

Down syndrome

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In This Publication:

- [Definition of Down syndrome](#)
- [Incidence](#)
- [Characteristics](#)
- [Help for babies and toddlers](#)
- [Help for school-aged children](#)
- [Health considerations](#)
- [Educating students with Down syndrome](#)
- [For high school students with Down syndrome](#)
- [Tips for parents](#)
- [Tips for teachers](#)
- [Organizations](#)

Definition

Down syndrome is the most common and readily identifiable chromosomal condition associated with intellectual disabilities. It is caused by a chromosomal abnormality: for some unknown reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth.

Just as in the normal population, there is a wide variation in mental abilities, behavior, and developmental progress in individuals with Down syndrome. Their level of intellectual disability may range from mild to severe, with the majority functioning in the mild to moderate range.

Because children with Down syndrome differ in ability, it's important that families and members of the intervention team place few limitations on potential capabilities and possible achievements. Each child with Down syndrome has his or her own talents and unique capacities, and it's important to recognize these and reinforce them. As the Family Doctor website states:

In many important ways, children who have Down syndrome are very much the same as other children. They have the same moods and emotions, and they like to learn new things, to play and enjoy life. You can help your child by providing as many chances as possible for him or her to do these things. Read to your child and play with him or her, just as you would any other child. Help your child to have positive experiences with new people and places. (1)

Down syndrome

Incidence of Down syndrome

Nearly 5,000 babies are born with Down syndrome in the United States each year. (2) This means that 1 in every 700 babies is born with this condition. (3) Although parents of any age may have a child with Down syndrome, 80% are born to women under the age of 35. (4)

Down syndrome is not a disease, nor is it contagious. Its most common forms usually do not occur more than once in a family.

Characteristics of Down syndrome

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Every child with Down syndrome is different.

Some common characteristics include:

- Poor muscle tone;
- Slanting eyes with folds of skin at the inner corners (called epicanthal folds);
- Hyperflexibility (excessive ability to extend the joints);
- Short, broad hands with a single crease across the palm on one or both hands;
- Broad feet with short toes;
- Flat bridge of the nose;
- Short, low-set ears; and
- Short neck and small head;
- Small oral cavity; and/or
- Short, high-pitched cries in infancy.

Individuals with Down syndrome are usually smaller than their nondisabled peers, and their physical as well as intellectual development is slower.

Help for Babies and Toddlers

When a baby is born with Down syndrome, his or her parents should know that there's a lot of help available—and immediately. Shortly after the diagnosis of Down syndrome is confirmed, parents will want to get in touch with the early intervention system in their community.

Early intervention is a system of services designed to help infants and toddlers with disabilities (before their 3rd birthday) and their families. It's mandated by federal law—the Individuals with Disabilities Education Act (IDEA), the nation's special education law. 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 Down syndrome. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.

To identify the EI program in your neighborhood:

- Ask your child's pediatrician for a referral.
- Call the local hospital's maternity ward or pediatric ward, and ask for the contact information of the local early intervention program.

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, Down syndrome.

There is a lot to know about the special education process, much of which you can learn at here at the Center for Parent Information and Resources, which offers a wide range of publications on the topic. To begin, however, and 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.

Down syndrome

Health Considerations

Besides having a distinct physical appearance, children with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are common in individuals with Down syndrome, as are mild to moderate hearing loss and speech difficulty. Approximately one third of babies born with Down syndrome have **heart defects, most of which are now successfully correctable**. Some individuals are born with gastrointestinal tract problems that can be surgically corrected. Some people with Down syndrome also may have a condition known as *Atlantoaxial Instability*, a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

Children with Down syndrome may have a **tendency to become obese as they grow older**. Besides having negative social implications, this weight gain threatens these individuals' health and longevity. A supervised diet and exercise program may help reduce this problem.

Educating Children with Down syndrome

When a child with Down syndrome reaches school age (after the 3rd birthday), the public school system becomes responsible for educating the child and for addressing the child's unique needs related to his or her disability. Parents and school personnel will work together to develop what is known as an Individualized Education Program (IEP) for the child.

The IEP is similar to an IFSP in that it describes the child's unique needs and the services that will be provided to meet those needs. The IEP will include annual goals for learning and much more. CPIR offers a great deal of information about the process for developing an IEP—especially the parent's guide called **Developing Your Child's IEP**—all of which can help parents learn how to participate effectively in their child's education.

Much information is also available for teachers to learn more about effective teaching practices for children with Down syndrome. It's important for teachers to take into consideration the degree of intellectual disability involved, the child's talents and interests, and the supports and services he or she needs, as specified in the IEP. Generally speaking, teachers will find it more effective to emphasize concrete concepts with a student who has Down syndrome, instead of abstract ideas. Teaching skills in a step-by-step fashion with frequent reinforcement and consistent feedback has proven successful. Other suggestions for teachers are given toward the end of this fact sheet.

Today, the majority of children with Down syndrome are educated in the regular classroom, alongside their peers without disabilities. This is in keeping with the inclusion movement of the last decade and the requirements of IDEA, which states that each school system must ensure that:

Special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (5)

Equally clear is this requirement of IDEA: A child with a disability [may not be] removed from education in age-appropriate regular classrooms solely because of needed modifications in the general education curriculum. (6)

For High School Students with Down syndrome

While the student is still in secondary school, parents, the IEP team, and the student himself (or herself!) will need to **plan for the future and the student's life as an adult**. This involves considering, for example, issues such as employment (with or without supports), independent living and self-care skills, the possibility of higher education or vocational training, and how to connect with adult service systems. Under IDEA, the process of

Down syndrome

planning for transition to adulthood should begin **no later than the student's 16th birthday**. (Z) For adolescents with Down syndrome, it's usually important to begin earlier than that.

Adult life for individuals with Down syndrome has changed noticeably from just two decades ago.

Opportunities to live and work independently in the community have greatly expanded for those with Down syndrome. This owes much to the more inclusive and comprehensive education IDEA promotes and to improved public attitudes towards disability. Today, there's a nationwide network of independent living centers, as well as apartments that are group-shared and supervised for those who need this level of support. Training, education, and assistance are also available to eligible adults with Down syndrome through service systems such as Vocational Rehabilitation and Social Security. Adult life holds many opportunities for those with Down syndrome, so it's important to plan ahead with optimism and vigor.

Tips for Parents

- **Learn about Down syndrome.** The more you know, the more you can help yourself and your child. See the list of organizations below.
- **Love and play with your child.** Treat your son or daughter as you would a child without disabilities. Take your child places, read together, have fun.
- **Encourage your child to be independent.** For example, help your son or daughter learn self-care skills such as getting dressed, grooming, and doing laundry.
- **Give your child chores.** Keep in mind his or her age, mental capacity, attention span, and abilities. Divide tasks into small steps. Explain what your child is supposed to do, step by step, until the chore is done. Demonstrate. Offer help when it's needed and praise when things go well.
- **Work with the professionals who are working with your child.** Participate in team meetings where your child's education or program is being planned, share your unique knowledge of who your son or daughter is, advocate that the program address your child's needs.
- **Find out what your child is learning at school.** Look for ways to apply it at home. For example, if the teacher is reviewing concepts of money, take your child to the supermarket with you to help keep track of what money you're spending.
- **Look for social opportunities in the community** (such as Scouts) or activities offered through the department of sports and leisure. Joining in and taking part will help your child develop social skills and have fun.
- **Talk with other parents whose children have Down syndrome.** They can be a fountain of practical advice and emotional support. Visit the websites of the organizations listed below to see if they have a parent group nearby.
- **Be patient, be hopeful.** Your child, like every child, has a whole lifetime to learn and grow.
- **Take pleasure in your beautiful one.** He—she—is a treasure. Learn from your child, too. Those with Down syndrome have a special light within—let it shine.

Tips for Teachers

- **Learn as much as possible about Down syndrome.** The organizations mentioned in this fact sheet can help you identify techniques and specific strategies to support the student's learning. We've included some additional suggestions below.
- This may seem obvious, but sometimes the appearance of Down syndrome can give the mistaken impression that the child cannot learn. **Focus on the individual child and learn firsthand what needs and capabilities he or she has.**
- **Realize that you can make a big difference in this student's life!** Use the student's abilities and interests to involve and motivate. Give lots of opportunities for the student to be successful.

Down syndrome

- **Talk candidly with your student's parents.** They're experts and can tell you a great deal about their daughter's or son's special needs and abilities.
- **Work with the student's parents and other school personnel** to develop and implement a special educational plan (IEP) that addresses the individual needs of the student. Share information on a regular basis with parents about how things are going for the student at home and in school.
- If you're not part of the student's IEP team, **ask for a copy of this important document.** The student's educational goals will be listed there, as will the services and accommodations that he or she is supposed to receive, including in your class.
- **Talk to specialists in your school** (for example, special educators), as necessary. They can help you identify methods that are effective for teaching a student with disabilities, ways to adapt the curriculum, and how to address the student's IEP goals in the classroom.
- **Be as concrete as possible with the student.** Demonstrate what you want to see happen instead of giving only verbal instructions. When you share concrete information verbally, also show a photograph. Give the student practical materials and experiences and the opportunity to touch and examine objects.
- **Divide new tasks and large tasks into smaller steps.** Demonstrate the steps. Have the student do the steps, one by one. Offer help when necessary.
- **Give the student immediate, concrete feedback.**

Down syndrome

Organizations

National Down Syndrome Society

1.800.221.4602 | www.ndss.org/ (English)

<http://www.ndss.org/Resources/NDSS-en-Espanol/> (Spanish)

NDSS offers authoritative information about Down syndrome, including a new parent video, *A Promising Future Together: A Guide for New Parents of Children with Down Syndrome*.

National Down Syndrome Congress

1.800.232.6372 | www.ndsccenter.org (English)

<http://www.ndsccenter.org/bienvenidos/> (Spanish)

NDSC is also an authoritative source of information on Down syndrome, offering such resources as its *New Parent Package*, a collection of materials refined over years to provide new and expectant parents with an initial understanding of the challenges— and joys—of raising a child with Down syndrome.

Resource of Special Note

Woodbine House publishes an impressive collection of low-cost books and DVDs on Down syndrome, including a Parent's Guide (in English and Spanish) and materials for teachers. Call 1.800.843.7323 or visit: www.woodbinehouse.com/Down-Syndrome.29.0.0.2.htm

References

1 Family Doctor. (2005). *Down syndrome: How to know if your child has Down syndrome*. This article is no longer available, but you can read the new article on Down syndrome,

at: <http://familydoctor.org/familydoctor/en/diseases-conditions/down-syndrome.html>

2 National Down Syndrome Society. (n.d.). *What is Down syndrome?* Available online

at: <http://www.ndss.org/Down-Syndrome/What-Is-Down-Syndrome>

3 Ibid.

4 National Down Syndrome Congress. (n.d.). *New and expectant parents*. Available online

at: <http://www.ndsccenter.org/new-and-expectant-parents/>

5 Sección 300.114(a)(2)(ii) of IDEA.

6 Sección 300.116(e) of IDEA.

7 Sección 300.320(b) of IDEA, Transition services.