

Matthew's Story

Matt is 15 years old. Because Matt has an intellectual disability, he has been receiving special education services since elementary school. These services have helped him tremendously, because they are designed to fit his special learning needs. Last year he started high school. He, his family, and the school took a good hard look at what he wants to do when secondary school is over. Does he want more education? A job? Does he have the skills he needs to live on his own? Answering these questions has helped Matt and the school plan for the future. He's always been interested in the outdoors, in plants, and especially in trees. He knows all the tree names and can recognize them by their leaves and bark. So this year he's learning about jobs like forestry, landscaping, and grounds maintenance. Next year he hopes to get a part-time job. He's learning to use public transportation, so he'll be able to get to and from the job. Having an intellectual disability makes it harder for Matt to learn new things. He needs things to be very concrete. But he's determined. He wants to work outside, maybe in the park service or in a greenhouse, and he's getting ready!

What is an Intellectual Disability?

Intellectual disability is a term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills. These limitations will cause a child to learn and develop more slowly than a typical child. Children with intellectual disabilities (sometimes called *cognitive disabilities* or *mental retardation*) may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. They *will* learn, but it will take them longer. There may be some things they cannot learn.

What Causes an Intellectual Disability?

Doctors have found many causes of intellectual disabilities. The most common are:

- *Genetic conditions.* Sometimes an intellectual disability is caused by abnormal genes inherited from parents, errors when genes combine, or other reasons. Examples of genetic conditions are Down syndrome, fragile X syndrome, and phenylketonuria (PKU).
- *Problems during pregnancy.* An intellectual disability can result when the baby does not develop inside the mother properly. For example, there may be a problem with the way the baby's cells divide as it grows. A woman who drinks alcohol or gets an infection like rubella during pregnancy may also have a baby with an intellectual disability.
- *Problems at birth.* If a baby has problems during labor and birth, such as not getting enough oxygen, he or she may have an intellectual disability.
- *Health problems.* Diseases like whooping cough, the measles, or meningitis can cause intellectual disabilities. They can also be caused by extreme malnutrition (not eating right), not getting enough medical care, or by being exposed to poisons like lead or mercury. An intellectual disability is not a disease. You can't catch an intellectual disability from anyone. It's also not a type of mental illness, like depression. There is no cure for intellectual disabilities. However, most children with an intellectual disability can learn to do many things. It just takes them more time and effort than other children.

How Common are Intellectual Disabilities?

Intellectual disability is the most common developmental disability. Approximately 6.5 million people in the United States have an intellectual disability. More than 545,000 children (ages 6-21) have some level of intellectual disability and receive special education services in public school under this category in IDEA, the nation's special education law. In fact, 1 in every 10 children who need special education have some form of intellectual disability.

What are the Signs of Intellectual Disability?

There are many signs of an intellectual disability. For example, children with an intellectual disability may:

- sit up, crawl, or walk later than other children;
- learn to talk later, or have trouble speaking,
- find it hard to remember things,
- not understand how to pay for things,
- have trouble understanding social rules,
- have trouble seeing the consequences of their actions,
- have trouble solving problems, and/or
- have trouble thinking logically.

How are Intellectual Disabilities Diagnosed?

Intellectual disabilities are diagnosed by looking at two main things. These are:

- the ability of a person's brain to learn, think, solve problems, and make sense of the world (called IQ or *intellectual functioning*); and
- whether the person has the skills he or she needs to live independently (called *adaptive behavior*, or adaptive functioning). Intellectual functioning, or IQ, is usually measured by a test called an IQ test. The average score is 100. People scoring below 70 to 75 are thought to have an intellectual disability. To measure adaptive behavior, professionals look at what a child can do in comparison to other children of his or her age. Certain skills are important to adaptive behavior.

These are:

- daily living skills, such as getting dressed, going to the bathroom, and feeding one's self;
- communication skills, such as understanding what is said and being able to answer;
- social skills with peers, family members, adults, and others. To diagnose an intellectual disability, professionals look at the person's mental abilities (IQ) and his or her adaptive skills. Both of these are highlighted in the definition of this disability in the box on this page. This definition comes from the Individuals with Disabilities Education Act (IDEA). IDEA is the federal law that guides how early intervention and special education services are provided to infants, toddlers, children, and youth with disabilities. Providing services to help individuals with intellectual disabilities has led to a new understanding of how we define the term. After the initial diagnosis is made, we look at a person's strengths and weaknesses. We also look at how much support or help the person needs to get along at home, in school, and in the community. This approach gives a realistic picture of each individual. It also recognizes that the "picture" can change. As the person grows and learns, his or her ability to get along in the world grows as well.

Definition of "Intellectual Disability" under IDEA

Until Rosa's Law was signed into law by President Obama in October 2010, IDEA used the term "mental retardation" instead of "intellectual disability." Rosa's Law changed the term to be used in future to "intellectual disability." The definition itself, however, did not change. Accordingly, "intellectual disability" is defined as "...significantly sub-average general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance." [34 CFR §300.8(c)(6)]

Help for Babies and Toddlers

When a baby is born with an intellectual disability, his or her parents should know that there's a lot of help available—and immediately. Shortly after the diagnosis of ID is confirmed, parents will want to get in touch with the **early intervention** system in their community. We'll tell you how in a moment. Early intervention is a system of services designed to help infants and toddlers with disabilities (until their 3rd birthday) and their families. It's mandated by IDEA. Staff work with the child's family to develop what is known as an *Individualized Family Services Plan*, or *IFSP*. The IFSP will describe the child's unique needs as well as the services he or she will receive to address those needs. The IFSP will also emphasize the unique needs of the family, so that parents and other family members will know how to help their young child with intellectual disability. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income. To access early intervention services in your area, consult NICHCY's *State Resource Sheet* for your state. It's available online at: <http://nichcy.org/state-organization-search-by-state> There, you'll find a listing for early intervention under the first section, **State Agencies**. The agency listed will be able to put you in contact with the early intervention program in your community. To learn more about early intervention, including how to write the IFSP, visit NICHCY at: <http://nichcy.org/babies/overview/>

Help for School-Aged Children

Just as IDEA requires that early intervention be made available to babies and toddlers with disabilities, it requires that **special education and related services** be made available free of charge to every eligible child with a disability, including preschoolers (ages 3-21). These services are specially designed to address the child's individual needs associated with the disability—in this case, an intellectual disability. School staff will work with the child's parents to develop an *Individualized Education Program*, or *IEP*. The IEP is similar to an IFSP. It describes the child's unique needs and the services that have been designed to meet those needs. Special education and related services are provided at no cost to parents. To access special education services for a school-aged child in your area, get in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start. There is a lot to know about the special education process, much of which you can learn at NICHCY, which offers a wide range of publications on the topic. Enter our special education information at: <http://nichcy.org/schoolage/>

Educational Considerations

A child with an intellectual disability can do well in school but is likely to need the individualized help that's available as special education and related services. The level of help and support that's needed will depend upon the degree of intellectual disability involved.

General education. It's important that students with intellectual disabilities be involved in, and make progress in, the general education curriculum. That's the same curriculum that's learned by those without disabilities. Be aware that IDEA does not permit a student to be removed from education in age appropriate general education classrooms solely because he or she needs modifications to be made in the general education curriculum.

Supplementary aids and services. Given that intellectual disabilities affect learning, it's often crucial to provide supports to students with ID in the classroom. This includes making *accommodations* appropriate to the needs of the student. It also includes providing what IDEA calls "supplementary aids and services." Supplementary aids and services are supports that may include instruction, personnel, equipment, or other accommodations that enable children with disabilities to be educated with nondisabled children to the maximum extent appropriate. Thus, for families and teachers alike, it's important to know what changes and accommodations are helpful to students with intellectual disabilities. These need to be discussed by the IEP team and included in the IEP, if appropriate. Some common changes that help students with intellectual disabilities are listed in the "Tips for Teachers" box on the next page. The organizations listed in the Resource Section also offer a great deal of information on ways to

help children with intellectual disabilities learn and succeed in school. And you can also consult NICHCY, beginning online at: <http://nichcy.org/schoolage/accommodations/>

Adaptive skills. Many children with intellectual disabilities need help with adaptive skills, which are skills needed to live, work, and play in the community. Teachers and parents can help a child work on these skills at both school and home. Some of these skills include:

- communicating with others;
- taking care of personal needs (dressing, bathing, going to the bathroom);
- health and safety;
- home living (helping to set the table, cleaning the house, or cooking dinner);
- social skills (manners, knowing the rules of conversation, getting along in a group, playing a game);
- reading, writing, and basic math; and
- as they get older, skills that will help them in the workplace.

Transition planning. It's extremely important for families and schools to begin planning early for the student's transition into the world of adulthood. Because intellectual disability affects how quickly and how well an individual learns new information and skills, the sooner transition planning begins, the more can be accomplished before the student leaves secondary school. IDEA requires that, at the latest, transition planning for students with disabilities must begin no later than the first IEP to be in effect when they turn 16. The IEP teams of many students with intellectual disabilities feel that it's important for these students to begin earlier than that. And they do. For more information, visit NICHCY's Transition pages, beginning at: <http://nichcy.org/schoolage/transitionadult/>

Tips for Teachers

Learn as much as you can about intellectual disability. The organizations listed below will help you identify techniques and strategies to support the student educationally. We've also listed some strategies below. Recognize that you can make an enormous difference in this student's life! Find out what the student's strengths and interests are, and emphasize them. Create opportunities for success. If you are not part of the student's IEP team, ask for a copy of his or her IEP. The student's educational goals will be listed there, as well as the services and classroom accommodations he or she is to receive. Talk to others in your school (e.g., special educators), as necessary. They can help you identify effective methods of teaching this student, ways to adapt the curriculum, and how to address the student's IEP goals in your classroom. Be as concrete as possible. Demonstrate what you mean rather than giving verbal directions. Rather than just relating new information verbally, show a picture. And rather than just showing a picture, provide the student with hands-on materials and experiences and the opportunity to try things out. Break longer, new tasks into small steps. Demonstrate the steps. Have the student do the steps, one at a time. Provide assistance, as necessary. Give the student immediate feedback. Teach the student life skills such as daily living, social skills, and occupational awareness and exploration, as appropriate. Involve the student in group activities or clubs. Work together with the student's parents and other school personnel to create and implement an IEP tailored to meet the student's needs. Regularly share information about how the student is doing at school and at home.

Tips for Parents

- Learn about intellectual disability. The more you know, the more you can help yourself and your child. See the list of organizations below.
- Be patient, be hopeful. Your child, like every child, has a whole lifetime to learn and grow.
- Encourage independence in your child. For example, help your child learn daily care skills, such as dressing, feeding him or herself, using the bathroom, and grooming.

- ❑ Give your child chores. Keep her age, attention span, and abilities in mind. Break down jobs into smaller steps. For example, if your child's job is to set the table, first ask her to get the right number of napkins. Then have her put one at each family member's place at the table. Do the same with the utensils, going one at a time. Tell her what to do, step by step, until the job is done. Demonstrate how to do the job. Help her when she needs assistance.
- ❑ Give your child frequent feedback. Praise your child when he or she does well. Build your child's abilities.
- ❑ Find out what skills your child is learning at school. Find ways for your child to apply those skills at home. For example, if the teacher is going over a lesson about money, take your child to the supermarket with you. Help him count out the money to pay for your groceries. Help him count the change.
- ❑ Find opportunities in your community for social activities, such as scouts, recreation center activities, sports, and so on. These will help your child build social skills as well as to have fun. ❑ Talk to other parents whose children have an intellectual disability. Parents can share practical advice and emotional support. Visit NICHCY's State-Specific Resources page and find a parent group near you. Look in the Disability-Specific section, under "intellectual disabilities." State Sheets are online at: <http://nichcy.org/state-organization-searchby-state>
- ❑ Meet with the school and develop an IEP to address your child's needs. Keep in touch with your child's teachers. Offer support. Find out how you can support your child's school learning at home.
- ❑ Take pleasure in your beautiful one. He—she—is a treasure. Learn from your child, too. Those with intellectual disabilities have a special light within—let it shine.

The Arc of the United States

800.433.5255 | info@thearc.org | www.thearc.org

Find a local chapter near you: <http://www.thearc.org/page.aspx?pid=2437>

American Association on Intellectual and Developmental Disabilities

800.424.3688 | www.aaid.org/

The AAIDD definition manual contains the world's most current and authoritative information on intellectual disability, including best practice guidelines on diagnosing and classifying intellectual disability and developing a system of supports for people living with an intellectual disability.

Division on Autism and Developmental Disabilities (DADD)

This division of the Council for Exceptional Children offers many publications and journals for professionals. <http://daddcec.org/>