

HISTORY OF INTELLECTUAL DISABILITY

This introductory chapter provides a brief but significant discussion concerning how intellectual disability (ID) has been defined and conceptualized historically by the different classification systems: *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, American Association on Mental Retardation/American Association on Intellectual and Developmental Disabilities (AAMR/AAIDD), and Individuals with Disabilities Education Act (IDEA). This background information lays the foundation for a more complete understanding of issues associated with the diagnosis of intellectual disability and the evolution that has occurred in the ways the disorder is conceptualized today. This chapter will discuss the shift in conceptualization from variations in the degree to which the disorder is manifested (*DSM*: mild, moderate, severe, profound) to variations in the intensity of services needed (AAIDD: intermittent, limited, extensive, pervasive). The 2010 *AAIDD Operational Definition of Intellectual Disability* is addressed.

EARLY BEGINNINGS

Historically, distinctions between “idiots” and the “insane” began to emerge out of necessity, at the end of the Middle Ages, as laws were being developed. Within this context, idiots were thought to be less responsible for crimes committed resulting from their lack understanding due to their state of ignorance. On the other hand, those who were insane had the ability to understand and plan but committed crimes based on their lack of adherence to moral standards, which was considered an offence that was punishable by law (Wickman, 2013). However, the first reported documentation of the distinction between mental capacity and mental illness came in 1838, when the scientist Jean Esquirol

(1772–1810) published his manuscript on mental health. In his book, Esquirol devoted a large section to the topic of idiocy and stated that there was a distinction between an “idiot”, who is never able to develop his or her mental capacity, and a “mentally deranged” person, who developed normal intellectual ability but then had lost it (Sattler, 2001, p. 129). Later it was recognized that Esquirol’s description of the characteristics of those with idiocy closely matched features of what we currently know as Down syndrome (Roubertouz & Kerdelhue, 2006).

The system of care and support for individuals with intellectual disabilities had its roots in the beginning of the 19th century with Jean Itard’s attempts to educate Victor (the wild boy of Aveyron), a boy in his early teens who had been living on his own in the forest. Although Itard eventually abandoned his efforts due to slow progress and minimal gains, he did open the door for future efforts in the intervention and training of skills in individuals with intellectual disabilities. By the mid-1800s, advocates such as Cheyne Brady, a London lawyer, published a volume titled *What Can Be Done for the Idiot*, in which he wrote that although idiocy is “unquestionably one of the most fearful of the host of maladies,” modern science shows the promise that “there is no class of unfortunates of our species to whom enlightened treatment may be applied with a more cheering hope of success” (Brady, as cited in Ferguson, Ferguson, & Wehmeyer, 2013, p. 87).

In 1840, medical student and educationalist Edouard Seguin, who worked with Victor under Itard’s direction, established the first private school in Paris dedicated to the education of individuals with intellectual disabilities. In 1846, he published *Traitement Moral, Hygiène, et Education des Idiots* (The Moral Treatment, Hygiene, and Education of Idiots and Other Backward Children). Seguin created a program, called the *Physiological Method*, which was a sensory-based training program (dealing with vision, hearing, taste, smell, touch) developed to enhance the senses and potentially open the channels to increased cognitive functioning (Sheerenberger, 1983). He later expanded the program to include memory, imitation, reinforcement, and vocational training. Seguin relocated to the United States in 1850, where he continued to revolutionize education for individuals with intellectual disabilities. In 1876, he became the founding father of the American Association on Mental Retardation (AAMR). The next section outlines the history of intellectual disabilities, previously known as mental retardation (MR). Some of the key milestones in the historical progression are highlighted in **Rapid Reference 1.1**.

≡≡≡ *Rapid Reference 1.1 A Historical Look at Intellectual Disabilities*

- 1838 Jean Esquirol publishes a manuscript which contains a large section devoted to determining the difference between idiocy and mentally deranged persons.
- 1876 Seguin becomes the founding father of AAMR.
- 1905 The Binet Simon, published in France, becomes the first instrument to assess intelligence.
- 1910 AAMR publishes the first system of classification for MR. Henry Goddard, director of research at the Vineland Training School, publishes an American version of the Binet Simon.
- 1916 Terman renames the Binet-Simon the Stanford Binet and revises how intelligence is derived using the intelligence quotient (IQ).
- 1935 Edgar Doll publishes the Vineland Social Maturity Scale.
- 1952 *DSM-I* (American Psychiatric Association [APA]) introduces the classification category of *mental deficiency* for cases primarily presenting as a defect in intelligence. The category contains three levels of severity: mild, moderate, and severe.
- 1959 AAMR announces three criteria for establishing MR: low IQ (less than 85), impaired adaptive behavior, and onset before age 16. Five levels of severity are suggested: borderline, mild, moderate, severe, and profound.
- 1968 *DSM-II* (APA) changes the name from “mental deficiency” to “mental retardation” and adopts the five levels of severity suggested by the AAMR. Criteria are low IQ (less than 85), impaired adaptive skills, and onset during the developmental period.
- 1971 In *Wyatt v. Stickney*, a landmark class action suit in Alabama, Judge Johnson rules that individuals confined to residential centers have a right to treatment.
- 1975 Public Law 94-142: Rights of all children with disabilities to have a free and appropriate education. The law, The Education of all Handicapped Children Act (EHA), provides state grants for the provision of services for children with disabilities.
- 1979 As a result of the class action lawsuit *Larry P. v. Riles*, all California school districts were barred from using IQ tests as the sole means of determining placement of African American children in classes for the educable mentally retarded.
- 1980 *DSM-III* (APA) reduced “subnormal” intelligence from an IQ of 85 (1 standard deviation [SD] below the mean) to an IQ of 70 (2 SDs below the mean).

- 1990 EHA is revised and renamed the Individuals with Disabilities Education Act (IDEA).
- 1992 AAMR releases the revision of its manual replacing levels of severity of MR with patterns and intensity of supports needed: intermittent, limited, extensive, and pervasive.
- 1994 *DSM-IV* (APA) retains the four levels of severity—mild, moderate, severe, profound—which are no longer comparable to AAMR criteria; however, it makes comparisons to the education system (e.g., “mild” is equivalent to “educable”; “moderate” is equivalent to “trainable”).
- 1997 IDEA is reauthorized.
- 2004 IDEA reauthorized and renamed the Individuals with Disabilities Education Improvement Act of 2004.
- 2007 AAMR changes its name to the American Association on Individuals with Intellectual and Developmental Disabilities (AAIDD).
- 2010 President Obama signs “Rosa’s Law” on October 5.
- 2010 AAIDD publishes the most recent version, the 11th edition of AAIDD’s *Intellectual Disability: Definition, Classification, and Systems of Support* (AAIDD, 2010).
- 2013 *DSM-5* (APA) publishes the most recent criteria for intellectual disability in the section on Neurodevelopmental Disorders.

THE TURN OF THE CENTURY: 1900 TO 1950

In the United States, Samuel Gridley Howe, who had worked with children who were blind and deaf-blind, began to look for ways to bring this sense of optimism from Europe to the Western world and emphasized the importance of identifying levels of idiocy. He suggested that the levels ranged from pure idiocy (the most severe form) to fools and simpletons, whom he felt had the best chances for improvement, based on education and training (Ferguson et al., 2013). In the wake of the Industrial Revolution and the influx of many street children into the schools, the French government commissioned Alfred Binet (1857–1911), a lawyer and scientist, and Theodore Simon (1873–1961) to develop a method of screening which children might be identified as “mentally retarded” in order to better assist these children with special education interventions at school. The measurement, the Binet-Simon Scales (1905), became the first instrument of its kind to identify the degree of MR based on an individual’s response to a series of age-based questions (Sattler, 2001). However, by the beginning of the 20th century, optimism was replaced by a growing pessimism that, unlike insanity, idiocy or feeble-mindedness was not a disease but a defect that could not be cured. With

this attitude came the transformation of institutions of training into warehouses of custodial care (Ferguson et al., 2013).

Henry Goddard (1866–1957), who was the director of training at the Vineland Training School in New Jersey, published an English version of the Binet-Simon scale in 1910. However, his use of the instrument was based on his firm belief that intelligence was an inherited disposition which was not curable, and his sole purpose for giving the test was to identify those who were “feeble-minded” (Nietzel, Bernstein, & Milich, 1994). The rise of institutions also foreshadowed the demise of the family unit for many children, who were taken from families and placed in institutions/asylums under the guise of the “child’s best interest,” thus placing blame for their “defect” on the family environment, which was often impoverished. In a transition to a less humane and pessimistic outlook, “the goal was to remediate if possible, but to incarcerate in any case. Custody had replaced cure; therapy had become control” (Ferguson et al., 2013, p. 112).

DON'T FORGET

Goddard spent considerable time researching the history of families with “feeble-minded” offspring. One of the most famous studies was his research on the Kallikak family that traced two sets of children born to Martin Kallikak from his liaison with a feeble-minded tavern girl and later a Quaker woman from a good family. While all offspring from the tavern girl were plagued with feeble-mindedness and other sordid outcomes (epilepsy, lechery, alcoholism), all offspring from the Quaker woman were successful members of society. While some professors were impressed by Goddard’s studies, there was a mixed reaction from the scientific community (Zenderland, 2004). However, the studies’ influence on the eugenicist movement, which brought compulsory sterilization laws in 30 states, cannot be underrated.

At this time in the United States, terms like “feeble-mindedness” and “mental deficiency” were commonly used to refer to those who had MR. However, in 1910, the American Association on Mental Retardation (AAMR) developed what would become the first system of classification for MR. AAMR announced that arrested development, which resulted in feeble-mindedness, should be identified based on the individual’s level of functioning; the term “idiot” was reserved for those who had a developmental level equivalent to 2 years of age; “imbecile” was reserved for those who functioned between 2 and 7 years of age; and “moron” was used for those with a mental age equivalent between 7 and 12 years of age (Biasini, Grupe, Juffman, & Bray, 1999).

With an increased need to better identify levels of MR, Terman revised the Binet scales, renaming them the Stanford-Binet (1916), and incorporated the idea of relating mental age to chronological age, or what he termed the “intelligence quotient (IQ),” which represented the ratio of the child’s mental age to his or her chronological age. Through the use of the IQ score, it would now be possible to compare two children of the same age who were functioning at very different levels. After many revisions, the ratio IQ was replaced by a more sophisticated method of calculation based on the deviation IQ.

DON'T FORGET

Terman's original formula for obtaining the IQ score was to divide mental age by chronological age and multiply by 100. Using the original formula, we can compare Sally, Suzy, and Sarah, each of whom is 8 years old. On an IQ test, Sally has a mental age of 10, Suzy has a mental age of 8, and Sarah has a mental age of 6. Based on Terman's formula, Sally would have an IQ of $(10 / 8 \times 100)$ 125; Suzy would have an IQ of $(8 / 8 \times 100)$ 100; and Sarah would have an IQ of $(6 / 8 \times 100)$ 75. In this case, Sally, who is 8 years old and functioning at her age level, has an IQ of 100, which is the average IQ score.

THE AGE OF ASSESSMENT: LATE 1950S TO 1970

In 1950, over 124,000 individuals lived in state institutions for the mentally retarded. By 1967, the number had escalated to over 194,000 individuals (Wehmeyer & Schalock, 2013). Overcrowding and poor resources eventually led to discontent with large institutions, and communities began to provide more local services. The growing trend toward deinstitutionalization came at a time when there was increasing visibility of disabilities in the numbers of disabled war veterans returning to the United States at the end of World War II.

In 1950, representatives from 23 parent groups formed the National Association of Parents and Friends of Mentally Retarded Children in Minneapolis, Minnesota (currently called The Arc of the United States), and by 1975 the organization had 214,000 members (Wehmeyer & Schalock, 2013). Although initially focused on reducing the stigma associated with intellectual disabilities and raising awareness that children with mental disabilities were innocent and deserving of love, as the children grew into adulthood, advocates fought for the rights of these individuals as citizens, and the name of the association changed in 1975 to the National Association for Retarded Citizens to reflect this trend.

By the end of the 1950s, the AAMR announced full support for expanding the criteria for the identification of individuals with MR beyond the sole criterion of the IQ score to include:

- an IQ score of less than 85;
- impairment in adaptive behavior; and
- onset prior to 18 years of age.

Although the Vineland Social Maturity Scale had been available for some time, at this time estimates of adaptive behavior were made based on subjective reports.

DON'T FORGET

When the AAMR announced the three criteria, it also advanced the identification process by naming five different levels of MR:

1. Borderline (IQ 67–83)
2. Mild Retardation (IQ 50–66)
3. Moderate Retardation (IQ 33–49)
4. Severe Retardation (IQ 16–32)
5. Profound Retardation (IQ < 16) (Heber, 1961)

These five levels of severity were introduced into the *DSM-II* (APA, 1968).

By the mid-1960s, increasing numbers of children were being tested and placed in residential centers as attitudes shifted from prevention and treatment to identification and placement. At that time, a university professor, Burton Blatt, and his friend and photographer Fred Kaplan published a photographic essay titled *Christmas in Purgatory: A Photographic Essay of Mental Retardation* (Blatt & Kaplan, 1966). The volume described state institutions as “human warehouses” filled with children and adults who were mentally retarded. Mental health issues were placed on the back burners since the prevailing mind-set was that children were miniature adults and that they were either too young to experience mental disorders, or, if they did, then these disorders would be experienced in the same way as adults.

During the 20-year span from 1950 to 1970, advocacy groups lobbied for the rights of individuals with MR, culminating in such Federal court class-action lawsuits as the *Wyatt-Stickney* federal court case in Alabama in the 1970s, which established the right to treatment for individuals living in residential facilities and made purely custodial care unacceptable (Biasini et al., 1999). In addition, the growing opposition and concern of the overrepresentation of minority children

in special education led to changes in the criteria for MR, lowering the IQ to 70 from 85 (Grossman, 1973). It was during this time period that the famous case of *Larry P. v. Riles* surfaced in the California courts, resulting in an injunction preventing the San Francisco school district from using IQ scores to place black children in special education classes for the educable mentally retarded. The result was that the school district was no longer allowed to justify placement in special education classes based on IQ score alone.

DON'T FORGET

The IQ test is based on the standard distribution with an average IQ of 100 and an *SD* of 15. Approximately 68% of the population will score within 1 *SD* of the mean (e.g., IQ 85–115). The drop in IQ score from 85 to 70 meant a shift that would require an individual to score 2 *SDs* below the mean on an IQ test to be within the MR Range. Approximately 2% of the population would obtain an IQ of 70 or less.

Increased pressure to acknowledge the rights of children with disabilities to have a free and appropriate education resulted in the passing of Public Law (P.L.) 94-142 in 1975, which supported the AAMR initiatives to include adaptive measures as part of the process of identifying children with MR in the educational system. The law, titled the Education of All Handicapped Children Act (EHA), was instrumental in legislating grants to fund educational programs for children with disabilities. The law has seen several revisions and was renamed the Individuals with Disabilities Education Act (IDEA) in 1990 and was most recently reauthorized and renamed the Individuals with Disabilities Education Improvement Act of 2004 (IDEA, 2005) (Wilmshurst & Brue, 2010).

1980S TO THE PRESENT

Although the current status of intellectual disability will be discussed in depth in Chapter 3, this section will provide a brief update as to the shift in thinking that has led to changes in the way that intellectual disability is currently conceptualized. This shift is best understood by addressing the definitions and criteria within the context of three different classification systems: *DSM*, AAMR/AAIDD, and IDEA.

Diagnostic and Statistical Manual of Mental Disorders (DSM)

When the *DSM* was first released in 1952, the classification category of *mental deficiency* was introduced to account for “those cases presenting primarily a defect of intelligence existing since birth, without demonstrated organic brain disease or known prenatal cause.” Cases were to include only individuals with familial or idiopathic (unknown origin) mental deficiencies, and severity was to be determined by IQ scores in the following three ranges: *mild* (an IQ of approximately 70–85); *moderate* (IQ 50–70); *severe* (IQs below 50). Although IQ scores were necessary to determine the range and expectations, the *DSM* noted the importance of considering other factors and emphasized that “The degree of defect is estimated from other factors than merely psychological test scores, namely, consideration of cultural, physical and emotional determinants, as well as school, vocational and social effectiveness” (APA, 1952, pp. 23–24). Alternatively, an individual could be diagnosed with chronic brain syndrome with mental deficiency, in cases where “This categorization relegates the defect of intelligence to the sphere of symptomatology, rather than recognizing it as a primary mental disturbance” (APA, 1952, p. 10). However, in this first attempt to define the disorder, the *DSM* made it clear that the terms used were not completely satisfactory:

An unsuccessful attempt was made to find a substitute for the long used term “mental deficiency.” Mental deficiency is a legal term, comparable to the term “insanity,” it has little meaning in clinical psychiatry. The term has been defined by law in England, and in some parts of the United States. The same objection is raised to the terms “idiot,” “imbecile,” and “moron.” They have the further fault of being based upon psychological testing alone. In the borderline areas of each term, groupings vary with the immediate condition of the patient, as well as with the skill and training of the examiner. These last named terms have been eliminated.

(APA, 1952, p. 10).

In the next revision of the *DSM* (APA, 1968), the term “mental retardation” replaced “mentally deficient.” At this time, the *DSM-II* better aligned with the AAMR and also supported five ranges of severity—borderline, mild, moderate, severe, and profound—with the borderline range for IQ scores in the 68 to 85 range. There was an additional category, called “Unspecified MR,” which was defined as “subnormal general intellectual functioning which originates during the developmental period and is associated with impairment of either learning and social adjustment or maturation, or both” (APA, 1968, p. 14).

The *DSM* spent considerable effort listing clinical codes for 9 subcategories for the disorder, based on the circumstances of origin (e.g., following infection and intoxication; following trauma or physical agent, etc.). The *DSM-III* (APA, 1980) introduced a new chapter to the manual specific to “Disorders Usually First Evident in Infancy, Childhood, or Adolescence” and MR was placed in this section. The three main criteria for a diagnosis of MR remained consistent with the previous version (e.g., impaired IQ, impaired adaptive behaviors, and onset during the developmental period); however, these criteria were further refined at this time. Subnormal intelligence was now set 2 *SDs* below the mean (IQ of 70) instead of 1 *SD* (IQ of 85), with the addition of a five-point interval to be considered (IQ 65–75) to account for the standard error of measure. Onset during the developmental period was defined as occurring before 18 years of age. Impairments in adaptive functioning were required; however, the *DSM* noted that current measures were not considered valid to be used in isolation to make this decision and recommended that clinical judgment should evaluate adaptive functioning in individuals relative to similar-aged peers.

In the fourth revision of the classification manual, the *DSM-IV* (APA, 1994), MR was retained in the section on “Disorders Usually First Diagnosed in Childhood or Adolescence.” The decision was made to code MR on Axis II of the Five Axis System, along with the personality disorders, to avoid not giving the disorder enough recognition, if the focus was on another primary disorder occurring on Axis I.

DON'T FORGET

The text revision of the *DSM-IV* (*DSM-IV-TR*; APA, 2000) specified four different ranges of severity for MR based on the IQ score:

Mild MR: IQ 50–55 to approximately 70

Moderate MR: IQ 35–40 to 50–55

Severe MR: IQ 20–25 to 35–40

Profound MR: IQ below 20–25

The four ranges of severity represented a change from the five ranges of the *DSM-II* (APA, 1968) and retained the change to four ranges proposed in the *DSM-III* (APA, 1980).

The three core criteria were retained from the previous revision; however, the criteria of adaptive functioning was further defined as requiring deficits in

2 of 10 possible areas—functional academic skills, social/interpersonal skills, communication skills, self-care, home living, use of community resources, self-direction, work, leisure and health/safety—as determined by an individual’s score on an adaptive measure that was two standard deviations below the norm. These criteria remained consistent in the subsequent text revision of the *DSM*, *DSM-IV-TR* (APA, 2000).

There have been many changes in the way that disorders have been conceptualized in the most recent revision of the *DSM*: *DSM-5* (APA, 2013). In an attempt to move away from a purely categorical classification system and to incorporate more of a dimensional approach to regarding disorders along a continuum, the *DSM* has organized the manual based on a developmental framework. The section on “Disorders Usually First Diagnosed in Childhood or Adolescence” has been removed and in its place a new section, on “Neurodevelopmental Disorders,” has been added.

The term “mental retardation” (MR) has been replaced by “intellectual disabilities (ID),” also known as “intellectual developmental disorders (IDD),” which include categories for global developmental delay (for children under 5 years of age who demonstrate delays and have not yet been assessed) and unspecified intellectual disability (for cases over 5 years of age where assessment cannot be conducted due to other factors, such as severe behavior problems or sensory/motor impairments). The *DSM-5* (APA 2013) continues to use specifiers to identify the severity of the disorder; however, unlike previous versions of the *DSM*, the severity no longer is based on IQ scores but now refers to levels of adaptive functioning in the conceptual, social, and pragmatic domains. The current *DSM* criteria are discussed in depth in Chapter 3.

AAMR/AAIDD

Throughout the course of history, the AAMR has been a vital force in shaping how MR has been conceptualized. In 1992, the organization made a controversial decision to shift the emphasis from focusing on the severity of the disorder—mild, moderate, severe, and profound—to focusing on the intensity of services that are required to provide the necessary supports: intermittent, limited, extensive, or pervasive. As a result, the definition for MR took on a more applied focus, and the defining feature of “substantial limitations in present functioning” was described as including “significant subaverage functioning, existing concurrently with limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self direction, health and safety functional academics, leisure and work” (Luckasson et al.,

2002). This definition also stated that onset of MR had to be prior to 18 years of age; this was an increase of 2 years from the previous definition, which had onset prior to 16 years of age.

The definition for MR continued to evolve. In 2002, the AAMR released the 10th revision of *MR: Definition, Classification and Systems of Support* (Luckasson et al., 2002). This revision built on changes made in the 10 years earlier but also made a strong statement that caused further separation from how MR was conceptualized in the *DSM-IV-TR*. The AAMR emphasized that even though MR was contained in the *DSM*, it should not be considered a mental disorder; instead, it should be conceptualized as “a state of functioning” beginning in childhood that is characterized by limitations in intellectual and adaptive skills. Within this framework, the focus was shifting toward greater recognition of the individual strengths and weaknesses and the ecological influences that can help shape interventions in the conceptual, social, and practical adaptive areas of development.

In keeping with its focus on advocating for the rights of those with MR, in 2007 the AAMR made a landmark decision to change the name of the disorder from “mental retardation” to “intellectual and developmental disability” (IDD). It then followed suit by changing the name of the organization to the American Association on Intellectual and Developmental Disabilities (AAIDD; Schalock et al., 2007). In October 2010, President Barack Obama signed “Rosa’s Law” (P.L. 111-156), which authorized the use of the term “intellectual disability” to replace the term “mental retardation” in all federal, health, and labor laws.

DON'T FORGET

The most recent definition for intellectual disability is a concise definition that emphasizes the three diagnostic criteria:

1. Significant limitations of intellectual functioning
2. Significant limitations in adaptive behavior
3. Onset during the developmental period

The most recent revision of the definition can be found in the 11th edition of AAIDD’s *Intellectual Disability: Definition, Classification and Systems of Supports* (AAIDD, 2010). Main ideas found in this revision are summarized in the “Don’t Forget” box and will be discussed, at length, in Chapter 3.

AAIDD continues to emphasize a supports-based definition for intellectual disability, which is a condition characterized by significant

limitations in intellectual functioning and adaptive behavior. The problems must have originated during one’s developmental period.

This definition is based on five assumptions, the last two of which emphasize supports:

1. Limitations in present functioning must be considered within the context of the individual's community with regard to age/peers/culture.
2. Assessment must recognize the importance of cultural and linguistic diversity as well as limitations in communication, sensory, motor, and behavior.
3. Within an individual, limitations often coexist with strengths.
4. The purpose of describing limitations is to develop a profile to assist with the planning of needed supports.
5. Appropriate personalized supports over time will generally lead to improved quality of life for the individual. (AAIDD, 2010, p. 7)

Although historically, classification was based on IQ scores, Schalock et al. (2012) emphasized that the nature of contemporary questions, such as queries concerning issues of competency, place IQ on the "wayside," and draw increased attention to multidimensional aspects of classification, including intellect, adaptation, health, participation, and context. The concept of intellectual disability proposed in the AAIDD's 2010 manual is discussed in greater depth in Chapter 3.

Education System and Special Education Law

In 1975, the Education for All Handicapped Children Act (EHA) came into effect with the passing of P.L. 94-142, which provided federally funded programs and services for children with disabilities from 3 to 21 years of age. Although the *DSM* and AAMR were working toward aligning their definitions for MR, the educational system based its classification on children's predicted ability to learn (Kirk, Karnes, & Kirk, 1955). Children were considered *educable* if they could learn simple academic skills that did not progress above a fourth-grade level. Children were considered *trainable* if they could learn simple self-care skills but could learn very few academic skills. Children were considered *untrainable* if they were totally dependent on others or required custodial care, such as a residential setting.

In 1990, EHA was renamed the Individuals with Disabilities Education Act (IDEA). In 2004, when the act was reauthorized, it was renamed the Individuals with Disabilities Education Improvement Act, and was passed into law in 2005. The US Department of Education (DOE) is responsible for insuring that public schools comply with educational rights and laws (IDEA, 2004) and laws related to civil liberties (Americans with Disabilities Act Amendments Act of 2008 and

Section 504 of the Rehabilitation Act of 1973). IDEA 2004 is responsible for special education (individualized education programs [IEPs]) and related services (e.g., speech and language therapy, physical and occupational therapy, counseling) for children who meet criteria for one of the 13 categories of exceptionalities. Mental retardation is one of the 13 categories of exceptionalities listed under IDEA. However, with the passing of Rosa's Law in 2010, the term "intellectual disability," initially adopted by AAIDD (AAIDD, 2010), is growing throughout federal law. Rosa's Law "replaced the terms mental retardation and mentally retarded with intellectual disability and intellectually disabled in federal health, education, and labor statutes. These statutes include such critical laws as the Public Health Service Act, the Individuals with Disabilities Education Act (IDEA), and the Rehabilitation Act (Ford, Acosta, & Sutcliffe, 2013, p. 109). Since the vast majority of individuals with intellectual disabilities fall within the mild range (scores ranging from 50 to 70), it is most likely that these individuals will be serviced by schools in the local community and meet criteria for special education and related services under IDEA. As a result, the most recent reauthorization of the law has incorporated efforts to enhance the identification and intervention procedures. The law has four main parts: Parts A and B focus on the eligibility criteria of children 3 to 21 years of age; Part C targets services for infants and toddlers with disabilities under 3 years of age; and Part D addresses national activities that have been developed to enhance education services for children with disabilities. How these sections apply specifically to children with an intellectual disability and developmental delays is discussed in greater detail in Chapter 3.

SUMMARY

It becomes increasingly evident that our understanding of intellectual disabilities has evolved historically through the work of advocates and families who have fought for the rights of individuals with intellectual abilities and who have fought against the stigma that was initially attached to this disorder. With the advent of the intelligence test in the early 1900s, educators and psychologists were able to identify which children had intellectual disabilities and, hopefully, remediate and enhance skills by placement in residential training programs. However, there was disillusionment with the lack of success of these programs that often provided only custodial care. Through movements such as the National Association of Retarded Citizens (ARC) and the President's Commission on Mental Retardation in the 1970s, laws were passed to protect and preserve the rights of those with an intellectual disability to receive appropriate treatment in residential facilities. However, disfavor with the residential system resulted in many of

the children with an intellectual disability seeking placement in local community schools. With the passing of P.L. 94-142-142, the right to a free and appropriate public education was now properly funded and guaranteed for children with disabilities. During this time, and for several years to follow, identification and definitions for individuals with an intellectual disability would continue to reflect changes in criteria and terminology used by the medical profession (APA), advocacy organizations (AAMR/AADID), and the educational system.



TEST YOURSELF



1. In the mid-1800s, this individual was one of the first to develop a program, the *Physiological Method*, to enhance sensory skills in those with intellectual disabilities. He later relocated to the United States and became the founding father of AAMR.

- (a) Jean Itard
- (b) Eduard Seguin
- (c) Cheyne Brady
- (d) Jean Esquirol

2. In 1910, the AAMR published the first system of classification for intellectual disabilities. Which of the following is true regarding that system?

- (a) The term “idiot” was reserved for those with a developmental level equivalent to 2 years of age.
- (b) The term “moron” was reserved for those with a mental age equivalent between 2 and 7 years of age.
- (c) The term “imbecile” was reserved for those with a mental age equivalent between 7 and 12 years of age.
- (d) The term “feeble-mindedness” was replaced by “mental deficiency.”

3. All of the following are true about Goddard’s legacy, except:

- (a) he researched the Kallikak family, finding two strains of offspring: the feeble-minded and others who were successful members of society.
- (b) he published an English version of the Binet-Simon Scale.
- (c) he was an advocate for the rights of the feeble-minded to have fair and equal opportunities, and he developed programs to reverse feeble-mindedness.
- (d) he was the director of training at the Vineland Training School.

4. In the late 1950s, AAMR expanded the criteria for the identification of individuals with mental retardation. Which of the following was included in the expanded criteria?

- (a) An IQ of less than 85
- (b) Impairment in adaptive behavior
- (c) Onset prior to 18 years of age
- (d) All of the above

5. In 1970s, the Wyatt- Stickney federal court case in Alabama established the right to:

- (a) a free and appropriate education.
- (b) treatment for individuals in residential facilities.
- (c) vote for individuals with disabilities.
- (d) legal counsel for individuals with disabilities.

6. In the DSM-IV (APA, 1994), the important decision was made to:

- (a) increase the number of categories (ranges of severity) from four to five.
- (b) decrease the IQ cutoff from an IQ of 70 to an IQ of 85.
- (c) code MR on Axis II of the Five Axis System, along with the personality disorders.
- (d) merge the severity categories of Mild and Moderate Severity to the category of Minimal Severity to increase the prevalence of individuals in the upper level of the disability.

7. In 2002, the AAMR released the 10th revision of its manual, which emphasized a significant difference in the way MR was conceptualized by this advocacy group and the DSM. The AAMR emphasized:

- (a) that MR was not a “mental disorder” but “a state of functioning.”
- (b) a shift in emphasis from weaknesses to patterns of individual strengths and weaknesses.
- (c) increased focus on ecological influences and interventions.
- (d) all of the above.

8. With the passing of “Rosa’s Law,” what major change was made?

- (a) The developmental age for identification of intellectual disability was increased from 18 to 21.
- (b) Individuals with intellectual disabilities were given the right to treatment.
- (c) The terms “mental retardation” and “mentally retarded” were replaced with “intellectual disability” or “intellectual developmental disability.”
- (d) Gender discrimination for those with intellectual disabilities was given increased awareness.

Answers: 1. b; 2. a; 3. c; 4. d; 5. b; 6. c; 7. d; 8. c.