Key Points

- NAMING, DEFINING, AND CLASSIFYING COGNITIVE/INTELLECTUAL DISABILITIES (CIDs)\(^1\)—All three processes are important when characterizing individuals with CIDs.
- EVOLUTION OF THE DEFINITION—Early descriptions of individuals with CIDs date back to 1500 B.C. Attempts were made to differentiate CID from mental illness and to identify possible causes.
- AAMD/AAMR/AAIDD DEFINITIONS—The association known by several names over the years has provided definitions since 1921, the most recent in 2010.
- CLASSIFICATION OF CIDs—CIDs have been classified by etiology, mental ability (IQ), educational needs, and more recently, by levels of needed supports.
- PREVALENCE—The number of individuals with CIDs is generally reported to be about 1% of the population but varies based on age, geographic region, socioeconomic status, and ethnic background.

As pointed out in Chapter 1, the area of CIDs has had a rich and interesting history. Both attitudes toward, and practices for, individuals with CIDs have certainly evolved over the last two centuries. With these changes in attitudes have come constant, ongoing attempts to change and improve the description and definition of what is a CID. These attempts have closely paralleled the changes in attitude and practices. Over the past decade, there has been a strong movement to eliminate the term *mental retardation*, led by many professional organizations that focus on this population. For example, the Division on Mental Retardation and Developmental Disabilities of the Council for Exceptional Children dropped the term *mental retardation* from its title in 2002 and is now called the Division on Autism and Developmental Disabilities. Similarly, the American Association on Mental Retardation (AAMR) changed its name to

NAMING, DEFINING, AND CLASSIFYING CIDS

Three issues relate to terminology and were used, in part, to change our views of mental retardation, the term used for so many years. These are naming, defining, and classifying. Luckasson and Reeve (2001) wrote an influential article discussing these issues that ultimately helped in changing the term mental retardation to intellectual and developmental disabilities, now in use by the AAIDD.

Naming

In this context, naming involves the assignment of a specific term or label to a condition or disability. As noted in the cliche, “It’s all in the name,” naming is very important because the specific term chosen to represent the condition can impact perceptions and attitudes about that condition. In fact, the very act of naming or labeling has been criticized by a number of professionals over the years. Historically, various researchers have reported that the label of “mental retardation” resulted in lower teacher expectations and poor self-concept for the person being labeled (e.g., Algozzine & Sutherland, 1977; Jacobs, 1978; Taylor, Smiley, & Ziegler, 1983). Another issue is that identifying an individual by a label (e.g., he is mentally retarded) provides a very narrow description and, in many ways, devalues the person. For this reason, the Individuals with Disabilities Education Act (IDEA) in 1990 required a change to “person first” terminology (e.g., he is an individual with a disability). Although the term mental retardation is still used in IDEA 2004, the change at least emphasizes that you are a person first and foremost. As noted in Chapter 1, future legislation will undoubtedly substitute intellectual disability or some other more appropriate term for mental retardation and IDEA does allow states to use alternative terms now.

Also as noted in Chapter 1, the historical names used for this disability such as idiot and feebleminded are viewed as very negative and inappropriate in today’s society. Such terms do, however, paint a picture of how CIDs were viewed at other particular points in time. In other words, names change as perceptions and attitudes change. For example, the AAIDD was founded in 1878 as the Association of Medical Officers of American Institutions for Idiotic and Feebleminded Persons. That name changed to the American Association for the Study of the Feebleminded in 1906, then the American Association of Mental Deficiency (AAMD) in 1933. In 1987, the name was changed to the American Association on Mental Retardation (AAMR) and is now the American Association on Intellectual and Developmental Disabilities.

Choosing the name to represent a certain disability should be done so very carefully and should serve a clear purpose. The following questions were identified to consider when names or terms are being considered (Luckasson & Reeve, 2001):

- Does the term name this and nothing else?
- Does this term provide consistent nomenclature?
• Does this term facilitate communication?
• Does this term incorporate current knowledge and is it likely to incorporate future knowledge?
• Does this term meet the purposes for which it is being proposed?
• Does this term contribute positively to the portrayal of people with this disability?

(pp. 48–49)

Luckasson et al. (1992) in the AAMR Definition and Classification Manual commented on the naming issue. “Mental retardation is not something you have, like blue eyes or a bad heart. Nor is it something you are, like being short or thin. . . . Mental retardation refers to a particular state of functioning that begins in childhood and in which limitations in intelligence coexist with limitations in adaptive skills. In this sense, it is a more specific term than developmental disability because the level of functioning is necessarily related to an intellectual limitation” (p. 9). This statement did leave the door open for the possible use of the term intellectual disability. Perhaps this rationale led, in part, to the organization's current use of the term intellectual and developmental disabilities.

According to Webster’s dictionary, defining involves “a statement of what a thing is” or “a statement of the meaning of a word, phrase, etc.” Luckasson and Reeve (2001) noted that the main role of a definition is to separate something from some other (named) thing. Thus, defining CID involves a precise description of the meaning and boundaries of the term. They suggested that eight questions be asked when considering a definition:

• Does this definition indicate the boundaries of the term, that is, who or what is inside the boundaries and who or what is outside the boundaries?
• Does this definition indicate the class of things to which it belongs?
• Does this definition differentiate the term from other members of the class?
• Does this definition use words that are no more complicated than the term itself?
• Does the definition define what something is, not what it is not?
• Does this definition allow some generalizations about characteristics of the individual or group named by the term?
• Is this definition consistent with a desired theoretical framework?
• Does this definition contribute positively to the portrayal of people included in the term?

(p. 49)

Haywood (1997) urged professionals in the field to seek new definitions, “recognizing the inadequacy of present concepts and definitions to incorporate what is known about the behavior and development of persons with mental retardation” (p. 5). Schalock (2002), in his perspective on the history and future of the mental retardation definition, identified six factors that he felt have affected and will continue to impact the conceptualization and definition of the term. Among these were the population of persons with CIDs, biochemical advances that will result in
prevention and cures for certain conditions, and the demise of typological thinking. As an example of this latter point, Schalock noted that the idea of the incurability of CIDs as well as the notion that persons with CIDs are inherently different from others had been abandoned in definitions by 2002. He accurately predicted that the search for new definitions will follow three paths. First, the fundamental terms, concepts, and practices will continue to be questioned. Second, the potential conflict between the requirements of science and the needs of individuals with CIDs will need to be resolved. Finally, sensitivity to disability culture and disability pride must be instilled and the acceptance of a strong self-advocacy movement must be continued. Clearly, the issue of defining CIDs is complex and multifaceted with significant implications for those individuals who are identified as well as for those concerned with their education and welfare.

Classifying

Classifying has to do with identifying subgroups of individuals within the defined group according to certain criteria. For example, individuals could be classified according to medical diagnosis (e.g., Down syndrome), or IQ level (mild, moderate, severe, or profound), or the needed levels of support (e.g., intermittent support needed). The goal of classifying should be to provide more precision so that individuals with the same classification have similar attributes or characteristics. This, in turn, should provide information regarding funding, educational and service delivery needs. The question that must be asked is “On what basis should you classify individuals?” As will be discussed later in this chapter, for example, attempts at classifying based on etiology (causes) became prominent as early as the end of the 19th century (see Event Box 2.1).

2.1 EVENT THAT MADE A DIFFERENCE

1898—William W. Ireland Develops Classification System Based on Medical Causes

William W. Ireland was a physician who spent much of his career studying the diagnosis and classification of CIDs. In 1898, he published a book entitled *The Mental Affections of Children: Idiocy, Imbecility, and Insanity*. In it, he described a classification system based on etiology. He identified 10 categories: (1) Genetous, (2) Microcephalic, (3) Eclampsic, (4) Epileptic, (5) Hydrocephalic, (6) Paralytic, (7) Cretinism, (8) Traumatic, (9) Inflammatory, and (10) Idiocy by Deprivation. Ireland actually referred to many of these categories in his earlier work. For example, he refers to genetous idiocy in an article published in the *Edinburgh Medical Journal* in 1882. He stated that “Of all known diseases, perhaps idiocy is most frequently propagated by heredity” (Ireland, 1882; p. 1072). The full text of this article, “On the Diagnosis and Prognosis of Idiocy and Imbecility,” is available on the website.
To complete the set of questions related to the issues of naming, defining, and classifying CIDs, Luckasson and Reeve (2001) offered the following:

- Does this classification system allow coding into groups based on some consistent and meaningful criteria?
- Does this classification system facilitate record keeping?
- Does this classification system provide consistent nomenclature?
- Does this classification system facilitate communication?
- Does this classification system allow some generalizations about the individual or the group?
- Does this classification system create a principled organizing system for incorporating new knowledge?
- Does this classification system promote planning and allocation of resources?
- Does this classification system contribute to meaningful predictions for individuals or groups?
- Is this classification system consistent with a desired theoretical framework?
- Does this classification system contribute positively to the portrayal of individuals or groups?

Perhaps partially as a result of these guiding questions, the current system of classifying individuals with CIDs based on needed levels of support (discussed later in this chapter) rather than an individual’s IQ level is emphasized by the AAIDD. This is a much more positive, proactive approach. However, schools may still use terms such as mild, moderate, severe, or profound that are largely linked to IQ levels. The definition of CIDs has substantively reflected and influenced change over time.

**EVOLUTION OF THE DEFINITION**

As chronicled in Chapter 1, efforts to describe CIDs began as early as 1500 B.C. in ancient Greece. However, it wasn’t until about the 16th century that attempts were made at a definition. An example is that of Fitz-Hebert who wrote in 1534:

> And he who is said to be a sot (i.e., simpleton) and idiot from his birth is such a person who cannot account or remember 20 pence, nor can he tell how old he is, etc. so as it may appear that he hath no understanding or reason of what shall be for his profit nor what for his loss

(cited in Grossman, 1983, p. 8)

**19th Century**

Blanton (1975) in his classic discussion of the history of CIDs (see Research Box 2.1) noted that the first clear definition was provided by the psychiatrist, Esquirol, in 1845. That definition read:

Idiocy is not a disease, but a condition in which the intellectual faculties are never manifested, or have never been developed sufficiently to enable the idiot to acquire
such amount of knowledge as persons his own age and placed in similar circumstances with himself are capable of receiving.

(Esquirol, 1845; p. 446)

As noted in Chapter 1, Esquirol was one of the first persons to formally attempt to differentiate CIDs from mental illness. Many of his thoughts on the subject influenced later thinking as well. For example, he felt that a CID was not an all-or-nothing condition but rather a condition that existed on a continuum. That is, CIDs manifested in different levels of severity in the population. Esquirol also opened a school for “idiots” with Edouard Seguin. Seguin was one of the first to attribute a specific cause for CIDs.

Idiocy is a specific infirmity of the cranio-spinal axis, produced by deficiency of nutrition in utero and neo-nati. It incapacitates mostly the functions which give rise to the reflex, instinctive, and conscious phenomena of life; consequently, the idiot moves, feels, understands, wills but imperfectly; does nothing, thinks of nothing (extreme cases), he is legally irresponsible; isolated, without associations; a soul shut up in imperfect organs, an innocent.

(Seguin, 1866; p. 39)

2.1 RESEARCH THAT MADE A DIFFERENCE


This chapter in Hobbs’s classic text on classification traces the history of CID as well as the issue of classification. Blanton provided a good account of the mental testing movement and its role in the classification of this disability. He also included an excellent discussion of the eugenics movement and the role that Goddard played with his treatise on the Kallikak family (see Chapter 1). In addition, he addressed the controversial issue of the role of heredity vs. environment as a cause of CID in a section called “The Nature-Nurture Problem.” Finally, he provided a brief discussion of special education and the training of teachers. It is interesting to see how little was really known about this important area in the 1970s. He does make, however, clear references to research (e.g., Dunn, 1968) that suggests that students with CID should be taught in the regular education classroom, a notion that predates the concept of inclusion by almost three decades.

Early 20th Century

In terms of the conceptual understanding and descriptions of CIDs, the 20th century began a transition, although as noted in Chapter 1, attitudes about CIDs were still very negative as evidenced by trends such as the eugenics movement. The
predominant term used in the early 20th century was *mental defective* or *mental deficiency*. An early 20th century definition that was influential was proposed by Tredgold (who actually was a member of the British Eugenics Society). His definition of mental deficiency was:

> It is a state of incomplete mental development of such a kind and degree that the individual is incapable of adapting himself to the normal development of his fellows in such a way to maintain existence independently of supervision, control or external support.

(Tredgold, 1937; p. 4)

Note that this early definition uses the phrase “incapable of adapting himself” and addresses the issues of social development and independence. These concepts had a major influence on subsequent, and even current, definitions. About the same time, the research of Edgar Doll (1941) began to impact the concept of CIDs (see Research Box 2.2), specifically the various definitions proposed by the AAMD/AAMR/AAIDD.

### 2.2 RESEARCH THAT MADE A DIFFERENCE


In this article, published by the American Association of Mental Deficiency, Doll established six criteria for the definition of mental deficiency. Those were: (1) social incompetence, (2) mental subnormality, (3) developmental arrest, (4) obtains at maturity, (5) of constitutional origin, and (6) essentially incurable. Like Tredgold, Doll mentioned social incompetence as a specific part of the definition. In fact, Doll is perhaps best known as the author of the *Vineland Social Maturity Scale*, a widely used adaptive skills assessment in its current edition. Social maturity later evolved into what is now known as adaptive behavior, which is a critical component of current definitions. Doll also mentioned that the disability was a developmental phenomenon that occurs at maturity. Current definitions now specify that CIDs occur during the developmental period (prior to age 18). The main criterion noted by Doll that did not stand the test of time was that CID is essentially incurable. In fact, current definitions of CIDs stress just the opposite.

**Reflection**

Do you agree with Edgar Doll’s assumption that CIDs are essentially “incurable”? Even if there is no known medical cause, can an individual’s overall functioning be “cured”?
AAMD/AAMR/AAIDD DEFINITIONS

There is little doubt that the AAIDD and its predecessors (AAMD and AAMR) have been leaders in defining CIDs. These definitions were included in manuals on terminology and classification published by the organization. The first manual was published in 1921, followed by new editions every 10 or 15 years. For example, manuals followed in 1933 and 1941. In 1957, a classification manual was developed based on etiology. At that time the AAMD recommended the “development of a comprehensive manual on terminology and classification in mental retardation” (Grossman, 1983; p. 5). That recommendation led to the fifth edition (Heber, 1959) of the manual that included a dual classification system: medical and behavioral. That manual also had a significant impact on how we defined and classified CIDs. Heber suggested the use of the mean and standard deviation of an intelligence test to help determine the IQ level required for identification (see Box). Heber established the IQ cutoff at one standard deviation below average (usually 85) and introduced the requirement of a deficit in adaptive behavior in addition to a deficit in intelligence. Adaptive behavior is difficult to define but generally refers to a person’s ability to deal effectively with personal and social demands and expectations (Taylor, Smiley, & Richards, 2009). The importance of the role of adaptive behavior in the identification of CIDs is discussed in Chapter 3. Specifically, Heber defined mental retardation as:

subaverage general intellectual functioning that originates during the developmental period and is associated with impairment in adaptive behavior.

(cited in Schalock, 2002; p. 30)

INTERPRETING SCORES FROM INTELLIGENCE TESTS

The mean represents the average score for a test whereas the standard deviation (SD) represents the variability of the test scores. Approximately 68% (2/3) of the population will score between + one SD from the mean. Approximately 96% will score between + two SDs. For example, if a test has a mean of 100 and an SD of 15, approximately 2/3 of those taking the test will score between 85–115, and 96% will score between 70–130.

The wording for this definition has remained relatively constant for over 50 years. It establishes three characteristics of CIDs: an intellectual deficit, an adaptive behavior deficit, and manifestation during the developmental period. As will be discussed, however, the criteria for what constitutes these characteristics have changed considerably over the years.

Heber (1961) made some minor changes to the definition but it wasn’t until 1973 that a significant change in the criteria was recommended (Grossman, 1973). After considerable debate, the decision was made to lower the IQ cutoff from one SD below average to two SDs below average. Thus, individuals who previously were identified as
having a CID whose IQs were between approximately 70 and 85 (termed borderline mental retardation in previous manuals) no longer were identified as having a CID after this change in definition. Grossman was concerned that the 85 IQ cutoff would lead to a very high percentage of individuals being identified. In fact, approximately 16% of the population would be expected to score below 85. Heber, however, had reasoned that having the dual requirement of IQ and adaptive behavior deficits would address this issue. Unfortunately, the lack of a clear understanding of the concept of adaptive behavior, how it is measured, and what constituted a deficit created problems. Grossman also added the word significantly before “subaverage general intellectual functioning.” In fact, by changing the IQ criterion to two SDs below average, he reduced the expected percentage to meet that criterion from 16% to 2%. He also raised the age limit of the developmental period to birth to age 18 (it had previously been birth–age 16). The actual definition read:

Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period.

(Grossman, 1973, p. 5)

Clearly, the 1973 definition affected the makeup of those who were to be identified as having mental retardation.

The next AAMR definition was published in 1977 (Grossman, 1977). The actual definition was identical to the 1973 definition. However, another change was made in the criteria used to determine a CID. At that time, the issue of clinical judgment was introduced (see Box). This provided greater flexibility and changed the definition from a purely quantitative perspective. For example, it meant that in certain cases, an individual whose adaptive behavior was extremely deficient might be considered as having a CID even if his or her IQ was above 70. In fact, Grossman indicated that in rare situations a person whose IQ was as high as 80 might be considered as having a CID based on his or her adaptive behavior functioning. He also, however, acknowledged the difficulty in assessing adaptive behavior.

**WHAT IS CLINICAL JUDGMENT?**

AAIDD (2010) provided a definition of clinical judgment based on previous information. It indicated that it is a special type of judgment rooted in a high level of clinical expertise and experience and that emerges directly from extensive data.

The last AAMR definition for which Grossman was responsible was in 1983. Again, the general definition remained the same as the 1973 and 1977 definitions. Similar to the 1977 definition, there was encouragement to use IQ limits cautiously. In fact, significantly subaverage general intellectual functioning was defined as an “IQ of 70
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or below on standardized measures of intelligence. This upper limit is intended as a guideline; it could be extended upward through IQ 75 or more, depending on the reliability of the intelligence test used” (Grossman, 1983; p. 11). This reemphasized that IQ was only one criterion for a CID and that there was no single score that could result in the diagnosis. One subtle but notable change in the 1983 Manual was the definition of developmental period. It was changed from birth–age 18 to conception–age 18, thus acknowledging the prenatal causes of CIDs. One interesting finding regarding the 1983 AAMR definition was reported by Denning, Chamberlain, and Polloway (2000). They surveyed all 50 states and the District of Columbia regarding the actual guidelines that were used in defining and classifying students with CIDs. They found that 44 used the actual or a modified version of the 1983 definition, even though more recent definitions were available.

Luckasson et al. (1992) developed the next AAMR definition. It retained the basic features of the previous definitions although it also specifically identified adaptive behavior areas for the first time. Perhaps the frustration of having an adaptive behavior deficit as a requirement for over 30 years (without specific criteria) led to this change. That definition read:

Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18.

(p. 5)

Luckasson et al. also indicated four assumptions related to the application of the definition:

1. Consideration of cultural and linguistic diversity as well as communication and behavioral factors;
2. The existence of adaptive skill areas occurs within the context of the community environment;
3. Specific adaptive skill deficits can coexist with strengths in other adaptive skill areas; and
4. With appropriate supports over a sustained period of time, life functioning will generally improve.

The 1992 Manual also provided one of the most drastic changes in the conceptualization of CIDs by eliminating the mild, moderate, severe, and profound levels of mental retardation and replacing them with levels of needed supports (discussed later in this chapter; also see Event Box 2.2). Although such a change was supported and encouraged as a means of better serving students (Wehmeyer, 2003), its actual practice in the school appeared to be limited. As Denning et al. (2000) found, the majority of states still used a system based on levels of CIDs; only four states had adopted the
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1992 classification system. Over the past decade, however, more and more states have moved to the newer system that uses levels of support.

2.2 EVENT THAT MADE A DIFFERENCE
1992—American Association on Mental Retardation Eliminates Levels of Retardation

In 1992, the American Association on Mental Retardation (AAMR) made a controversial move that had a significant impact. In its previous Manuals (e.g., Grossman, 1983), individuals could be classified based on their intellectual level. The following criteria were used: mild (IQ 50–55 to approximately 70), moderate (35–40 to 50–55), severe (20–25 to 35–40), and profound (below 20–25). Critics of this approach, however, argued that it did little to indicate the actual educational and other support needs that the individuals had. They also felt that it was emphasizing the intellectual deficits that they have. In 1992, when the AAMR revised its Manual (Luckasson et al., 1992), it replaced the intellectual levels with level of supports (i.e., the intensity of necessary supports). These were intermittent, limited, extensive, and pervasive. Thus, an individual was classified as having mental retardation requiring ____________ supports. With this change, however, came new critics who felt that the new system did not provide enough description.

In 2002, the AAMR published the 10th edition of its manual called Mental Retardation: Definition, Classification, and Systems of Supports (Luckasson et al., 2002). This definition was fundamentally similar to the 1992 definition, although, once again, adaptive behavior was treated somewhat differently and the 10 adaptive skill areas were collapsed into three areas: conceptual, social, and practical. That definition read:

Mental retardation is a disability characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

(p. 1)

There were several assumptions similar to those in the 1992 definition specifically stated regarding the 2002 definition. Those were:

1. Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture;
2. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors;
3. Within an individual, limitations often coexist with strengths;
4. An important purpose of describing limitations is to develop a profile of needed supports; and
5. With appropriate personalized supports over a sustained period, the life functioning of the person with mental retardation generally will improve.

This definition retained the three basic components of previous definitions: a deficit in intellectual functioning, a deficit in adaptive behavior, and onset before age 18. However, the adaptive behavior areas were reduced from 10 specific skill areas to the three broader areas of conceptual, social, and practical skills. This change was made on the basis of statistical (factor analytic) research that supported the existence of these three broader areas. Further, Luckasson et al. suggested that adaptive behavior be considered in light of four dimensions: (a) intellectual abilities; (b) participation, interactions, and social roles; (c) health; and (d) context. For the first time, the specific criterion for an adaptive behavior deficit also was identified: “performance that is at least two standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, or practical, or (b) an overall score on a standardized measure of conceptual, social, or practical skills” (p. 14). Table 2.1 provides a comparison of the criteria used for the three main aspects of the various AAMD/AAMR/AAIDD definitions.

In 2010, the 11th Manual was published by what had become the AAIDD (Schalock et al., 2010). (Henceforth, this manual will be referenced to as AAIDD, 2010 throughout this text.) Prior to the 11th edition, Schalock et al. (2007) provided justification why the term mental retardation should be changed. They stated, among other things, that the term intellectual disability (a) aligns better with current professional practices that are focused on functional behaviors and contextual factors; (b) provides a logical basis for individualized supports provision due to its basis in a social-ecological framework; (c) is less offensive to persons with disabilities; and (d) is more consistent with international terminology. The 2010 AAIDD definition reads:

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

(p. 5)

The 2010 definition was unchanged in any significant way from the previous definition but for the use of the term intellectual disability. This definition includes five assumptions that are critical in its application:

- Limitations in present functioning includes conceptual, social or practical adaptive skills and must consider the individual’s community environments that are typical of chronological and cultural peers;
- Assessment of limitations in present functioning considers cultural and linguistic diversity as well as the impact of communication, sensory, or other factors that may affect assessment outcomes or present functioning;
• Strengths exist for every individual as well as limitations;
• One important reason for identifying limitations is to plan for individual supports; and
• When appropriate individualized supports are provided across the lifespan, the individual’s functioning will typically improve.

(AAIDD, 2010)

Finally, AAIDD (2010) stresses the new definition with the term *intellectual disability*, and these five assumptions, still includes anyone who is or would be diagnosed with the term *mental retardation*.

Two other organizations also have provided definitions of mental retardation and intellectual disability. The World Health Organization published the *International Statistical Classification of Diseases—10th Edition (ICD-10)* in 1993 (republished as the *ICD-10 Clinical Modification* in 2010) and the American Psychiatric Association published the *Diagnostic and Statistical Manual of Mental Disorders—5th Edition (DSM-V)* in 2013. *DSM-V* now uses the terms *intellectual disability* and *intellectual developmental disorder* rather than *mental retardation*. Similar to AAIDD, *DSM-V* emphasizes that overall functioning should be considered in diagnosis as well as intelligence testing. The *ICD-11* is currently scheduled to be published in 2015, and may

| Table 2.1 Comparison of AAMD/AAMR/AAIDD Definitions |
|----------------|----------------|---------------------------------|----------------|
| **Definition** | **IQ Deficit** | **Adaptive Behavior Deficit** | **Developmental Period** |
| Heber (1961)   | < 85           | Required, noting that it can be related to motivation, learning, and/or socialization | Before age 16   |
| Grossman (1973)| < 70           | Required, defined as effectiveness or degree with which the individual meets the standards of personal independence and social responsibility expected of his/her age and cultural group Note: General areas are identified by age groups | Before age 18   |
| Grossman (1983)| < approximately 70 | Required, defined as significant limitations in an individual’s effectiveness in meeting the standards of maturation, learning, personal independence, or social responsibility that are expected for his/her age and cultural group | Before age 18   |
| Luckasson et al. (1992) | < 70–75 | Identified 10 adaptive skills areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work | Before age 18   |
| Luckasson et al. (2002) | Approximately 2 standard deviations below the mean, considering the standard error of measurement | Identified three areas of adaptive behavior: conceptual, social, and practical; also identified four dimensions in which a deficit might exist | Before age 18   |
also include a change in terminology from mental retardation to intellectual disability or a similar term.

Reflection
Should “clinical judgment” have a place in the identification of an individual with CIDs?

CLASSIFICATION OF CIDS

In addition to the evolution of the terminology and the criteria used to define CIDs, changing views of how to classify it into meaningful categories have taken place. Currently, classification is primarily used for “funding, research, provision of services and supports, and communications about selected characteristics of persons and their environment” (AAIDD, 2010; p. 73). Perhaps one of the first attempts at classification was made by Willis in 1672. He noted “Some are unable to learn their letters but can handle mechanical arts; others who fail at this can easily comprehend agriculture; others are unfit except to eat and sleep; others merely dolts or driviling fools” (quoted in Grossman, 1983). Legal definitions also provided a basis for classification. For example, the Mental Deficiency Act of 1913 identified the following classes:

- Idiot—Unable to protect themselves from common dangers
- Imbecile—Could protect themselves from common dangers, but unable to take care of themselves
- Feeble-minded—Required care to protect themselves
- Moral Defectives—Criminal or vicious personalities

Later classification systems began to focus more and more on etiology. Blanton (1975) noted that Duncan and Millard in 1866 suggested two major classes: congenital and noncongenital. The congenital type were further identified as “profound idiots,” those who could stand and walk, those able to use hands to eat and do mechanical work, and feebleminded who required supervision. Grossman (1983) also pointed out the causal orientation of many early classification systems. For example, also in 1866, Langdon Down (after whom Down syndrome was later named) provided a system that included three major categories: congenital idiocy (microcephaly, hydrocephaly, and paralysis and epilepsy), developmental idiocy due to anxiety (associated with cutting teeth or with puberty), and accidental (due to injury [mechanical] or illness). In the latter part of the 19th century, systems became even more medically oriented and focused on brain pathology and CIDs. As noted in Event Box 2.1, by 1898 more elaborate systems such as that by Ireland were being used (Blanton, 1975). MacMillan (1985) pointed out that the most complete medical classification systems appeared in the various AAMD/AAMR Manuals.
The current AAIDD (2010) Manual stresses a multidimensional classification system that “depicts how human functioning and the manifestation of intellectual disability involve the dynamic, reciprocal engagement among intellectual ability, adaptive behavior, health, participation, context, and individualized supports” (p. 13). The system also indicates the level of supports needed. These five dimensions are further discussed in AAIDD (2010) as:

• Intellectual ability is not merely academic skill learning, but also a broader and deeper capacity to understanding our surroundings, making sense of what is going on, and then problem solving about how to respond;
• Adaptive skill abilities and limitations should be considered in the context of typical daily routines in community environments and linked to needed supports;
• Health, including physical, mental and social well-being influence how well a person functions;
• Participation in typical activities of life (including social activities) are critical to human development; and
• Context includes the individual’s personal environments, the broader neighborhood and community environments, and the cultural social, national, and geopolitical influences that affect human functioning, services, etc.

Conceptualizing cognitive and intellectual disabilities through the lens of these five dimensions helps to recognize the complexity and diversity of human development and characteristics (AAIDD, 2010).

Classification by Etiology

As noted, the AAMD/AAMR, and now the AAIDD, have led the field in developing classification systems for the causes or etiologies of CIDs. The various causes of CIDs will be discussed in depth in Chapters 4 and 5. Note that the systems include primarily medical causes, although each contains categories based on environmental causes as well.

The 1961 manual (Heber, 1961) categorized CIDs into these eight groups.

1. Infection
2. Intoxication
3. Trauma or physical agent
4. Disorder of metabolism, growth, or nutrition
5. New growths (tumors)
6. Unknown prenatal influence
7. Unknown or uncertain causes with structural reactions alone manifest
8. Uncertain (or presumed psychological) cause with functional reactions alone manifest.

Grossman (1973) used more familiar terms and included 10 groups instead of 8. Those were:
1. Infections and intoxications
2. Trauma or physical agent
3. Metabolism or nutrition
4. Gross-brain disease (postnatal)
5. Unknown prenatal influence
6. Chromosomal abnormality
7. Gestational disorders
8. Psychiatric disorder
9. Environmental influences
10. Other conditions

The 1983 system (Grossman, 1983) was the same as the 1973 system except for the following changes: (a) “Chromosomal abnormalities” was changed to “Chromosomal anomalies”; (b) “Gestational disorders” was dropped and replaced with “Other conditions originating in the perinatal period”; and (c) “Psychiatric disorder” was changed to “Following psychiatric disorder (specify).” More significant changes were made in 1992 (Luckasson et al, 1992). For one thing, there was a clear delineation of pre-, peri-, and postnatal causes.

In the 2002 AAMR Manual, Luckasson et al. actually discuss other systems, including the previously mentioned ICD-10 and the DSM-IV, as well as the ICD-9 Clinical Modification (Medicode, 1998) and the International Classification of Functioning, Disability, and Health (World Health Organization, 2001). In the chapter on etiology and prevention, Luckasson et al. (2002) describe “etiologic risk factors” as well as strategies for assessing them. These risk factors relate to pre-, peri-, and postnatal factors. The latest manual (AAIDD, 2010) also identifies etiologic risk factors. Those are provided in Table 2.2. However, AAIDD (2010) stresses that defining and classifying individuals should be linked to developing needed personal supports to improve functioning over the life span.

Table 2.2 Classification System by Etiology Proposed by Luckasson et al. (1992)

<table>
<thead>
<tr>
<th>Prenatal Causes</th>
<th>Perinatal Causes</th>
<th>Postnatal Causes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chromosomal disorders</td>
<td>Intrauterine disorders</td>
<td>Head injuries</td>
</tr>
<tr>
<td>Syndrome disorders</td>
<td>Neonatal disorders</td>
<td>Infections</td>
</tr>
<tr>
<td>Inborn errors of metabolism</td>
<td></td>
<td>Demyelinating disorders</td>
</tr>
<tr>
<td>Developmental disorders of brain</td>
<td></td>
<td>Degenerative disorders</td>
</tr>
<tr>
<td>formation</td>
<td></td>
<td>Seizure disorders</td>
</tr>
<tr>
<td>Environmental influences</td>
<td></td>
<td>Toxic-metabolic disorders</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Malnutrition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Environmental deprivation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hypoconnection syndrome</td>
</tr>
</tbody>
</table>
Classification by Mental Ability

At the beginning of the 20th century, another factor affected classification—the development and use of intelligence tests. Perhaps the greatest influence on the area of intelligence testing was made by Alfred Binet. He was asked (along with Theodore Simon) by the Ministry of Education in France to develop a test that would differentiate individuals with and without CIDs. That test (the Binet-Simon) was translated into English in 1905, revised in 1908 to include the concept of mental age, and was revised again by Terman in 1916 to become the Stanford-Binet Intelligence Scale. This was the first instrument to use Stern’s (1914) term intelligence quotient (Bryant, 1997). The most recent Stanford-Binet Intelligence Scale and other intelligence tests are discussed in Chapter 3. Goddard, perhaps best known for his views on the Kallikak family (see Chapter 1), developed a classification system based on the mental age score from the Binet-Simon. A person with a mental age above 12 years was considered “normal,” between 8 and 12 years a “moron,” between 3 and 7 years an “imbecile,” and fewer than 2 years an “idiot.”

There were several other advances in mental testing in the early part of the 20th century as a result of differing theories about the nature of intelligence and how it is measured (e.g., Spearman, 1927; Thurstone, 1938). However, it was David Wechsler who perhaps had the greatest influence on our current practices related to intelligence testing. He developed the Wechsler-Bellevue Intelligence Scale in 1939 (see Event Box 2.3). That instrument was the predecessor to the Wechsler Scales currently in use. Those are the Wechsler Preschool and Primary Scale of Intelligence-IV (WPPSI-IV), the Wechsler Intelligence Scale for Children-IV (WISC-IV), and the Wechsler Adult Intelligence Scale-IV (WAIS-IV). The Wechsler Scales provide an IQ with a mean of 100 and a standard deviation of 15 (the Stanford-Binet-5 also has a mean of 100 and a standard deviation of 15). As noted earlier, the mean of a test represents the average score whereas the standard deviation represents the variability of the scores. For example, approximately 68% (2/3) of the population will score between +1 and –1 standard deviation from the mean. Using the mean and standard deviation from the Wechsler Scales, approximately 68% of individuals will score between 85 and 115. Wechsler recommended the guidelines for interpreting the IQs obtained from his tests (see Table 2.3). Indirectly, Wechsler used the standard deviation as a basis for his guidelines. For example, “very superior” is two standard deviations above average whereas “mentally impaired” is two standard deviations below average. As mentioned earlier, most of the AAMD/AAMR/AAIDD definitions have used the standard deviation to help determine the level of CIDs, based on how much a person’s IQ deviates from the average (see Table 2.4). The latest AAIDD definition defines significant limitations in intellectual functioning as “an IQ score that is approximately two standard deviations below the mean, considering the standard error of measurement for the specific instruments used and the instruments’ strengths and limitations” (AAIDD, 2010; p. 31). This is unchanged since the Luckasson et al. (2002) interpretation.
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2.3 EVENT THAT MADE A DIFFERENCE

1939—David Wechsler Develops the Wechsler-Bellevue Intelligence Scale

David Wechsler was born in Romania in 1896 and moved to the United States in 1902. He eventually became the Chief Psychologist at Bellevue Psychiatric Hospital in New York City. During this time, he developed the Wechsler-Bellevue Intelligence Scale, the test that was to become the predecessor of the most widely used, current intelligence scales. Wechsler was working primarily with adults and felt...
that the Stanford-Binet was not appropriate for that population. He argued that the test items on the Stanford-Binet were designed for children and that there was too much emphasis on speed, which would put older adults at a disadvantage. He also felt that a single IQ was not appropriate. As a result, Wechsler introduced the addition of a verbal IQ and a performance IQ within the same test (although this feature was eliminated in the most recent Wechsler Scale; see Chapter 3).

The ICD-10 classification system also includes guidelines based on intellectual level. The ICD-10 identifies four levels of disability: F70 (mild, IQ 50–69), F71 (moderate, IQ 35–49), F72 (severe, IQ 20–34), and F73 (profound, IQ below 20). Two other categories are F78 (other mental retardation) and F79 (unspecified mental retardation). F78 is used when associated physical or sensory impairments make it difficult to establish the intellectual level. F79 is used when there is evidence of a CID but not enough to establish the level of functioning (such as a young child whose IQ cannot be reliably determined). Again, this system may change with the publication of the ICD-11. As noted previously, the DSM-V definition now uses the term intellectual disability and emphasizes present functioning.

**Educational Classification**

When more formal programs for students with CIDs became prominent in the schools in the 1960s, a classification based on general, educational expectations became popular. One very outdated system once commonly used was based on educational classification that used the terms educable mental retardation (EMR), trainable mental retardation (TMR), and severe and profound mental retardation (SPMR). Similar to the classification systems based on mental ability, the IQ was typically used to place a student into a specific educational category. The EMR category included individuals whose IQs ranged from approximately 50–75. The TMR category included IQ levels from about 25–50, and the SPMR category included individuals whose IQs were below approximately 25.

Some systems may still use IQ levels as the primary determinant for classification, but use the terms mild (IQ of 50–70), moderate (35–50), severe (20–35), and profound (20 and below). Historically, the reliance on IQ has been one criticism of this system because educational expectations are based on limited information. Additionally, this system implies that IQ is the most relevant (and perhaps immutable) factor in determining the level or types of supports needed.

**Classification by Needed Supports**

As noted previously, the 1992 AAMR Manual first eliminated the levels of CIDs based on IQ and replaced them with levels of needed supports; this approach subsequently was retained in the 2002 and 2010 Manuals. The rationale was to provide a more proactive, intervention-based system, a major departure from previous ones that classified the individual based on the intellectual level of the CID. The supports classification
system focused on the individual’s needs rather than the individual’s deficits, with the goal of providing information that will assist in intervention planning. As mentioned earlier, when an individual is diagnosed as having a CID, the level of needed supports should be identified for the following areas: intellectual ability, adaptive behavior, participation, interactions and social roles, health, and context (environments and cultures). The following are the definitions of the four levels of support (Luckasson et al., 2002; p. 152). More information on these supports can be found in Chapter 8.

INTERMITTENT—Supports on an “as needed basis,” characterized by their episodic, (person not always needing the support[s]), or short-term nature (supports needed during life-span transitions, e.g., job loss or acute medical crisis). Intermittent supports may be high or low intensity when provided.

LIMITED—An intensity of supports characterized by consistency over time, time-limited but not of an intermittent nature, may require fewer staff members and less cost than more intense levels of support (e.g., time-limited employment training or transitional support during the school-to-adult period).

EXTENSIVE—Supports characterized by regular involvement (e.g., daily) in at least some environments (such as school, work, or home) and not time-limited nature (e.g., long-term support and long-term home living support).

PERVASIVE—Supports characterized by their constancy, high intensity, provision across environments, potentially life-sustaining nature. Pervasive supports typically involve more staff members and intrusiveness than do extensive or time-limited supports.

More recently, the AAIDD (2010) emphasized that supports should be personalized and designed to encourage improved functioning over the life span. Because how a person functions intellectually and in adaptive skill areas (conceptual, social, and practical adaptive skills) is used to identify individuals with CIDs, the “centrality of supports to understanding people with ID is evident when considering these manifestations” (p. 110). In other words, to classify an individual as having a level of CID without considering to what extent that individual has had or is receiving needed personal supports is to ignore a major facet of who that person is.

Reflection
Is it better to classify individuals with CIDs based on the level of IQ or the level of needed supports? Why or why not?

PREVALENCE

One important, yet surprisingly complex, issue is the determination of the number of individuals who have a CID. One reason is related to terminology. In general, two terms are often used to describe the number of individuals who have a specific
condition. **Incidence** refers to the number of individuals who fall into a specific category (in this case CID) for the first time during a specific period of time. Although the period of time used to determine incidence figures varies, one year is frequently used. So, for example, incidence figures might indicate the number of individuals who are initially identified as having a CID in 2013. The other term, **prevalence**, refers to the total number of individuals who have a specific condition at a given point in time. Grossman (1983) gave a good example of why incidence and prevalence are not interchangeable. He pointed out that in underdeveloped countries the incidence of CIDs is high because of factors such as poor nutrition and lack of prenatal care. In other words, the number of new cases of CIDs is high. On the other hand, because of excessive infant mortality the prevalence rate is comparatively low. Because of the death rate, the number of individuals with CIDs at a given point in time is lower.

In general, prevalence figures are those that are more frequently reported; the number of individuals with CIDs is generally reported to be around 1% of the population. Using a national survey, Larson et al. (2001) reported the prevalence rate to be .78%. Based on another national study, Oswald, Coutinho, Best, and Nguyen (2001) found that 1.33% had a CID. In a recent meta-analysis of 52 international studies reporting the prevalence rates of CIDs, Maulik, Mascarenhas, Mathers, Dua, and Saxena (2011) found the rate to be 1.04%.

The percentage of students actually served in classes for CIDs has remained relatively constant. The report to Congress on the implementation of IDEA indicated that 0.9% of students aged 6 through 21 were served from 1997 to 2003. For 2004 and 2005, 0.8% were served and 0.7% were served in 2007 (U.S. Department of Education, 2008).

Prevalence figures for CIDs are affected by several variables. These include ethnic status, socioeconomic status, gender, age, geographic region, and even the effect of the judicial system. This is particularly true for mild CIDs, which constitute approximately 75%–85% of all cases of CIDs. The overrepresentation of ethnic minority students in classes for CIDs is well documented (see Chapter 8 for further discussion). For example, the *Larry P. v. Riles* court case (see Chapter 3 for more information) brought attention to the fact that African-American children were grossly overrepresented in classes for students with mild CIDs. In 2007, for example, 12.8% African-American students aged 6 through 21 were served under IDEA 2004, whereas 7.1% White students were served. One reason for this phenomenon seems to be that more minority children are referred for special education in the first place. Hosp and Reschly (2003) conducted a meta-analysis of the referral rate based on the students’ racial status and found that African-Americans were significantly more referred than their White counterparts.

Gender also makes a difference. For example, the prevalence of CIDs due to Fragile X syndrome, a common genetic disorder (discussed in Chapter 4) is higher in males than in females whereas Rett syndrome (also described in Chapter 4) occurs almost exclusively in females. Gender also interacts with ethnicity to affect prevalence rates. Oswald et al. (2001) reported a range of .44% for Asian females to 3.15% for black males. Age is also a variable that affects prevalence. Almost 20 years ago, MacMillan, Siperstein, and Gresham (1996) pointed out, “The rate in the age range of 6–17 years
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(i.e., the school years) dwarfs the rates found in any other comparable age range precisely due to the detection of the mild cases by the public schools—cases that are frequently dropped from case registers upon their leaving school” (p. 366). In fact, Larson et al. (2001) found that almost four times as many individuals ages 6–17 had a CID compared to adults. The meta-analysis by Maulik et al. (2011) reinforces the fact that prevalence is affected by many variables. They reported higher rates in low- and middle-income countries and for populations of children and adolescents compared with adults.

Reflection
Why do you think the prevalence of CIDs is higher for those from low socio-economic and/or ethnic minority backgrounds?

SUMMARY CHECKLIST

Naming, Defining, and Classifying

- Naming—Assigning a specific term or label to a disability
- Defining—Providing a precise description of the meaning and boundaries of a term
- Classifying—Identifying subgroups of individuals within a defined group according to some criteria

Evolution of the Definition

- 1534 Fitz-Hebert
- 1845 Esquirole
- 1866 Seguin
- 1937 Tredgold
- 1941 Doll

AAMD/AAMR/AAIDD Definitions

- First Manual published in 1921
- Manuals followed in 1933, 1941, and 1957
- Heber (1959) introduced levels of CIDs based on IQ; 85 was cutoff for “borderline mental retardation”; introduced requirement of adaptive behavior deficit
  - Adaptive behavior—Ability to deal effectively with personal and social demands and expectations
  - Mean—The average score on a test
  - Standard deviation (SD)—An indication of the variability of test scores. Approximately 68% of the population will score between + one SD of the average score of a test
- Grossman (1973) lowered the IQ cutoff from 85 (one standard deviation below average) to 70 (two standard deviations below average)
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- Grossman (1977) introduced clinical judgment to the definition
  - Clinical judgment—The use of more subjective/additional information to allow more flexibility in interpreting the definition
- Grossman (1983) expanded the developmental period from birth to age 18 to conception to age 18; continued recommendation of IQ as a guideline only
- Luckasson et al. (1992) operationally defined 10 adaptive skill areas; eliminated levels of CIDs based on IQ
- Luckasson et al. (2002) retained elimination of levels of CIDs; changed adaptive behavior criteria to include conceptual, social, and practical skills
- Schalock et al. (2010) (AAIDD, 2010) retained the 2010 definition but changed the term mental retardation to intellectual and developmental disability
- ICD-10 and DSM-V—Two other current definitions that are sometimes used

Classification

- Duncan and Millard (1866) used the terms Congenital and Noncongenital
- Ireland (1898) proposed a more medically oriented system based primarily on biological causes

Classification by Etiology

- Heber (1961) identified 8 categories
- Grossman (1973) included 10 categories
- Grossman (1983) made minor changes to the 1973 system
- Luckasson et al. (1992) grouped etiologic risk factors based on prenatal, perinatal, and postnatal causes
- Luckasson et al. (2002) described “etiologic risk factors” similar to the causes listed in the 1992 Manual
- AAIDD (2010) retained the etiologic risk factors (Table 2.4)

Classification by Mental Ability

- Alfred Binet had perhaps the greatest influence on intelligence testing
- 1905—Binet-Simon Intelligence Scale translated into English
- 1916—Terman revises the test that becomes the Stanford-Binet Intelligence Scale
- Goddard develops a system based on the mental age from the Binet-Simon Intelligence Scale
- Wechsler develops the Wechsler-Bellevue Intelligence Scale in 1939
- Subsequent Wechsler Scales are the most widely used intelligence tests (WPPSI-IV, WISC-IV, WAIS-IV)
- ICD-10 includes IQ guidelines
- AAMD/AAMR Manuals prior to 1992 used IQ to determine levels of CIDs
- AAIDD Manuals from 2002 onward have emphasized consideration of personal supports

Classification by Needs

- Educational System—Mild, IQ approximately 50–75; moderate, IQ approximately 35–50; severe, IQ approximately 20–35; and profound, IQ below 20
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Classification by levels of support—Luckasson et al. (1992, 2002) identified four levels of support: Intermittent, Limited, Extensive, and Pervasive.

AAIDD (2010) emphasizes that what supports that have or have not been provided are essential in understanding the disability of an individual.

Prevalence

- Incidence—Number of individuals who fall into a category for the first time during a specific time period (usually one year)
- Prevalence—Total number of individuals who have a condition at a given point in time
  - Prevalence estimates are about 1% of the population
  - A number of variables affect prevalence including ethnic and socioeconomic status, gender, and age

ADDITIONAL SUGGESTIONS/RESOURCES

Discussion Questions

1. Discuss the important role that naming, defining, and classifying have in the field of CIDs.
2. What are the similarities and differences among the 1983, 1992, 2002 AAMR and AAIDD 2010 definitions and classification systems? Which do you think is more appropriate? Why?
3. Identify several reasons why the prevalence rate of CIDs is lower for preschool children and adults compared to school-aged individuals.

Activities

1. Interview a teacher, pediatrician, and a psychologist to determine their perspectives on the definition of a CID. How are they the same? How are they different?
2. Read the original “On the Diagnosis and Prognosis of Idiocy and Imbecility” (see Event Box 2.1 for website). How have attitudes changed since the 1880s?
3. Check with your local school district to determine what definition/classification system it uses for students with CIDs. Can you determine its origin based on the information presented in this chapter?

E-sources

www.ibis-birthdefects.org/start/mr.htm
This is the website for the International Birth Defects Information Systems. It includes several links to websites of other organizations, including the AAIDD and the ARC. It also has links to scholarly works like book chapters on the definition and classification of CIDs, and selected annotated bibliographies.

http://www aaidd.org
This website, sponsored by the American Association on Intellectual and Developmental Disabilities, provides its definition and links to frequently asked questions about the definition and a video definition. It also provides a link to access the entire 2010 Manual.
Introduction to CIDs

http://nichcy.org/disability/specific/intellectual
This website is published by the National Information Center for Children and Youth with Disabilities. It provides 13 links about various aspects of CIDs including the IDEA definition, prevalence, and a brief case study.

NOTE
1. The acronym CID is used for cognitive/intellectual disability and CIDs is used for the plural cognitive/intellectual disabilities.