



## Intellectual and Developmental Disabilities (IDDs)

IDDs are a primary focus of NICHD's research support. IDDs include disabilities and disorders that affect the nervous system, metabolism, and cell function and survival.

NICHD supports and conducts research to understand the causes and effects of IDDs and to help identify effective therapies for these disorders. NICHD invests heavily in supporting many areas of IDD research, including genetic and developmental causes of IDDs; ways that IDDs affect learning, communication, cognition, and memory; interactions of the family and community with individuals with IDDs; and effect of individual factors on social interactions, behavior, and emotions.

### About Intellectual and Developmental Disabilities (IDDs)

#### What are IDDs?

IDDs are differences that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems.

Intellectual disability<sup>1</sup> starts any time before a child turns 18 and is characterized by differences with both:

- Intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and
- Adaptive behavior, which includes everyday social and life skills.

The term "developmental disabilities" is a broader category of often lifelong challenges that can be intellectual, physical, or both.<sup>2</sup>

"IDD" is the term often used to describe situations in which intellectual disability and other disabilities are present.<sup>3</sup>

It might be helpful to think about IDD in terms of the body parts or systems they affect or how they occur. For example<sup>4</sup>:

- **Nervous system**

These disorders affect how the brain, spinal cord, and nervous system function, which can affect intelligence and learning. These conditions can also cause other issues, such as behavioral disorders, speech or language difficulties, seizures, and trouble with movement. Cerebral palsy,<sup>5</sup>[Down syndrome \(/health/topics/downsyndrome\)](#), [Fragile X syndrome \(/health/topics/fragilex\)](#), and [autism spectrum disorders \(ASDs\) \(/health/topics/autism\)](#) are examples of IDDs related to problems with the nervous system.

- **Sensory system**

These disorders affect the senses (sight, hearing, touch, taste, and smell) or how the brain processes or interprets information from the senses. [Preterm infants \(/health/topics/preterm\)](#) and infants exposed to infections, such as cytomegalovirus, may have reduced function with their eyesight and/or hearing. In addition, being touched or held can be difficult for people with ASDs.

- **Metabolism**

These disorders affect how the body uses food and other materials for energy and growth. For example, how the body breaks down food during digestion is a metabolic process. Problems with these processes can upset the balance of materials available for the body to function properly. Too much of one thing, or too little of another can disrupt overall body and brain functions. [Phenylketonuria \(PKU\) \(/health/topics/pku\)](#) and congenital hypothyroidism are examples of metabolic conditions that can lead to IDDs.

- **Degenerative**


Individuals with degenerative disorders may seem or be typical at birth and may meet usual developmental milestones for a time, but then they experience disruptions in skills, abilities, and functions because of the condition. In some cases, the disorder may not be detected until the child is an adolescent or adult and starts to show symptoms or lose abilities. Some degenerative disorders result from other conditions, such as untreated problems of metabolism.

The exact definition of IDD, as well as the different types or categories of IDD, may vary depending on the source of the information.

For example, within the context of education and the Individuals with Disabilities Education Act (IDEA), a law that aims to ensure educational services to children with disabilities throughout the nation, the definition of IDD and the types of conditions that are considered IDD might be different from the definitions and categories used




by the Social Security Administration (SSA) to provide services and support for those with disabilities. These definitions and categories might also be different from those used by healthcare providers and researchers.

For more information about disabilities included in IDEA, visit

<https://www.parentcenterhub.org/disability-landing/> (<https://www.parentcenterhub.org/disability-landing/>).  (/external-disclaimer). For information about SSA and disabilities, visit <https://www.ssa.gov/planners/disability/> (<https://www.ssa.gov/planners/disability/>).

## Citations



1. Centers for Disease Control and Prevention. (n.d.). *Intellectual disability fact sheet*. Retrieved August 9, 2012, from <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts-about-intellectual-disability.html>
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4. National Dissemination Center for Children with Disabilities (NICHCY). (2011). *NICHCY disability fact sheet #8: Intellectual disabilities*. Retrieved August 9, 2012, from <https://www.parentcenterhub.org/disability-landing/> 
5. Centers for Disease Control and Prevention. (May 18, 2012). *Cerebral palsy: Facts about cerebral palsy*. Retrieved August 12, 2012, from <http://www.cdc.gov/ncbddd/cp/facts.html>

# What are the signs of intellectual and development disabilities (IDDs)?


The signs of IDDs vary for particular conditions.

IDDs that are more severe may show up sooner. Some of the signs of IDD may include<sup>1,2</sup>:

- Sitting up, crawling, or walking later than other children of similar age
- Learning to talk later or having difficulty speaking
- Finding it hard to remember things
- Having trouble understanding the rules of social behavior
- Having difficulty "seeing" or understanding the outcomes of actions
- Having trouble solving problems


**Developmental milestones** can be monitored to identify delays (e.g., in walking or talking) that could indicate an IDD.

To learn more about developmental milestones, and milestones for different ages, visit the following websites:

- American Academy of Pediatrics:  
<http://www.healthychildren.org/English/ages-stages/>  
(<http://www.healthychildren.org/English/ages-stages/>).  (/external-disclaimer)
- Centers for Disease Control and Prevention:  
<http://www.cdc.gov/ncbddd/actearly/milestones/>  
(<http://www.cdc.gov/ncbddd/actearly/milestones/>).

## Citations



1. Centers for Disease Control and Prevention. (n.d.). *Intellectual disability fact sheet*. Retrieved August 9, 2012, from <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts-about-intellectual-disability.html>
2. National Dissemination Center for Children with Disabilities. (2011). *NICHCY disability fact sheet #8: intellectual disabilities*. Retrieved August 9, 2012, from <https://www.parentcenterhub.org/disability-landing/> 

## How many people are affected/at risk for intellectual and developmental disabilities (IDDs)?

The exact number of people affected by IDDs is unknown. This is because IDDs cover a wide range of conditions, many of which are diagnosed several years after birth, rather than in newborns.


Current estimates suggest that 2% to 3% of children in the United States have some form of intellectual disability.<sup>1</sup>

According to the Centers for Disease Control and Prevention (CDC), about 1 in 33 newborns (or 3%) in the United States are born with conditions related to problems in prenatal development.<sup>2</sup>

For current statistics on the number of children born with specific types of these conditions, visit the CDC Data and Statistics webpage on birth defects.

### Citations



1. American Academy of Pediatrics. (2012). *Health issues: Children with intellectual disabilities*. Retrieved August 9, 2012, from <http://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Intellectual-Disability.aspx> 
2. Centers for Disease Control and Prevention. (2008). Update on overall prevalence of major birth defects-Atlanta, Georgia, 1978-2005. *Morbidity and Mortality Weekly Report*, 57, 1-5. Retrieved August 9, 2012, from <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5701a2.htm>

# What causes intellectual and developmental disabilities (IDDs)?

IDDs have a variety of causes. Some possible causes include (but are not limited to):<sup>1,2,3</sup>

- Genetic mutations, additions, or deletions: for example, most cases of [Rett syndrome \(/health/topics/rett\)](/health/topics/rett) are caused by a change in the *Methyl-CpG-binding Protein 2 (MECP2)* gene
- Chromosome abnormalities, such as an extra chromosome or a missing chromosome: for example, [Down syndrome \(/health/topics/downsyndrome\)](/health/topics/downsyndrome) results from having an extra copy or part of a copy of chromosome 21
- Exposure to certain substances while in the womb: for example, exposure to alcohol while in the womb can result in fetal alcohol spectrum disorder
- Infections during pregnancy: for example, infants whose mothers had cytomegalovirus during pregnancy may have hearing, vision, and neurological problems
- Problems during childbirth: for example, an umbilical cord that gets wrapped around a baby's neck during delivery could cut off the supply of blood and oxygen to the brain resulting in IDD
- [Traumatic Brain Injury \(TBI\) \(/health/topics/tbi\)](/health/topics/tbi)
- [Preterm birth \(/health/topics/preterm\)](/health/topics/preterm)

## Citations



1. American Academy of Pediatrics. (July 30, 2012). *Health issues: Outlook for children with intellectual disabilities*. Retrieved August 9, 2012, from <http://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Outlook-for-Children-with-Intellectual-Disabilities.aspx> ↗
2. National Dissemination Center for Children with Disabilities (NICHCY). (January, 2011). *NICHCY disability fact sheet #8: Intellectual disabilities*. Retrieved August 9, 2012, from <https://www.parentcenterhub.org/intellectual/> ↗
3. American Academy of Pediatrics. (July 30, 2012). *Health issues: Children with intellectual disabilities*. Retrieved August 9, 2012, from <http://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Intellectual-Disability.aspx> ↗

## How do healthcare providers diagnose intellectual and developmental disabilities (IDDs)?

The diagnosis of an intellectual disability is typically made through a test of intelligence or cognition, often assessed by the range of scores on an Intelligence Quotient (IQ) test.<sup>1</sup> This type of test will help the health care provider examine the abilities of a person to learn, think, solve problems, and make sense of the world.<sup>2</sup> Average IQ test score is around 100, and 85% of children with an intellectual disability score in the range of 55 to 70.<sup>3</sup> More severe cases of intellectual disability generally have lower IQ scores.

Clinicians will also observe a child's behavior for signs of a disability and assess adaptive behavior. Adaptive behaviors include coping skills and other behaviors that show how a child interacts with other people.<sup>2</sup> Health care providers can use this information to assess whether the individual has the skills needed to care for oneself and interact with others.

Some conditions that lead to IDDs may be diagnosed with a blood test, ultrasound, or another method, depending upon the condition. These tests may be conducted after birth or during pregnancy.

Newborn screening (</health/topics/newborn>) relies on testing blood samples taken from newborns while they are still in the hospital to help identify certain serious or life-threatening conditions, including some that lead to IDDs. Most tests use a few drops of blood obtained by pricking the infant's heel. If a screening test suggests a problem, the infant's doctor will follow up with further testing.<sup>4</sup>

### **Prenatal Screening**

Health care providers recommend that certain pregnant women, including those who are older than 35 years of age and those with a family history of certain conditions, have their fetuses tested prenatally, while still in the womb, for conditions that cause IDD. There are two main types of prenatal tests.

### **Amniocentesis<sup>5</sup>**

Amniocentesis is a test that is usually performed to determine whether a fetus has a genetic disorder. In this test, a doctor takes a small amount of fluid from the womb using a long needle. The fluid, called amniotic fluid, contains cells that have genetic material that is the same as the fetus's genetic material. A laboratory grows the cells and then examines their genetic material for any problems. Some IDDs

that can be detected with amniocentesis are [Down syndrome \(/health/topics/downsyndrome\)](/health/topics/downsyndrome) and certain types of [muscular dystrophy \(/health/topics/musculardys\)](/health/topics/musculardys).

Because amniocentesis can cause a miscarriage in about 1 out of 200 cases, it is usually only recommended for pregnancies in which the risk of genetic disorders or other problems is high.

## Chorionic Villus Sampling (CVS)<sup>6,7</sup>

This test extracts cells from inside the womb to determine whether the fetus has a genetic disorder. Using a long needle, the doctor takes cells from the chorionic villi, which are tissues in the placenta, the organ in the womb that nourishes the fetus. The genetic material in the chorionic villus cells is identical to that of the fetal cells.

Like amniocentesis, CVS can be used to test for chromosomal disorders such as [Down syndrome \(/health/topics/downsyndrome\)](/health/topics/downsyndrome) and other genetic problems. CVS can be done earlier in pregnancy than amniocentesis, but it is also associated with a higher risk of miscarriage—about 1 in 100 cases. Healthcare providers usually only recommend CVS in women who are at high risk for a condition or IDD.

## Citations



1. American Academy of Pediatrics. (July 30, 2012). *Health issues: Outlook for children with intellectual disabilities*. Retrieved August 9, 2012, from <http://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Outlook-for-Children-with-Intellectual-Disabilities.aspx>
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7. American College of Obstetricians and Gynecologists. (2007). Invasive prenatal testing for aneuploidy. Washington, DC: Author. Retrieved September 14, 2014, from <https://pubmed.ncbi.nlm.nih.gov/18055749/>



## What should I do if I think my child has an intellectual and developmental disability (IDD)?

Many IDDs have no cure, but there are often ways to treat their symptoms. For example:

- Children with [Down syndrome \(/health/topics/downsyndrome\)](/health/topics/downsyndrome), [Fragile X syndrome \(/health/topics/fragilex\)](/health/topics/fragilex), [Rett syndrome \(/health/topics/rett\)](/health/topics/rett), and other IDDs can often benefit from therapeutic speech therapy, occupational therapy, and exercises to improve their gross- and fine-motor skills. They might also be helped by special education and attention at school and by the efforts of parents, educators, and healthcare practitioners to encourage social contact and communication. In addition, for children with Down syndrome, surgery can help correct heart defects that may be present.
- A variety of treatment options are available to help with the symptoms of [autism spectrum disorders \(/health/topics/autism\)](/health/topics/autism). Options may include behavioral, occupational, physical, and speech-language therapy. In addition, educational specialists can help guide the child's school experiences.
- Treatment for hypothyroidism, or underactive thyroid, includes daily oral hormone treatment.
- The most effective treatment for [phenylketonuria \(PKU\) \(/health/topics/pku\)](/health/topics/pku) is a special diet that carefully limits intake of the amino acid phenylalanine. People with PKU who begin this diet at birth or shortly thereafter develop normally and usually have no symptoms of PKU. It is important that individuals with PKU stay on the special diet through adolescence and that women with PKU continue the diet before and during pregnancy to promote the best health outcomes.

# What are treatments for intellectual and developmental disabilities (IDDs)?

If you suspect that your child has an IDD, you should first talk with the child's healthcare provider. If the healthcare provider thinks there might be a problem, you should then see a developmental pediatrician or another specialist.

You can also contact your local early-intervention agency (for children under the age of 3 years) or public school (for children aged 3 years or older).<sup>1</sup>

In addition, your local school system can provide help in diagnosing a child's condition and evaluating her/his educational needs as part of the Individuals with Disabilities Education Act (IDEA), which aims to ensure educational services to children with disabilities throughout the nation.<sup>2</sup>

To learn more about the IDEA, visit: <https://www2.ed.gov/about/offices/list/osep/index.html> (<https://www2.ed.gov/about/offices/list/osep/>).

## Citations



1. Centers for Disease Control and Prevention. (n.d.). *Intellectual disability fact sheet*. Retrieved August 9, 2012, from <https://www.cdc.gov/ncbddd/developmentaldisabilities/facts-about-intellectual-disability.html>
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