes assessments (such as capital punishment proceedings), it has become standard practice to do "Flynn corrections" in which all full-scale scores are adjusted downward by multiplying the number of years of norm

obsolescence by 0.3 and subtracting the result from the obtained score. This ensures that all persons are being evaluated by the same standard. This is especially important in a death penalty case to assure that a life-affecting decision is not based on the accident of the age of a test edition that was used.

Problems with Content

Existing "gold-standard" intelligence tests are modeled after the Binet–Simon test that was substantially revised by Louis Terman. These tests were constructed by sampling items from different grades in the school curriculum and rank subjects in relation to age-matched peers. While intelligence tests have evolved considerably over the years, their items are still mainly representative of the logico-mathematical tasks that are taken highly predictive of school performance. More broad-based models of intelligence have been devised, which tap into other aspects of intelligence, such as what Guilford (1967) termed "behavioral" (social) and "mechanical" (practical) forms of intelligence. People with ID (IDD) all have problems in what Sternberg (1984) termed "academic intelligence" but if properly diagnosed also have problems in what he termed "everyday [social and practical] intelligence." But social and practical intelligence are not tapped directly by the IQ statistic, and thus an IQ score cannot adequately answer the question "how lacking in everyday intelligence is this person?" In theory, measures of adaptive behavior are attempts to assess practical and social functioning, but because they lack a cognitive focus, they have been criticized as inadequately tapping into the IDD taxon (which can be described as "low intelligence, broadly defined").

Problems with Use

Evolutionary biologist Gould (1981), in *The Mismeasure of Man*, a book about the mistaken uses of IQ testing, noted that these uses reflect two deep fallacies: the fallacy of ranking and the fallacy of reification. Ranking is based on the mistaken belief that all people (including individuals

with Down syndrome) can be adequately described by where they fall on a continuum on a single summary domain such as “g” (full-scale IQ). Reification refers to the tendency to turn an abstraction into a concrete entity, as reflected in the mistaken belief that one’s IQ score is an immutable and unchangeable property of a person, in essence a snapshot of the person’s brain. A reflection on the reification of IQ is the view, expressed by some experts in criminal proceedings, that if there is any variation among results of multiple IQ tests (which there invariably are, as human performance is inherently variable), then the highest score must be the only valid one, while the lower ones may reflect conscious malingering (attempt to look less competent than one is). In fact, there are many other explanations for IQ score variability, including mistakes of administration, improper scoring, and even (one would like to think rarely) examiner corruption (Greenspan & Olley, 2015).

Executive Functioning and Other Indices

Both DSM-5 and AAIDD define intelligence with a list of cognitive processes, originally adopted from a mainstream consensus statement devised by a committee of prominent psychologists (Gottfredson, 1997) mentioned earlier. The constituent elements are not sufficiently tapped by the two leading gold-standard intelligence tests or captured by a full-scale IQ score. This is clearly a problem for the diagnosing of ID (IDD), given the exclusive weight given by many diagnosticians to the results of an IQ test.

In the past few decades, executive functioning has become a subject of research and clinical assessment, both in research and in the armamentarium of tests administered by clinical neuropsychologists (Diamond, 2013). In recognition of the contribution that executive functioning measures play in capturing important aspects of intelligence, the ID (IDD) section of DSM-5 states that testing for executive functioning and IQ may provide a more comprehensive assessment. The important point here is that the first diagnostic prong (Criterion A in DSM-5) is not isomorphic with an IQ score (or even multiple IQ scores).

Efforts to Reduce Reliance on IQ Ceilings

The definitional history of IDD over the past half-century has been characterized by various efforts to minimize the distorting effects caused, when in 1973 the IQ cutting score was set at 70. At minus two standard deviation (z-score) units, that established ID (IDD) in regard to intelligence at the bottom 2 % of the population. As the general consensus was that the 3 %, based on statistical assumption about IQ being a normally distributed trait, was a more appropriate dividing line, a variety of steps have been taken to address the resulting problem of too many “false negatives” (people deemed to require the ID (IDD) label) but are denied it because of an IQ over 70). Moreover, because severe neurogenetic syndromes of ID (IDD) cluster in the severe range and there is increasing focus on polygenetic inheritance in the mild range. There is mounting evidence for the neurodevelopmental model and how it relates to IQ ceilings.

History of Adaptive Behavior and Adaptive Functioning

The concept of adaptive behavior originated in ethology (where it refers to competence of organisms in the wild as opposed to controlled laboratory, e.g., rat studies in a maze). This approach was borrowed by the American Association on Mental Deficiency (precursor of today’s AAIDD) in its 1961 diagnostic manual. Its inclusion was to emphasize that, when diagnosing intellectual disability ID (IDD), one should consider how an individual functions and solves problems in the real world, rather than in the controlled setting of an intelligence test. A problem with the construct is that it initially lacked a theoretical framework, and that problem has never been fully resolved.

The Heber (1961) manual in which adaptive behavior became part of the definition was preceded by a preliminary version published as a journal supplement (Heber, 1959). The earlier version referred to impairments in the three areas of “maturation,” “learning,” and “social adjustment.” Maturation was described as self-help

skills usually acquired in early childhood, learning was described as academic skills usually acquired in middle childhood, and social adjustment was described as interpersonal skills usually acquired early but reaching fullest development in adolescence and adulthood, as manifested in successful work, relationships, and socially appropriate law-abiding behavior. Instead of a single integrated construct to be applied at all life stages, one was to apply only one of the above three constructs, depending on whether the individual in question was a young child, an older child, or an adolescent/young adult. In spite of this work, few clinicians ever used these preliminary constructs.

This pattern continued to be largely the case for a decade or more with the 1961 replacement construct of adaptive behavior that incorporated the three abovementioned domains into a single construct intended to be applied at all subject ages. The failure of clinicians to routinely include the adaptive behavior criteria undoubtedly contributed to the decision by AAMR to drop the “borderline” (IQ 71–85) subcategory 12 years later (Grossman, 1973). Tassé et al. (2012) pointed out that although the field of ID (IDD) has veered into different directions with respect to defining adaptive behavior, 50 years after Heber (1959), the field has essentially returned to defining adaptive behavior with the same original framework: conceptual skills (learning), social skills (social adjustment), and practical skills (maturation).

The force driving the development of what was then termed the “dual criteria” definition of IDD (i.e., IQ and adaptive behavior) was concerned about the problem of “false positives” in the over-assignment to self-contained special education classes of low-socioeconomic-status children of ethnic minority groups. This group was described as the “6-h retarded children”; that is, they were identified as having an intellectual disability while in school but not outside of school. This phenomenon reflected two things: (a) the sole reliance on full-scale IQ scores as the basis for assigning the IDD label and (b) the (typically reported) lower IQ scores of low-socioeconomic-status minority children. Thus,

the introduction of the adaptive behavior prong can be seen as reflecting a desire to ground ID diagnosis on real-world functioning and to be less culturally biased than measures of intelligence particularly.

Developing adequate ways of measuring adaptive behavior/adaptive functioning has proven to be challenging. Initially AAMD developed its own rating measure—the AAMD Adaptive Behavior Scale (ABS, not to be confused with the later ABAS)—but this was handicapped by the absence of population norms and its development at an institution (Kansas’ Parsons State School) with a consequent emphasis on very basic skills such as self-toileting. This was remedied by the development of other rating measures—such as the ABAS, Vineland, and SIB—but there still has been a failure to fully address aspects of community functioning, such as negotiating the social world. Recently, AAIDD has again put out its own instrument (expected out at the end of 2015), the Diagnostic Adaptive Behavior Scale (DABS), which is justified as the first instrument to be devised primarily for diagnostic rather than for programming purposes. This instrument appears to be better at tapping social deficits (its several gullibility items are reported to strongly discriminate ID from non-ID samples) but is limited by age norms that do not go above 22. Use of rating instruments is justified by the absence of valid “direct” test measures, but they pose problems of possible third-party rater bias. Use of descriptive/qualitative information is encouraged for getting at aspects (such as gullibility) not covered adequately in existing measures and for more fully understanding a person’s functioning (Greenspan, Loughlin, & Black, 2001), but (perhaps reflecting the quantitative bias in the IDD field) such a qualitative supplement to rating data is typically not used.

IDD Equivalence

The term “IDD equivalence” refers to accommodations that are made by legal and other governmental entities when they provide services, supports, or protective arrangements to people

who—because of brain impairment—function as if they have IDD but fail to qualify for the IDD label because their IQ scores are a few points too high. Individuals with various brain-based syndromes are candidates for such an accommodation, as IQ scores often are around or above the 70–75 IQ ceiling, while adaptive functioning is typically much lower. IDD-equivalence accommodations are, thus, an attempt to free the human services field from the excessive constraints caused by rigid reliance on full-scale IQ ceilings to determine service eligibility.

IDD-equivalence solutions can take various forms. These include using the broader category of “developmental disabilities” (DD), establishing both categorical and non-categorical procedures for declaring people eligible for developmental services in spite of IQ over arbitrary IQ ceilings and raising the IQ ceiling itself. A full description of the history of DD and other ways of broadening IDD can be found in Greenspan, Brown, and Edwards (2015).

Service Eligibility Solutions to the IQ Ceiling Problem

Other solutions, some in response to lawsuits or lobbying efforts, have been devised to get around the straightjacketing effects of IQ ceilings in defining ID (IDD) and allowing access to developmental services. One solution has been the use of individual add-ons. Thus, in Connecticut, a 2006 state law defines ID (IDD) thusly, “Any person... who is, appears to be, or believes him/herself to be a person with mental retardation, as defined in Connecticut General Statutes 1-1 g [note: DSM definition] or *Prader-Willi Syndrome...*[italics added].” In other states, there are different add-ons. For example, in Minnesota, special mention is given to Patau syndrome (a trisomy on chromosome 13) and Edward syndrome (a trisomy on chromosome 18). Why these specific add-ons? The obvious answer is that there have been effective lobbying efforts by parents and advocates for individuals with these specific syndromes. It also does not hurt that these are rare disorders that can be very reliably medically diagnosed, and the consequences to public funding agencies are more limited than if, for example,

IDD equivalence were automatically granted to people with autism, a much more frequent disorder with relatively broad functional diagnostic criteria.

Another approach to IDD equivalence is used in California for what is termed the “fifth category.” This refers to developmental services provided to IDD for service purposes defined as ID (traditional criteria) and three other disorders (as long as adaptive functioning criteria are met): cerebral palsy, epilepsy, and autism. The fifth category refers to others who function adaptively as if they have ID (IDD) or who have service needs similar to those who have IDD (Greenspan et al., 2015).

From Institutional Care to Self-Determination

In the not-too-distant past, virtually all individuals with IDD, including children and adults with mild or even borderline levels of impairment, were often placed in large congregate public institutions. Today, many such institutions have been closed or are slated to close, relatively few of them are still operating, and the remaining few contain no children and only adults with the most severe forms of impairment. Many institutions were constructed during the height of the eugenics movement; a major reason for their existence was to prevent people with even the mildest forms of ID (IDD) from reproducing (people with severe or profound ID (IDD) are very unlikely to procreate). This is reflected both in strict gender segregation and discharge upon reaching a certain age. Sterilization, often without consent or even foreknowledge, was practiced during the eugenic era (Scheerenberger, 1983).

A variety of living arrangements have been developed to accommodate children and adults who cannot reside with their families or on their own, either because of inability to meet daily needs or because of self-abusive or aggressive behaviors. These range from specialized foster care to group homes to supported one- or two-person apartments with degree of support ranging from occasional dropping-in around specific issues to full-time monitoring to deal with all

issues. As a rule, the degree of support provided depends on the person's individualized needs and the risks (of death or great harm) associated with granting substantial freedom. The level of one's IQ and even of adaptive functioning is only mildly predictive of supports provided, as: (a) there is a bureaucratic tendency to put eligible persons into available residential slots regardless of specific need and (b) existing measures of competence, and even of support needs, do not automatically translate into or adequately tap needed supports, especially in the realm of interpersonal behavior (where one foolish action, in response to a confrontational situation, can produce life-threatening consequences for even a generally competent individual).

A current frontier in the evolution of individualized programming is the wrapping of individualized supports around people living in their own homes ("supported living"), work settings ("supported employment"), and even childrearing ("supported parenting") (Bradley & Knoll, 1995). An even more radical development in the movement to greater empowerment and autonomy is self-determination, which involves giving control of residential grants to the person with IDD, who can hire and even fire staff persons as they meet his or her needs (Wehmeyer & Schwartz, 1998). This development is a reflection of as well as a spur to definitional developments, as the field has come a very long way from the "defectology" view that was so pervasive a few decades ago.

The trend in developmental services, both for children and adults, has been toward greater respect, increased autonomy, lessened emphasis on global defects, and more emphasis on differentiated competence profiles. This trend is an external reflection of a shift in underlying values, driven generally by a philosophical system termed the "normalization principle" (Wolfensberger, 1972). That system is grounded in a view of people with IDD as having the potential to attain a good quality of life and the possibility of bringing pleasure and hope rather than a sense of tragedy and resignation to service providers and family members. Not surprisingly, this shift in underlying values is reflected in changes both in the terminology used to refer to people

with ID (IDD) and in the evolving definitions of ID (IDD).

When the two authors of this chapter became introduced to the IDD field, the field was referred to as "mental deficiency"; the switch to "mental retardation" was seen as a more respectful development; the subclassification system consisted of terms such as "idiot," "imbecile," and "feeble-minded"; research subjects were referred to as "retardates"; and the tendency was to use sentences with "is" (as in "John is retarded") and terms where the disability word comes first (as in "mentally retarded people"). A major development in the 1980s, in part initiated by people with disabilities (who referred to themselves as "self-advocates") themselves, was the shift to what is termed "people-first language" (Shoultz & Williams, 1982). This language is characterized by substituting the verb "has" for "is" (as in "John has mental retardation") as well as putting the disability word at the end preceded by "with" (as in "people with mental retardation"). Part of this shift also involves avoiding pity words, such as the once common "John suffers from" (or "is afflicted with") mental retardation. This terminology makes for lengthier and more cumbersome sentences, and that is a reason (among others) why professionals resisted its adoption initially. But today, any professional who does not adopt the people-first language is likely to be criticized, particularly when submitting papers to research journals.

A major development in North America was the change in 2006 of the name of the field's major professional and research organization from the "American Association on Mental Retardation" (AAMR) to the "American Association on Intellectual and Developmental Disabilities" (AAIDD). This was preceded two decades earlier, by a 1987 shift from the "American Association on Mental Deficiency" (AAMD) to AAMR. Adoption of the term "intellectual disability" (which has already come into widespread international usage) was initially resisted by professionals and agencies, as reflected in the fact that a first attempt at changing to AAIDD was rejected in a vote by a majority of the membership. Much of this resistance

was driven by concern expressed by agency directors who feared that the name change would presage a broadening of the class of people they would be expected to serve. Approval of the change was won by a promise that it would have zero impact on prevalence and incidence rates. This probably regrettable promise indicates that the “science” of disability classification is affected to some extent by political and economic considerations. In 2010, the US Congress passed, and the President signed, “Rosa’s Law” (Public Law 111–256), a bill named after a 9-year-old Maryland girl with Down syndrome. The law specified that henceforth any use of the words “mental retardation” or “mentally retarded” would be replaced by “intellectual disability” or “intellectually disabled” in any federal legislation, regulations, or proceedings.

Problem of Diagnostic Overshadowing

The term “diagnostic overshadowing” refers to the tendency to deny or overlook the possibility that someone could have an ID (IDD) diagnosis because of the existence of some salient or diverting characteristic of the person. Two forms of diagnostic overshadowing are particularly common: (a) psychiatric overshadowing and (b) cultural/racial overshadowing.

Psychiatric overshadowing refers to the tendency to overlook the existence of ID (IDD) in persons with a significant co-occurring mental disorder (Kanne, 2013). People with IDD have a higher likelihood—because of brain impairment or environmental deprivation—of also having co-occurring mental disorder. The existence of significant psychopathology should not be used to deny the possibility that the person may have an ID (IDD) diagnosis or that the ID (IDD) may predate the mental disorder. When faced with a person who has significant mental disorder, a diagnostician may falsely assume that the person’s cognitive difficulties are a reflection of behavioral or emotional issues, when instead the underlying cognitive disorder is a risk factor for a mental disorder.

Cultural/racial overshadowing refers to the tendency to assume that the learning difficulties of all poor or minority individuals are a reflection of their socioeconomic or racial background. Such overshadowing is commonplace, even when the individual has a significant neurodevelopmental disorder and even if he or she resides in a family where they are the only one who is significantly impaired.

A reverse form of diagnostic overshadowing can also occur, in that an individual with an ID (IDD) diagnosis may also have emotional problems or a psychiatric disorder that is not fully recognized. This is not uncommon with individuals diagnosed with Down syndrome, where the stereotype of being universally happy and well adjusted may obscure the fact that, for some individuals, the reality is very different (Menolascino & Stark, 2012).

The Psychological Nature of Intellectual Disability (Intellectual Developmental Disorder)

The Construct of Intelligence

The construct of intelligence, as reflected both in definitions and measures, is central to the definition of ID (IDD). Yet, the construct is controversial and considerable disagreement exists regarding its meaning. In an edited book, titled *What Is Intelligence?* (Sternberg & Detterman, 1986), over a dozen leading intelligence researchers were asked to provide a definition, and virtually every one came up with something different. Both DSM-5 and the AAIDD manuals refer to an operational definition comprising a number of general mental functions (“reasoning, problem solving, planning, abstract thinking, academic learning, and learning from experience”) based on a mainstream definition of intelligence that is a consensus of 52 psychologists (Gottfredson 1997). To this list, DSM-5 added judgment as a feature. But a diverse list is not the same thing as a focused definition. As earlier noted, some characteristics of the list of mental functions are more

in line with factors characterized by executive functioning than by full-scale IQ. This is one reason why DSM-5 proposed that both executive functioning measures and standardized IQ testing are often more useful than full-scale IQ alone. It is especially important to include executive functioning testing in the assessment of mild ID (IDD).

One distinction between various definitions of intelligence discussed in the ID (IDD) literature has to do with intelligence as a “learning” versus a “thinking” process and ID (IDD), by extension, as a “learning disorder” versus a “thinking disorder.” Learning has to do with the acquisition of cognitive schemas while thinking has to do with the flexible and effective application of those schemas to solve novel problems. Many people think of ID (IDD) as a learning disorder (in fact, in the UK, the term mental retardation or mental handicap was replaced by the term “learning disability”), and it is certainly the case that people with an ID (IDD) diagnosis, as a rule, are slower to acquire concepts and to master academic or vocational skills. But for people in the so-called mild range (where over 80 % of people with IDD can be found), we now understand that, with persistence and skilled teaching, many roles and activities, formerly considered impossible for them, can be learned. However, limitations in thinking are much more difficult to overcome, because novel and complex situations, especially those involving risk, will arise for which existing schemas cannot be used successfully.

Application of Psychometric Testing to ID (IDD)

In our classification systems of ID (IDD), we maintain the standardized measurement of general intelligence as a diagnostic criterion despite their being many different patterns of intellectual impairment in neurodevelopmental syndromes and people diagnosed with them with conditions that impact subtest score measurement. The disability approach is at the center of the AAIDD’s advocacy for normalization in using a normative approach to adaptive behavior and focusing on

the use of supports separately from the IQ. The APA’s DSM approach to diagnosis seeks to understand the etiology of neurodevelopmental disorders and seeks to apply neuroscience to our understanding of intelligence and the brain.

Our understanding of the core features of human intelligence is ongoing. There is a long-standing debate regarding whether there is a distinct general intelligence or if it derives from overlapping component processes. An alternative approach to the *g* model is the three-stratum model, proposed by Raymond Cattell and John Horn and modified by John Carroll (Carroll, 1993; Deary, 2012). This model proposed that individual tests draw from several broad factors. This account of the psychometric structure of intelligence has resulted in a consensus that there is meaningful variance with three strata: general intelligence (“*g*”); a second grouping of broad domains that include fluid intelligence, crystallized intelligence, general memory, visual perception, auditory perception, retrieval, or cognitive speed; and the third stratum is based on specific abilities, such as induction, lexical knowledge, associative memory, spatial relations, general sound discrimination, or ideational fluency. The main contribution of the three-stratum model is the second stratum. Here there are two cognitive factors fluid intelligence and crystallized intelligence (*Gf* and *Gc*), short-term memory factors, and factors related to sensory modalities, visual and auditory. Hunt (2011, p. 106) noted that “the body of evidence favors the three-stratum theory over a simple intelligence model” but added that a revision of the *g* theory, the *gVPR* model, statistically also deals with the evidence very well. The heart of the *gVPR* model focuses on verbal (*V*) and perceptual (*P*) skill factors and a perceptual ability of mental rotation (*R*).

Consistent with the importance of these two models, when evaluating current psychometric theories, Hunt (2011 p. 109) concluded that “a theory of intelligence has to include something like general intelligence ‘*g*’. But *g* alone is not enough.” Because of the complexity of brain functioning in neurodevelopmental disorders, the full-scale IQ score alone is not sufficient, and

additional neuropsychological testing is needed to describe an individual neurocognitive profile. The three-stratum model and the *gVPR* model provide the needed models to justify conducting both standardized intelligence testing and focused neuropsychological testing for the comprehensive evaluation and testing for people with an ID (IDD) diagnoses.

Social Incompetence

If you ask family members or experienced caregivers to list the top three concerns for an individual who has an ID (IDD) diagnosis, the list would almost surely include the difficulties that he or she has in navigating the social world (Turnbull & Turnbull, 1985). This lack of social competence puts the person with ID (IDD) at risk for a range of problematic outcomes, including: social isolation or friendlessness, bullying or social ostracism, and financial or sexual exploitation. Similar concerns are also expressed by knowledgeable service providers who echo research findings suggesting that failure in integrated work or residential settings is most likely to stem from inability to read social cues or to understand unstated behavior rules and expectations (Borthwick-Duffy, Greenspan, & Ho, 2006). In spite of the experience of family members and knowledgeable service providers about the critical role that social incompetence plays in the failure experiences of individuals with IDD, the social domain is very sparingly addressed by ID (IDD) researchers and clinicians, who tend to see the disorder mainly in cognitive terms. In fact, social incompetence can be, and largely is, a cognitive problem, if one approaches it in terms of social reasoning and judgment. However, the general approach to social competence in the main adaptive functioning instruments is inadequate. There is an overemphasis on maladaptive behavior items into the “social” subscales of adaptive behavior instruments.

Although people with IDD diagnoses are universally socially incompetent, it is important to understand exactly what that means. IDD

syndromes, such as Williams syndrome, are associated with extreme friendliness. But friendliness does not equate with social competence, as reflected, for example, in high rates of sexual victimization of women with Williams syndrome (Frigerio et al., 2006). The social incompetence of people with IDD reflects a lack of social judgment, particularly in the recognition and understanding of social risk.

Recognition that social competence has a cognitive component was not appreciated when the first adaptive functioning measures were under development. Although it was correctly understood that social competence is an aspect of adaptive functioning, social competence was conceptualized mainly in terms of temperament (emotional reactivity) and character (aggression or its absence) and social judgment was not directly addressed. While maladaptive behavior is no longer explicitly part of the diagnosis of ID (IDD) (e.g., the Vineland Adaptive Behavior Scale has a maladaptive behavior section that is more of a supplemental scale), there are few items that tap social judgment (e.g., the Vineland has one gullibility item, while the ABAS has none), and social competence is generally given little emphasis (e.g., the social component of the ABAS has two skills: “social,” which mostly taps character and temperament, and “leisure,” which has many items (such as “plays nicely by himself”) that are not social).

An aspect of deficient social functioning that is increasingly recognized by ID (IDD) researchers and clinicians is social vulnerability, especially gullibility: a high likelihood of being duped by manipulators using coercive methods grounded in deception. In fact, the first textbooks about individuals with ID (IDD) in the nineteenth century emphasized their unusual “credulity,” but that insight was lost until recently. In thinking about gullibility, it is important to keep in mind two facts: (a) gullibility does not occur in every interaction (not all interactions are coercive) but it only takes one such instance (as when giving a false confession to a crime) to destroy a life, and (b) gullibility can be considered to be a social subtype of a broader construct of “risk unawareness,”

something that is frequently found in the social histories of all people with IDD even if instances of gullibility may be harder to find.

Risk Unawareness as a Core Feature

As currently constituted, both AAIDD's "green book" (Schalock et al., 2010) and DSM-5 (APA, 2013) require deficiency in only one out of three adaptive domains (in DSM-IV-TR, it was 2 out of 11 adaptive skills). Thus, there is no single adaptive domain for which deficiency is critical to the diagnosis of ID (IDD). The rationale (that is questionable) given by AAIDD for only requiring one area of deficiency is that the domains are correlated, so global deficit is assumed even if not established. While we agree that global deficiency should not be a requirement, a better reason is that requiring deficiencies in all three domains might have made qualifying for IDD extremely difficult. Furthermore, while there is consensus that ID (IDD) is characterized by low intelligence (broadly defined) and some areas of deficient adaptive functioning, there is no unanimity yet regarding a specific adaptive domain or skill that should be universally impaired.

Given that broadly constituted low intelligence is the hallmark of IDD, the best candidate for any universal adaptive deficit should contain a strong cognitive component. Thus, while being independent in maintaining good personal hygiene is more likely than not to be a problem for people with ID (IDD), it cannot be a universal adaptive indicator because some people with ID (IDD) do maintain good hygiene. Many people with other disorders have poor hygiene, and there are strong noncognitive (e.g., motivational) factors that explain failure to maintain adequate hygiene. Failing to understand the probability of social rejection and potentially physical illness as consequences of poor personal hygiene, on the other hand, comes closer to capturing the essence of the IDD behavioral phenotype. Thus adaptive functioning must be framed in terms of cognition and judgment rather than behavior per se consistent

with DSM-5 with emphasis on the central importance of "adaptive reasoning."

It has been suggested that one aspect of adaptive reasoning that is especially indicative of IDD is a failure to recognize and give sufficient weight to risk, both social (e.g., dealing with a person with hidden malevolent intent) or practical (e.g., operating a common machine which has the potential to grievously harm person or property) (Greenspan, 2009). In light of the community revolution in disability services and the related shift away from paternalism and toward emphasizing potential and positive attributes, discussion of risk or deficit is increasingly unacceptable. But, people with ID (IDD) are more in danger of failing in various roles without supports, and the purpose of providing supports is to reduce risks to manageable and safe levels (Greenspan, Switzky, & Woods, 2011; Greenspan & Woods, 2014).

IDD Provides a Window into Human Competence

Although relatively few mental health professionals specialize in or are adequately knowledgeable about ID (IDD), the field has been the source of important conceptual and methodological advances and insights, beginning with the study and understanding of brain functioning and human intelligence. Parents have many hopes for their children, but the most basic hope is that they grow up to become competent individuals, capable of adequately negotiating age-appropriate roles within the societies in which they live. A necessary, but not sufficient, basis for achieving adequate competence at any age is having a normally developed and fully functional cognition.

The field of ID (IDD) is basically the study and provision of services to children and adults with neurodevelopmental disorders whose brains (for any number of reasons) have failed to develop or function normally. Impaired brain functioning poses obstacles to one's ability to competently navigate the academic, vocational, and community living challenges that confront him or her as he or

she goes through life. The connection between brain impairment and cognitive or social functioning is complex and has been the source of considerable research as discussed in the next section.

The Neurobiological Nature of Intelligence

Genetics

General intelligence is a human trait that is believed to account for much of the variation in cognitive abilities. Data from twin and family studies are consistent with a high heritability of intelligence. In a genome-wide association study involving nonclinical populations, a substantial proportion of individual differences in human intelligence was due to genetic variation and was consistent with many genes of small effects underlying additive genetic influences on intelligence (Davies et al., 2011). In nonclinical populations, intelligence is genetically stable throughout the life course. This longitudinal stability of IQ in neurotypical people is well documented, as is its increasing heritability with age. Although increased heritability of general cognitive abilities during the transition from childhood to adolescence is robust in typical development, cognitive abilities may plateau in adolescence in some syndromes such as the fragile X syndrome (Dykens et al., 1989).

Current neuroscience research on intelligence is focused on genetics—quantitative and molecular—and brain imaging. Quantitative genetic studies find additive genetic contributions to various facets of cognitive ability, in particular to general intelligence. Genetic studies show change through the lifespan. Studies of genetic correlations with behavior (behavioral phenotypes) and neurocognitive profiles of neurogenetic syndromes are rapidly progressing.

Genetic and neuroimaging studies are essential next steps to understand brain functioning in persons with an ID (IDD) diagnosis. In this regard, a reevaluation of the Thomson–Spearman debate is pertinent (Hunt, 2011). Thompson challenged Spearman’s *g* by proposing that there are

a large number of biological units (bonds) present in brains. When an individual attempts to solve mental test items, each of the items sampled a number of these bonds. The extent to which tests overlapped in the bonds they sampled accounted for their correlation. In modern parlance, his “bonds” might be considered to be distributed neuronal networks. There is recent support for this model and current research has documented that both Thompson and Spearman’s models of intelligence can both account for the psychometric patterning of tests’ intercorrelations (Barbey, personal communication, August 9, 2015). A central question regarding these models is how neuroscience evidence from brain imaging on human intelligence may inform psychological theory. Does general intelligence reflect a unitary construct (Spearman) or a broader set of competencies (Thomson)? The three-stratum model of intelligence is a model that can be investigated in genetic and in neuroimaging studies. For example, Christoforou et al. (2014) reported that GWAS-based pathway analysis can differentiate between fluid and crystallized intelligence.

Neuroimaging

Structural and functional brain-imaging studies have found differences in brain pathways that contribute to intelligence differences (Deary, Penke, & Johnson, 2010). The best evidence is for parietofrontal pathways (Colom, Karama, Jung, & Haier, 2010; Jung & Haier, 2007). Brain efficiency correlates positively with intelligence. Brain-imaging research may examine intelligence as a unitary construct (Spearman) or as a broader set of broader set of competencies (Thomson). The analysis is complicated because a given brain region may support multiple cognitive functions. Conversely, a given cognitive function can be implemented with multiple brain regions. This complicates the use of neuroscience evaluation of local versus distributed representations to inform the nature of cognitive representations of intelligence.

Nevertheless, recent studies of an integrative architecture for general intelligence and execu-

tive function have been initiated with lesion mapping (Barbey et al., 2012). The authors confirmed that psychometric *g* and executive function for the most part do depend on shared neural substrates and on the communication between frontal and parietal cortex. However, the analysis revealed other areas that were related to psychometric *g* and may not be involved with executive function. General intelligence and executive functioning scores shared 76 % of the variance but 24 % of the variance was unique. Areas related to executive function but that may not be involved with psychometric *g* were identified within the left anterior frontal pole that is consistent with anterior prefrontal cortex regions involved in the executive control of behavior. Overall, psychometric *g* is associated with a distributed network of brain regions, sharing common anatomical substrates with verbal comprehension, working memory, perceptual organization, and processing speed, while executive function deficits were associated with a distributed network of left lateralized brain areas, including regions that are necessary for executive control processes.

Moreover second-stratum fluid intelligence and working memory have been studied by neuroimaging (Barbey, Colom, Paul, & Grafman, 2014b). This approach allows the examination of the functional networks that support adaptive behavior and novel problem solving. The authors conclude that the frontolateral parietal network that is central to human intelligence may be lateralized with mechanisms for general intelligence being linked to the left hemisphere and fluid intelligence to the right hemisphere. Barbey, Colom, and Grafman (2014) have studied a distributed neural system for emotional intelligence by lesion mapping. Latent scores for measures of general intelligence and personality predicted latent scores for emotional intelligence. These processes depend on a shared network of frontal, temporal, and parietal brain regions. The results support an integrative framework for understanding the architecture of executive, social, and emotional processes. This group used similar methods to study social problem solving (Barbey et al., 2014a)

and report that working memory, processing speed, and emotional intelligence predict individual differences in everyday problem solving. Tasks included friends, home management, and information management. Social problem solving, psychometric intelligence, and emotional intelligence were found to engage a shared network of frontal, temporal, and parietal regions, including white matter association tracts. The results supported an integrative framework for understanding social intelligence. Finally, adaptive reasoning requires cognitive flexibility. Barbey and colleagues (Barbey et al., 2013) investigated the neural underpinning of cognitive flexibility. They examined mental flexibility. Lesion mapping results further indicated that these convergent processes depend on a shared network of frontal, temporal, and parietal regions, including white matter association. Unique variance was explained by selective damage within the right superior temporal gyrus, a region known to support insight and the recognition of novel semantic relations. These findings contribute to the neural foundations of adaptive behavior. This series of neural lesion studies highlight the importance of the adaptive reasoning construct and the prospects for extending this approach to people with ID (IDD) diagnoses.

Neurodevelopmental Perspective

A developmental perspective focuses on how an individual engages other people and masters environmental challenges. For people with a disorder of intellectual development, there may be progressive thresholds for capacity in cognitive problem solving. A developmental approach may be used to unravel developmental dynamics by focusing on the development of mental processing. Demetriou, Christou, Spanoudis, and Platsidou (2002) combined information processing models, differential psychology, and neo-Piagetian developmental theory. They proposed a framework for study by focusing on the emergence and maturation of working memory, executive functioning, and cognitive efficacy in problem solving.

Co-occurring Neurodevelopmental Disorders

Autism Spectrum Disorder

Autism spectrum disorder (ASD) has long been viewed as highly associated with ID (IDD) and to show a characteristic IQ subtest profile. It is difficult to diagnose IDD in infants and young children because of the lack of development of language of representational (symbolic) capacities. However, diagnosis is appropriate when social communication and interaction are impaired relative to the developmental level of the individual's nonverbal skills (fine motor, nonverbal problem solving). Because of the association with ID (IDD) in DSM-5, the specifier "with or without accompanying intellectual impairment" is required for ASD. Thus, it is not essential to diagnose both ID (IDD) and ASD. Severity rating is complicated because severe social communication deficits in ASD may result in placement in a severity level that is not commensurate with cognitive functioning. Moreover, because of discrepancies in verbal and performance scores, the full-scale IQ is not reflective of overall functioning in people with ASD.

The previous consensus suggested that up to 75 % of those with a diagnosis of ASD had a co-occurring IDD diagnosis with severe impairments in adaptive behavior. Typically, the performance IQ (PIQ) was higher than verbal IQ (VIQ). This PIQ/VIQ discrepancy (nonverbal advantage) has been linked to increased head circumference and enlarged brain volume. On the Wechsler test, a characteristic subtest profile was noted with higher scores on block design and lower ones on comprehension.

With increased recognition of the breadth of autism spectrum, the prevalence of ID (IDD) is less than before. In one comprehensive epidemiological study of 75 children with ASD based on IQ test score, 55 % had $IQ < 70$ and were diagnosed mild (Charman et al., 2011). Fewer than 1 in 5 were diagnosed as moderate to severe IDD. Twenty-eight percent tested in the average range ($115 > IQ > 85$). Three percent were of above-average intelligence ($IQ > 115$). The group

mean for PIQ was higher than the VIQ. The frequency of $PIQ > VIQ$ was more common than $VIQ > PIQ$, but higher PIQ was not associated with greater social impairment. On WISC subtests, neither block design nor object assembly was a significant strength. The relationship with ASD and intellectual deficits is the subject of genetic analysis. In one study, common polygenic risk for autism spectrum disorder (ASD) was found to be associated with cognitive ability in the general population (Clarke et al., 2015).

In summary, cognitive function must be assessed in all children and adolescents diagnosed with ASD and is an important prognostic feature. Thus, DSM-5 requires coding using the specifier with or without intellectual deficits. Overall, adaptive functioning is lower than expected for IQ in persons with an ASD diagnosis; this is most apparent in the higher-functioning people. A higher IQ score in ASD does not necessarily predict functioning in the everyday world because of the underlying social deficit.

Fetal Alcohol Spectrum Disorder (FASD)

Fetal alcohol syndrome is the most prevalent preventable cause of ID (IDD). In Western countries, it is the leading preventable cause. Fetal alcohol spectrum disorder (FASD) may affect up to 5 % of all pregnancies. Since the early 1970s, alcohol has been recognized as a severe teratogen. When consumed during pregnancy, it may result in serious structural and functional damage to the developing child's brain, particularly to midline structures. Following the recognition of fetal alcohol syndrome (FAS), it became apparent that there is a spectrum of impairment that is referred to as fetal alcohol spectrum disorder. This spectrum includes partial fetal alcohol syndrome (PFAS) and alcohol-related neurodevelopmental disorder (ARND). Individuals with full-fledged FAS are dysmorphic with distinctive facial features such as small horizontal eye opening, flattening of the philtrum between the nose and upper lip, and a thin upper lip. Those diagnosed with PFAS have subtler and fewer

facial anomalies; those with ARND do not have visible facial anomalies.

All persons with diagnosable FASD have executive functioning deficits and adaptive functioning deficits. This is the result of the extension of midline morphological abnormalities to involve the midbrain especially the shape and volume of the corpus callosum. There is smaller volume in the basal ganglia and hippocampi (Donald et al., 2015). Executive function weaknesses are most consistent for measures of planning, fluency, and set shifting (Kingdon, Cardoso, & McGrath, 2015). Neuropsychological testing for these executive functional deficits may improve differential diagnosis and facilitate treatment of FASD.

Behaviorally there is increased risk of inattention, hyperactivity, and impulsivity. Moreover, there is increased prevalence of oppositional defiant/conduct disorder (ODD/CD). Of particular concern is the lack of social judgment and failure to learn from experience that result in behavioral and legal problems (Kodituwakku, 2009). Children with FASDs show reduced intellectual functioning. Their average IQ scores fall within borderline to below-average ranges. Thus, although they generally do not qualify for an ID (IDD) diagnosis and fail to meet the first criterion, their deficits in social judgment and failure to anticipate the consequences of their behavior frequently meet the adaptive behavior criteria of ID (IDD).

The cognitive and behavioral deficits in FASD led to consideration being given to include it in DSM-5 as a mental disorder. The decision was not to include it in the body of the classification but include it instead in the appendix of DSM-5 among "Conditions for Further Study." The DSM-5 term is *Neurobehavioral Disorder Associated With Prenatal Alcohol Exposure*. The proposed definition requires impaired neurocognitive functioning manifested by one of the following 4: an IQ of 70 or below; deficits in executive functioning; memory impairment; or visual-spatial reasoning deficits along with deficits in adaptive functioning. The proposed DSM-5 definition does not specifically deal with the IQ-equivalent issue nor sufficiently describe the deficits in social func-

tioning. Further study is clearly needed before considering including it in the DSM-5.

Still in Minnesota, FASD is an IQ-equivalent condition. Minnesota statute 252.27 (2012) notes several "related conditions," defined as: "a condition that is found to be closely related to a developmental disability, including but not limited to, cerebral palsy, epilepsy, autism, fetal alcohol spectrum disorder, and Prader-Willi syndrome." Minnesota is one of a very small list of jurisdictions where FASD is specifically included in an expanded disorder list. However, Minnesota's eligibility document then goes on to state that, even if one has a qualifying medical underlying disorder, the condition must still cause "substantial functional limitations," as established by deficits in three out of the seven adaptive life activities.

ID (IDD) and the Law

Developmental Disabilities and Disability Law

Before the enactment of the Education for All Handicapped Children Act in 1975, US public schools accommodated approximately only 1 out of 5 children with disabilities. This situation dramatically changed with passage of the Education for All Handicapped Children Act (EHA) and its evolution in over the years between the years 1970 and 1990.

The term developmental disabilities (DD) was introduced as an umbrella term for "mental retardation, epilepsy, cerebral palsy, and other neurological conditions originating before the age of 18" (Gettings, 2011). The term is now widely used in many state and provincial eligibility statutes. In 1975, early legislation was expanded as Public Law 94-142. DD was defined categorically to include mental retardation plus conditions closely related to mental retardation including cerebral palsy, epilepsy, autism, and dyslexia with onset before the age of 18. The term "other neurological conditions" was dropped. In the long term, dropping "other neurological conditions" may have contributed to IQ equivalence being limited

to people in only these named diagnostic categories. The intent of the IQ-equivalence functional formulation appears to have been an attempt to capture the adaptive limitation profiles of individuals who functioned as if they had ID (IDD) in spite of having IQs that fell above the 70–75 IQ ceiling. However, at least two of the skills (language and mobility) were not specific to ID (IDD) (likewise, one also could argue that self-direction was not specific to ID equivalence). The source of this list is not clear. A limitation in this list is that none of the items address deficits in social functioning, which many people (and virtually all family members) consider to be at the top of any list of reasons why people with ID need protections and supports.

In 1990, Congress reauthorized the original education legislation but changed the name to the Individuals with Disabilities Education Act (IDEA). The current IDEA Public Law is No. 94-142. It is composed of four parts and includes six main elements. The six elements include individualized education program (IEP), free and appropriate public education (FAPE), least restrictive environment (LRE), appropriate evaluation, parent and teacher participation, and procedural safeguards.

Forensic Issues and ID (IDD)

In 2002, the Supreme Court ruled in *Atkins v. Virginia* (536 U.S. 304) that executing people with an ID (IDD) diagnosis violates the Eighth Amendment's ban on cruel and unusual punishment leaving it up to the individual states to define the criteria for ID (IDD). The court cited that an increasing number of states banned execution of people with ID (IDD). State law helped convinced a majority of the court that a national prohibition was justified under the principle of "evolving standards of decency."

Following *Atkins v. Virginia*, a possible diagnosis of IDD is often raised in a capital criminal proceeding regard to eligibility for the death penalty as a mitigating condition (Greenspan &

Switzky, 2006b). In such proceedings, the court—typically a judge, but occasionally a jury—decides taking into account expert testimony. There is a tendency for judge and/or jury to rely on their stereotypes of ID (IDD) drawn from the media or from experience with an affected family member or an acquaintance. Implicitly, the stereotype is that of severe impairment than that found in the great majority of people (or criminal defendants) with ID (IDD) who engage in such crimes. Psychiatrists, but much more commonly psychologists, testify about ID (IDD) in such criminal proceedings. They too may lack expertise in ID (IDD), particularly in community (noninstitutional) settings.

The main effect of stereotyping in forensically diagnosing ID (IDD) is termed as "cherry-picking," that is, isolated alleged accomplishments by the defendant (e.g., driving a car, holding a job, robbing a store, having a romantic relationship) are pointed out as proof that the person could not have ID (IDD) if they could carry out these tasks despite evidence that such "accomplishments" frequently turned out to involve significant failure (e.g., a roofer who kept falling off the roof; a robber who kept getting apprehended). However, official diagnostic manuals state that (a) the diagnosis does not require global impairment and (b) evidence of significant adaptive deficits need only be found in one domain. An example of stereotyping ID (IDD) occurred in an official court doctrine in Texas, *ex parte Briseno*, when the highest state court promulgated the so-called *Briseno* doctrine. The *Briseno* doctrine actually gave as an example of ID (IDD) a fictional character, Lennie, in the Steinbeck novel *Of Mice and Men*, of the kind of severely and obviously impaired person for whom judicial relief should be limited.

A number of other problems may arise in judicial determinations of ID (IDD), but the biggest problem is undoubtedly the tendency to rely rigidly and sometimes exclusively on the full-scale IQ test score numbers. Court proceedings illustrate some of the pitfalls of a strictly "disability"

(just the numbers) approach to the definition and diagnosis of ID (IDD).

The explanatory text of DSM-5 in the section on associated features supporting the diagnosis describes features that may be of importance in Atkins Hearings (DSM-5, p. 38). These include associated difficulties in “social judgment; assessment of risk; self-management of behavior, emotions and interpersonal relationships; or motivation in school or work environments. Lack of communication skills may predispose to disruptive and aggressive behavior.” Moreover it states that “gullibility and lack of awareness of risk may result in exploitation by others and possible victimization, fraud, unintentional criminal involvement, false confessions...” (APA Author, 2013).

Atkins v. Virginia and Hall v. Florida

Although the Supreme Court cites the DSM and AAIDD manuals as authoritative and refers to the three-prong model contained in those models, in *Atkins v. Florida*, it declined to provide operational guidance for the diagnosis of ID (IDD) and left it up to various state legislatures or high courts to do so. This has resulted in tremendous variability in state law that eventually forced the Supreme Court to clarify one issue that of a bright line IQ cutoff in some states. In its 2014 *Hall v. Florida* decision, the use of a rigid “bright line” (IQ of 70) ceiling score, without consideration of the standard error of measurement, was adjudicated. In this case, the US Supreme Court narrowed the discretion under which US states can designate an individual convicted of murder as too intellectually incapacitated to be executed by stating in its majority opinion that ID (IDD) is “a condition not a number” and rejected Florida’s use of a bright line IQ of 70 (*Hall v. Florida*. Majority opinion. 572 U.S. 2014, p. 21). Even though the death penalty may be seen as relatively peripheral to the broader field of ID (IDD), its use in legal proceedings has brought to the forefront heightened concern about limitations in existing definitions and diagnostic methods. The definition of ID (IDD) involves great stakes for an individual that have come about from these highly adversarial and contentious court cases.

Conclusion

This chapter reviewed the evolution of two approaches to classification that seek to improve the lives of people with deficits in intellectual functioning. Both emphasize a developmental perspective. The first of these focuses on the provision of services and may be traced back to the Itard’s efforts to habilitate Victor of Aveyron by testing a then current proposal that the mind at birth is a blank slate and all knowledge is gained through the senses. His partial success initiated a special education movement that began in Europe and spread to America that emphasized early intervention and has been increasingly refined over the years. Its focus is on normalization and most recently self-determination. The American Association on Intellectual and Developmental Disabilities adopted this approach in its classification system. It emphasizes the standardized measurement of intelligence but focuses on the provision of supports to help each person reach their potential. This approach is based on the disability model that emphasizes the importance of facilitating the optimal functioning of each person to the extent possible. It is an approach that advocates for the human rights of people with disability in education, community settings, and the law.

The other approach focuses on the etiology of the intellectual deficits and on their underlying neurobiology and biomedical treatment. It recognizes that the mind is not a blank slate at birth and that each individual has a distinct inherited neurobiology that interacts with environmental forces in development. Intellectual deficits are largely the result of atypical brain development whose causes must be ascertained. These deficits are assessed psychometrically by standardized measures of both general intelligence and specific neuropsychological measures, especially executive functioning. Both types of testing are needed because, although we maintain the standardized measurement of general intelligence as a diagnostic criterion in DSM-5, there are many different patterns of intellectual impairment in neurodevelopmental syndromes that impact

subtest score measurement and adaptive reasoning. The DSM-5 approach to diagnosis seeks to classify neurodevelopmental disorders and encourage finding their etiologies. Research in the basic neurosciences, genetics, and neuroimaging is providing new insights into our understanding of the underlying neurobiologies.

This chapter emphasized that the full-scale IQ is an inadequate basis for establishing an ID (IDD) diagnosis, especially when taking into account the new first criteria in DSM-5 based on the mainstream definition of intelligence. Both individualized standardized and culturally appropriate IQ testing and focused neuropsychological testing, especially for executive functioning, are needed. Moreover, it is not uncommon for people with brain dysfunction and/or neurodevelopmental disorders like FASD to have IQ scores over 75 but have severe deficits in adaptive functioning and reasoning in social judgment, social understanding, and other areas of adaptive functioning so that the person's actual functioning in the real world is comparable to that of individuals with a lower IQ score. This has led to the establishment of ID (IDD) equivalence pathways to developmental services for children and adults who are viewed as deserving services but do not receive them because their IQ score exceeds the standard cutoffs.

In closing, achievement of functional competence in age-relevant roles is a developmental goal for all human beings, including those who, because of brain-based limitations, need special supports in pursuing that achievement. The field of ID (IDD) thus contributes importantly to understanding various forms of human competence, the role of the brain in facilitating or impeding competence, and the kinds of interventions that may contribute positively to that process.

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