



## Intellectual Disability



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### Abstract

Intellectual disability is a disability that occurs before age 18. People with this disability experience significant limitations in two main areas: 1) Intellectual functioning and 2) Adaptive behavior. These limitations are expressed in the person's conceptual, social and practical everyday living skills. A number of people with intellectual disability are mildly affected, making the disability difficult to recognize without visual cues. Intellectual disability is diagnosed through the use of standardized tests of intelligence and adaptive behavior. In this article, we will examine the symptoms and causes of intellectual disability and go through the diagnosis of intellectual disability using standardized tests of intelligence and discuss the role of the community environment and needed support.

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### 1. Introduction

Intellectual Disability (ID), is also called intellectual development disorder (IDD) or general learning disability and formerly known as mental retardation (MR) is a generalized neurodevelopmental disorder characterized by significantly impaired intellectual and adaptive functioning. It is defined by an IQ score below 70 in addition to deficits in two or more adaptive behaviors that affect every day general living.

Intellectual disability, also known as mental retardation, is a term used when there are limits to a person's ability to learn at an expected level and function in daily life. Levels of intellectual disability vary greatly in children from a very slight problem to a very severe problem. Children with intellectual disability might have a hard time letting others know their wants and needs, and taking care of themselves. Intellectual disability could cause a child to learn and develop more slowly than other children of the same age. It could take longer for a child with an intellectual disability to learn to speak, walk, dress or eat without help, and they could have trouble learning in school. Intellectual disability can be caused by a problem that starts any time before a child turns 18 years old even before birth. It can be caused by injury, disease, or a problem in the brain. For many children, the cause of their intellectual

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disability is not known. Some of the most common known causes of intellectual disability – like Down syndrome, fatal alcohol syndrome, fragile X syndrome, genetic conditions, birth defects, and infections happen before birth. Others happen while a baby is being born or soon after birth. Still other causes of intellectual disability do not occur until a child is older; these might include serious head injury, stroke, or certain infections. Usually, the more severe the degree of intellectual disability, the earlier the signs can be noticed. However, it might still be hard to tell how young children will be affected later in life.

Intellectual disability is a specific type of disability. It is caused by limited mental capacity (intelligence). These limitations make it difficult for someone to care for themselves without additional support. An estimated 1-3% of the population have intellectual disabilities.

Limited mental capacity makes it difficult to develop important mental abilities. This includes reasoning, planning, thinking, and judgment. This limited mental capacity makes it difficult to learn new things. The ability to learn is a very important mental ability. We learn new information and skills in school. We learn from our past mistakes. We learn how to do many things by watching others. When this ability to learn is lacking, it causes many problems in everyday life.

When people have limited mental abilities, it makes it difficult to acquire the skills needed for independent living. Without these skills, it is hard to live in a safe and socially responsible manner. Children with intellectual disabilities develop more slowly than other children. They usually sit, walk, and talk much later than other children. The delayed development means they do not act their age.

Intellectual disability (ID) or mental retardation is one of the most common disabilities. Braddock & Parish (2002) have defined disability as a socially determined interpretation of impairment by others. Thus the whole concept of ID and how to define or categorize people with ID (PWID) has been affected by how people in different cultures and in different periods of time have defined it and understood it. Rehabilitation of PWID has similarly been affected by changing concepts and attitudes. The following discussion of the history of intellectual disability (ID) relies on documents published in English and consequently focuses more on the history of ID in English-speaking countries – particularly the U.S. – than on that of other regions of the world. Our objective is to describe coherently one populous country's history with reference to other countries' histories, rather try to describe fully the experience of several countries. Furthermore, historical accounts and policy changes towards PWID are available to the largest extent from the U.S. Early history

It is important to understand the terms that are associated with intellectual disabilities. The first term is a disability. Disability is an individual performing which includes physical, sensory, cognitive, intellectual mental illness impairments, and various types of chronic diseases. The next term involves intelligence. This term is the ability to think logically, reason out problems, prepare, understand difficult ideas, examine intellectually, and the ability to determine quickly and or acquire from experience. The third term is an adaptive behavior. Adaptive behavior is the collection of conceptual, social, and practical skills that all individuals learn in order to perform in their everyday lives. An example of conceptual skills is the idea of numbers. Following rules are an example of social skills. Practical skills involve the use of money in society.

Intellectual disability is a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

Developmental disabilities are severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before the age of 22 and are likely to be life-long. Some developmental disabilities are largely physical issues, such as cerebral palsy or epilepsy. Some individuals may have a condition that includes a physical and intellectual disability, for example, Down syndrome or fatal alcohol syndrome.

The term or name for the condition we know today as an intellectual disability has changed over time; most recently the condition was primarily known as mental retardation.

### *Definition*

AAIDD, the world's largest and oldest organization of intellectual disability professionals, has played a major role in evolving ideas about and approaches to intellectual disability. In fact, the Association, founded in 1876, has published 11 editions of its definitional manual between 1908 and 2010, each edition containing the latest scientific understanding of the condition.

The first definitions of the condition focused on a failure to adapt socially to the environment. Later definitions added a medical approach that considered heredity and pathology and called for individuals with intellectual disability to be segregated. Then the rise of the cognitive 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.

The third element of the definition involves age of onset. Early definitions mentioned “the developmental period.” AAIDD’s 2002 definition clarified that the disability originates “before the age of 18”. It is important to note that the 1992 definition was the first to view intellectual disability as a condition that could be enhanced by the provision of supports, rather than as a static, lifelong disability.

## 2. Materials and Methods

### *Research on the views of people with an intellectual disability:*

Intellectual disability is seen primarily as a difficulty in learning. It is not surprising. Therefore, that many of our support systems focus on this primary characteristic. Practices such as “needs assessments” and “individual program planning” can place the person with an intellectual disability in the position of a “perpetual learner”.

Williams & Robinson (2000) studied the views of 51 careers and the people with an intellectual disability they cared for, about their community care assessments and individual service reviews. Very few of the people with an intellectual disability understood what these processes were about. Many of them thought such meetings were about monitoring their progress, rather than helping them to plan for a future that they wished to achieve. As Williams and Robinson explain.

*People with learning disabilities (intellectual disability) are constantly surrounded by others who are judging them, and their whole life can seem to them like an educational journey, with intermittent progress reports sent to their parents.*

With this type of conception of themselves, acquiring a view of themselves as “adult”, with its notions of autonomy and responsibility, is likely to be very difficult. Are people with an intellectual disability aware of the label and do they apply this to themselves? Is the label part of their self-identity? A UK study of 60 young people with a range of abilities and communication skills (Davies & Jenkins, 1997) sought answers to these questions. The two areas of research focus were the participants’ views of being an adult, and their understanding and self-application of the terms “learning difficulties” and “mental handicap”. The responses of the 53 young people with sufficient communication skills to discuss their understanding of these terms fell into five categories. The largest category (42%) showed complete incomprehension of the terms but showed no discomfort or embarrassment as to the questions. The second most frequent response (30%) provided a definition but one that excluded themselves. Most of these definitions focused on a physical impairment or a specific disability. Only 28 percent included themselves in their understanding of the terms “mental handicap” or “learning difficulties”.

The role of parents in controlling their offspring’s understanding of intellectual disability was also explored by Todd & Shearn (1997). Parents of 33 adults with an intellectual disability (who still lived at home) were interviewed on three or four occasions.

This research found that while parents had had to deal with the stigma of intellectual disability themselves, they deliberately tried to prevent their sons or daughters from having to deal with similar problems. The parents acted as mediators between their offspring and the outside world “filtering out” the stigma of the label, and minimising the effects of the label of intellectual disability on their offspring’s self- identities. Parents clearly have a major role to play in shaping the self- identities of their adult sons and daughters.

Todd & Shearn (1997) also identified the problems experienced by parents and their adult offspring with the notion of an “adult identity.” While parents did not deny the reality of adulthood in terms of age and physical development, they felt that the perceived dependency of their offspring meant that they viewed them generally as “non-adults”. As neither adults nor children, therefore, “adolescent status” was accepted by many parents as the most accurate description of their offspring’s identity. As the assumption of an adult status is often a contested one for adolescents, so “their sons and daughters were seen as stuck at an adolescent stage of resistance to parental authority” (Todd & Shearn, 1997: p 349). Parents often described them as “living in a fantasy world”, with which they often colluded, rather than providing their sons and daughters with accurate information about their disabilities and the demands of the real world. Thus parents were “keepers of secrets” about their offspring’s intellectual disability, to protect them from the perceived pain and negative impact of “telling” on their offspring’s sense of self.

These researchers conclude that “many people with learning (intellectual) disabilities may be invisible to themselves” (p 363). This conclusion has, however, been challenged by other researchers.

Rapley, Kiernan, and Antaki (1998) reviewed some of the data from Todd & Shearn (1997), and additional data of their own, to challenge the notion that people with an intellectual disability have little awareness of their own disability and ascribed social identity. All of the participants in the Rapley et al research were described as having a “mild or moderate intellectual disability”, and able to communicate verbally. Rapley et al argue that the conversations show many examples of the recognition and rejection of the identity of an “intellectually disabled person”. They also point out that social identity is far more dynamic and fluid than is often portrayed. In numerous social interactions, most people spend a lot of time “doing being ordinary” (Sacks, 1984), and many people with an intellectual disability do this too. Replay et al provide a number of extracts which support their interpretation that

*While they may not have offered their interviewers a textbook diagnostic definition of the term ‘intellectual disability’, close examination of what is said reveals clear understandings of the interactional and social realities of their lives.*

There is considerable evidence that some people with an intellectual disability are only too well aware of the derogatory stereotypes, connotations, and stigma of the label of intellectual disability or one of its synonyms. The early work of Robert Edgerton (1967) described how people who had moved out of institutions in the early 1970s put strenuous efforts into denying the label and their personal history and “passing” as “normal”. The label itself, even today, acts as a “social identifier”, placing the individual in the category of “abnormal”, and often calls forth fear reactions (Danforth & Navarro 1998), such as the NIMBY (Not in my Backyard) Syndrome.

The beginning of this civil rights movement was located in Sweden in 1970 when a group of 50 young adults (who had an intellectual disability) reviewed their lives, unmet needs, and aspirations (Blatt, 1987). The movement grew significantly since then, from the establishment of the first “People First” organization in Oregon, the USA in 1974 to over 505 such groups in the USA by 1994 (Ward 1996). People with an intellectual disability in New Zealand have been an active part of this movement since the mid-1980s, although the development has not been all “plain sailing” (Gosling & Gerzon 1994). Most groups call themselves “People First”, reflecting a strong assertion that their individuality and similarity to all people is more important than their disability label.

### 3. Results and Discussions

#### 3.1 Symptoms

Intellectual disabilities are identified by two key diagnostic criteria. The first criterion is limited mental ability. This is measured by IQ score. Severely limited mental abilities cause many problems. First, it is difficult to learn. Second, it is difficult to make wise decisions and use good judgment. Third, it does not easily solve problems. Fourth, it makes people more vulnerable to victimization.

The second diagnostic criterion is deficient adaptive functioning. Adaptive functioning refers to the skills needed to live independently in a safe and socially responsible manner. There are three essential sets of skills. The first is conceptual skills. These are skills related to language, literacy, mathematics, time, and self-direction. The second set is social skills. These skills help us get along with other people. The third skill set is practical skills. These are the skills needed self-care, employment, health, and safety.

In summary, people with intellectual disabilities may experience a broad range of difficulties. These include problems with communication, self-care, independent living, interpersonal relationships, accessing community resources, self-direction, employment, education, health, and safety.

Possible signs of intellectual disability:

- 1) Delayed development such as sitting, crawling, standing, walking, or talking;
- 2) Persistence of childlike behavior possibly demonstrated in speaking style;
- 3) Trouble understanding social rules and customs such as taking turns, or waiting in line;
- 4) Failure to appreciate and avoid dangerous situations such as playing in the street, or touching a hot stove;
- 5) A lack of curiosity or interest in the world around them;
- 6) Difficulty learning new information despite significant effort and repetition;
- 7) Difficulty learning new skills despite significant practice;
- 8) Difficulty solving ordinary, simple problems;
- 9) Trouble remembering things;

- 10) Difficulty meeting educational demands;
- 11) Excessive behavioral problems such as impulsivity and poor frustration tolerance.

When caregivers or teachers notice these signs, they should talk to a qualified healthcare provider. They may recommend a formal assessment and evaluation. It may be difficult to assess very young children for intellectual disability. Therefore, most clinicians are reluctant to diagnose intellectual disability in children less than two years old. The exceptions to this are when a child has a condition that is known to cause intellectual disabilities. A common example would be a child with Down syndrome.

### 3.2 Causes

There are many causes of intellectual disabilities. Some are preventable; others are not. These causes can be grouped into four categories:

- 1) Medical conditions;
- 2) Brain injury;
- 3) Genetic conditions;
- 4) Psychiatric conditions.

The leading causes are Autism, Down syndrome, Fragile X syndrome, and fatal alcohol syndrome or FAS. Among these, the only preventable cause is fatal alcohol syndrome.

Medical conditions that lead to intellectual disabilities fall into three groups. These are:

- 1) Pre-natal exposure to alcohol and other drugs;
- 2) Exposure to certain toxins; and
- 3) Some types of infections.

Prenatal exposure to alcohol and drugs is entirely preventable. Even drinking three drinks a day during pregnancy can cause fatal alcohol syndrome (FAS). FAS is a leading cause of intellectual disabilities. It is not clear how much alcohol is safe. Therefore, most doctors recommend pregnant women do not drink. Other drugs also harm a developing fetus. This includes nicotine, cocaine, and heroin. A pregnant woman should tell her doctor if she uses alcohol or drugs. Her doctor may be able to help her reduce the risks to her unborn child.

Pre and post-natal exposure to toxins can cause intellectual disabilities. Of particular concern are lead, mercury, and radiation. Avoiding exposure to these toxins reduces the risk of developing an intellectual disability. Large fish such as shark, mackerel, and swordfish contain higher amounts of mercury. Low mercury fish include shrimp, salmon, and Pollack. Lead based paints are present in pre-1970s homes and in the soil surrounding older homes. Families can find lead abatement programs through their county and state public services. High radiation exposure is associated with intellectual disabilities. Fortunately, modern radiation equipment has drastically reduced the amount of radiation exposure. However, it is uncertain what a safe level of exposure is. For this reason, women who may be pregnant should speak up before receiving any radiation procedures.

Certain types of infections can also lead to intellectual disabilities. Pregnant women can take simple steps to reduce these risks. Pregnant women should avoid any contact with cat feces. Cats can carry a parasite that causes Toxoplasma infection. This infection is known to cause intellectual disabilities. Pregnant women should not handle cat litter boxes. They should not garden in places where cats may have defecated.

Common causes occur from genetic conditions (Down syndrome and Fragile X syndrome are examples), problems during pregnancy (a pregnancy of the mother who drinks alcohol while pregnant can result in FASD), and problems at the time of birth, health problems such as whooping cough, measles or meningitis and exposure to environmental toxins like lead or mercury.

Some of the childhood disorders we will discuss in this article can be cured or otherwise resolved, while others end up becoming chronic (long-term) problems that resist the best state-of-the-art interventions. The disorders we will discuss also vary in terms of prevalence and severity. Prevalence refers to a ratio, or percentage, of how often a disease or disorder occurs within a group of people in a population at a given time. Recently, the American Psychological Association has noted an increase in the prevalence of childhood mental illnesses as a whole. Estimates of the current prevalence suggest that between 17.6% and 22% of children have symptoms of one or more

childhood disorders and that 15% of American children suffer from a mental illness that is severe enough to cause some level of functional impairment.

Beyond that, there are specific programs that people with developmental disabilities can take part in wherein they learn basic life skills. These "goals" may take a much longer amount of time for them to accomplish, but the ultimate goal is independence. This may be anything from independence in tooth brushing to an independent residence. People with developmental disabilities learn throughout their lives and can obtain many new skills even late in life with the help of their families, caregivers, clinicians and the people who coordinate the efforts of all of these people.

Despite how common they may be, childhood disorders are not part of the normal developmental process that children are expected to go through. The diagnostic criteria for childhood mental disorders require that children's behavior and/or development deviates from normal age-appropriate behavior and/or development, so understanding normal child development is important. For this reason, you might want to read over our extensive material concerning normal childhood development.

Common childhood mental illnesses and developmental disorders include Depression, Bipolar Disorder and Anxiety Disorders, Autism and similar Pervasive Developmental Disorders, Attention Deficit and Hyperactivity Disorder, Learning Disabilities, Adjustment Disorders, Oppositional Defiant Disorder, and Conduct Disorder. The first three of these disorders are not strictly childhood disorders, but instead, affect both children and adults. Since we've already discussed these disorders in detail elsewhere, we will not go into much detail about them here.

- 1) Major Depression is not strictly a childhood disorder, but children do become depressed. Major depression is diagnosed in children of all ages but appears to increase significantly throughout adolescence. By age 18, prevalence rates appear to be 20%, with depression found in girls more often than boys.
- 2) Bipolar Disorder involves alternating periods of depression and mania (high energy levels that result in a decreased need for sleep, talkativeness, impulsivity, excessive pleasure-seeking behaviors, etc.). As is the case with Major Depression, bipolar disorder is not exclusively a childhood disorder. Though both adults and children may be diagnosed with Bipolar, children display a somewhat different set of symptoms than do adults. For example, in children, mania often looks more like an extreme temper tantrum or severe irritability than the euphoric, hyperactive condition characteristic of adults.
- 3) The Bipolar diagnosis as applied to children is currently considered controversial, because the Bipolar disorder is often difficult to distinguish from other disorders that can occur in children, and may often be misdiagnosed as something else. Children may experience varying degrees of symptom severity, the timing between mood fluctuations, et cetera. Some studies have indicated prevalence rates of Bipolar Disorder among children as high as 1% (e.g., meaning that one in every hundred children may display some signs of bipolar disorder).
- 4) Anxiety Disorders, described in our Anxiety Disorders topic center, are the most common mental illnesses among youngsters today, with prevalence rates ranging between 10% and 20%. Children with anxiety disorders are more likely to develop (or to continue experiencing) anxiety disorders in adulthood and have an increased risk of developing major depression, attempting suicide, and being hospitalized for mental illnesses. One particular type of anxiety disorder, Obsessive-Compulsive Disorder (a combination of obsessions, or intrusive, repetitive, unwanted thoughts; and compulsions, or anxiety-reducing behavior such as repeated checking or counting) is found in about 5% to 2% of children and adolescents.
- 5) Causes of mental retardation are numerous, but a specific reason for mental retardation is determined in only 25 percent of cases.

Failure to adapt normally and grow intellectually may become apparent early in life or, in the case of mild retardation, may not become recognizable until school age or later. An assessment of age-appropriate adaptive behaviors can be made by the use of developmental screening tests. The failure to achieve developmental milestones is suggestive of mental retardation.

The degree of impairment from mental retardation ranges widely, from profound impairment to mild or borderline retardation. Less emphasis is now placed on the degree of retardation and more on the amount of intervention and care required for daily life.

Causes of mental retardation can be roughly broken down into several categories:

- 1) Unexplained (the largest category)
- 2) Trauma (prenatal and postnatal) such as oxygen deprivation before, during or after birth
- 3) Infection (congenital and postnatal)

- 4) Chromosomal abnormalities
- 5) Genetic abnormalities and inherited metabolic disorders
- 6) Metabolic disorders
- 7) Toxins such as lead or mercury poisoning
- 8) Nutritional deficits such as severe malnutrition
- 9) Environment

Lastly, certain psychiatric conditions are associated with intellectual disabilities. The most common disorder is called autism spectrum disorder (ASD). Like genetic abnormalities, there is no known way to predict or prevent ASD.

### 3.3 Diagnosis

The purpose of establishing a diagnosis of intellectual disability is to determine eligibility in order to receive various services and supports and to ensure rights are protected, including:

- 1) Special education services
- 2) Home and community-based waiver services
- 3) Social Security Administration benefits
- 4) Specific treatment within the criminal justice system (e.g., In 2002, the U.S. Supreme Court ruled in *Atkins v. Virginia* that executing the mentally retarded violates the Eighth Amendment's ban on cruel and unusual punishment).

Intellectual disability is diagnosed through the use of standardized tests of intelligence (testing a person's I.Q.) and adaptive behavior (the ability of a person to function and perform everyday life activities). The American Association on Intellectual and Developmental Disabilities (AAIDD) states the following must be present:

- 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 the difference 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.*
- 5) *With appropriate personalized supports over a sustained period, the life functioning of the person with an intellectual disability generally will improve (AAMR, 2002).*

Intelligence refers to general mental capability and involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience.

Common causes occur from genetic conditions (Down syndrome and Fragile X syndrome are examples), problems during pregnancy (a pregnancy of the mother who drinks alcohol while pregnant can result in FASD), problems at the time of birth, health problems such as whooping cough, measles or meningitis and exposure to environmental toxins like lead or mercury.

The impact of having an intellectual disability varies considerably, just as the range of abilities varies considerably among all people. Children may take longer to learn to speak, walk and take care of their personal needs, such as dressing or eating. It may take longer to learn in school.

The aim of this section is to describe prenatal screening procedures and tests designed to assess the functioning of children and adults. It will cover not just the technical aspects of these procedures, but the impact which the process of testing per se has on parents and on individuals who are themselves thought to have intellectual and other disabilities. A number of genetic and behavioral syndromes are discussed in some detail, in many cases with statistical information on their prevalence in a variety of populations. The effects of maternal malnutrition and pre- and antenatal environment on the development of intellectual disabilities are also brought to the attention of the reader. These authors offer their experience of initiatives which have addressed these causes, often very successfully.

As adults, some people are able to lead independent lives in the community without paid supports. A small percentage will have serious, lifelong limitations in functioning. However, with early intervention, an appropriate education and supports as an adult, all can lead satisfying lives in the community.

Sometimes intellectual disability is also referred to as developmental disability which is a broader term that includes ASD (autism spectrum disorders), epilepsy, cerebral palsy, developmental delay, fetal alcohol syndrome (or FASD) and other disorders that occur during the developmental period (birth to age 18).

The major differences are in the age of onset, the severity of limitations, and the fact that a person with a developmental disability definition may or may not have a low I.Q. While some people with intellectual disability will also meet the definition of developmental disability, it is estimated that at least half do not meet the requirements for the developmental disability definition.

#### 4. Conclusion

Overall, the study has yielded better detail about the intellectual disability based on the health conditions and other factors. In conclusion, people with intellectual disabilities can live meaningful, satisfying and productive lives, within their own communities, when provided adequate supports. We salute the courage and dedication of families and other advocates who have tirelessly worked to improve the lives of these deserving citizens.

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##### *Statement of authorship*

The author(s) have a responsibility for the conception and design of the study. The author(s) have approved the final article.

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