

aaidd

American Association on Intellectual and Developmental Disabilities
www.aaidd.org

What is intellectual disability?

Intellectual disability is a disability characterized by significant limitations both in **intellectual functioning** (reasoning, learning, problem solving) and in **adaptive behavior**, which covers a range of everyday social and practical skills. This disability originates before the age of 18.

Is intellectual disability the same as developmental disability?

Not exactly. Developmental disability is an umbrella term that includes intellectual disability but also includes physical disabilities. Some developmental disabilities can be strictly physical, such as blindness from birth. Some individuals have both physical and intellectual disabilities stemming from genetic or other physical causes (e.g., Down Syndrome, fetal alcohol syndrome). Sometimes intellectual disabilities can stem from nonphysical causes, such as the level of child stimulation and adult responsiveness.

Is intellectual disability just determined by an IQ test?

No, but the IQ test is a major tool in measuring intellectual functioning, that is, mental capacity for learning, reasoning, problem solving, and so on. A test score of around 70—or as high as 75—indicates a limitation in intellectual functioning.

Other tests determine limitations in adaptive behavior, which covers three types of skills:

- Conceptual skills—language and literacy; money, time, and number concepts; and self-direction
- Social skills—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules, obey laws, and avoid being victimized
- Practical skills—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone

But evaluation and classification of individuals with intellectual disabilities is a much more complex issue. The major function of the American Association on Intellectual and Developmental Disabilities (AAIDD) is to publish the most advanced thinking in its manual, *Mental Retardation: Definition, Classification and Systems of Supports*. The most recent edition was published in 2002; the next is due in 2010.

In defining and assessing intellectual disability, AAIDD stresses that professionals must consider such factors as

- community environment typical of the individual's peers and culture
- linguistic diversity
- cultural differences in the way people communicate, move, and behavior

What causes intellectual disability?

Some disabling conditions classified as developmental disabilities—such as autism or cerebral palsy—might include intellectual disabilities. Other developmental disabilities, such as Down Syndrome, fetal alcohol syndrome, and fragile X syndrome, could well include intellectual disabilities. Intellectual disabilities could also be caused by social factors, such as the level of child stimulation and adult responsiveness, and educational factors, such as the availability of family and educational supports that can promote mental development and greater adaptive skills.

Nevertheless, according to the AAIDD manual, *Mental Retardation: Definition, Classification and Systems of Supports*, approximately 40 to 50 percent of the causes of intellectual disabilities currently have no identifiable origin.

What's the most modern thinking about how to help people with intellectual disabilities?

AAIDD stresses that the overarching reason for evaluating and classifying individuals with intellectual disabilities is to tailor supports for each individual, in the form of a set of strategies and services provided over a sustained period.

The goal is to enhance people's functioning within their own culture and environment in order to lead a more successful and satisfying life. Some of this enhancement is thought of in terms of self-worth, subjective well being, pride, engagement in political action, and other principals of "disability identity."

Is intellectual disability the same as mental retardation? Why do programs still say mental retardation?

Mental retardation and intellectual disability are two names for the same thing. But intellectual disability is gaining currency as the preferred term. In fact, the American Association on Mental Retardation changed its name in 2007 to the American Association on Intellectual and Developmental Disabilities.

It is crucial that 'mental retardation' and 'intellectual disability' should be precisely synonymous in definition and in all related classification because current federal and state laws contain the term 'mental retardation'. That is the term used in law and public policy to determine eligibility for state and federal programs, including the Individuals With Disabilities Education Act—IDEA (2004), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver.

Also, the term ‘mental retardation’ is used for citizenship and legal status, civil and criminal justice, early care and education, training and employment, income support, health care, and housing and zoning.

How are intellectual disability and developmental disability different?

Intellectual disability forms a subset within the larger universe of developmental disability, but the boundaries often blur as many individuals fall into both categories to differing degrees and for different reasons.

Developmental disabilities are defined as severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before the age of 22 and are likely to be lifelong.

Intellectual disabilities encompass the “cognitive” part of this definition, that is, those disabilities that are broadly related to thought processes. Because intellectual and other developmental disabilities often co-occur, intellectual disability professionals often work with people who have both types of disabilities.

Some developmental disabilities are purely physical, such as congenital deafness or visual impairment resulting from the individual’s mother contracting rubella while pregnant. These are not intellectual disabilities. Other developmental disabilities can be caused by cerebral palsy, epilepsy, autism, or other disabling conditions. These conditions might or might not include intellectual disabilities.

Still other developmental disabilities can result from chromosomal disorders, such as Down Syndrome, fetal alcohol syndrome, and fragile X syndrome. These instances could well include intellectual disabilities—but not always. For example, according to the Centers for Disease Control, males with fragile X syndrome generally have mild to severe intellectual disabilities, whereas females can have average intelligence.

On the other hand, some causes of intellectual disabilities are not physical. These include social factors, such as the level of child stimulation and adult responsiveness, and educational factors, such as the availability of family and educational supports that can promote mental development and greater adaptive skills.

Why did AAIDD change the term from ‘mental retardation’ to ‘intellectual disability’?

AAIDD’s move to replace ‘mental retardation’ with ‘intellectual disability’ does not change the basic definition of the term, but it does reflect a change of vision.

AAIDD stresses that the term ‘intellectual disability’ has exactly the same definition as the association’s most recent (2002) definition of mental retardation. It covers the same population of individuals who were previously diagnosed with mental retardation or who were eligible for that diagnosis. This exact fit is crucial because the term ‘mental retardation’ is used in law and public policy to determine eligibility for state and federal programs, including the Individuals With Disabilities Education Act—IDEA (2004), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver.

Also, the term ‘mental retardation’ is used for citizenship and legal status, civil and criminal justices, early care and education, training and employment, income support, health care, and housing and zoning.

But the word change from ‘mental retardation’ to ‘intellectual disability’ does reflect a revised focus.

- It is less offensive to persons with disabilities.
- It is more consistent with internationally used technology.
- It emphasizes the sense that intellectual disability is no longer considered an absolute, invariable trait of a person.
- It aligns with current professional practices that focus on providing supports tailored to individuals to enhance their functioning within particular environments.
- It opens the way to understanding and pursuing “disability identity,” including such principles as self-worth, subjective well being, pride, engagement in political action, and more.¹

What role does AAIDD play in defining mental retardation and intellectual disability?

AAIDD, the world’s oldest organization of intellectual disability (ID) professionals, has played a major role in evolving ideas about and approaches to intellectual disability. In fact, the association, founded in 1876, revised its definition of mental retardation ten times between 1908 and 2002.

The first definitions of mental retardation focused on a failure to adapt socially to the environment. Later definitions added a medical approach that considered heredity and pathology and called for the mentally retarded to be segregated. Then the rise of the mental testing movement brought an emphasis on measuring intellectual functioning by IQ test. The IQ test became the way to define the group and classify the people within it.

In its 1959 definition and classification manual, AAIDD first attempted a dual-criterion approach: a definition that mentioned both intellectual functioning and “impairments in maturation, learning, and social adjustment.” In its 1961 manual, AAIDD folded the “impairments” description into the phrase “adaptive behavior,” a term still used today.

The third element of the definition involves age of onset. Early definitions mentioned “the developmental period.” AAIDD’s most recent 2002 definition states that the disability “originates before the age of 18.”

1992 saw a major change, when AAIDD added to and refocused the definition of mental retardation to reflect a new way of understanding and responding to it. AAIDD moved away from a diagnostic process that identified deficits solely on the basis of an intelligence test score. It considered social, environmental, and other elements as well.

Most crucially, the emphasis shifted from providing programs to people with intellectual disabilities to designing and delivering support tailored to individuals to help them reach their highest level of functioning.

The 1992 definition was the first to view intellectual disability as a condition that could be enhanced by provision of supports, rather than as a static, lifelong disability.

Since 1992, the association has worked to further develop and refine this paradigm shift. In the association's most recent manual, Mental Retardation: Definition, Classification and Systems of Supports, published in 2002, discussion of the support system was dramatically expanded and improved.

The next manual in which "mental retardation" is universally replaced by "intellectual disability," is scheduled for release in 2010.

1 Robert L. Schalock, Ruth A. Luckasson, and Karrie A. Shogren, "Perspectives: The Renaming of Mental Retardation: Understanding the Change to the Term Intellectual Disability," *Intellectual and Developmental Disabilities*. 45:2 (2007): 116-124.

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501 3rd Street, NW Suite 200

Washington, D.C. 20001

Telephone: 202/387-1968 or 800/424-3688

Fax: 202/387-2193