

Down Syndrome Fact Sheet

What Causes Down Syndrome?

Down syndrome occurs when some or all of a person's cells have an extra full or partial copy of chromosome 21. The most common form of Down syndrome is known as Trisomy 21. Individuals with Trisomy 21 have 47 chromosomes instead of the usual 46 in each of their cells. The condition results from an error in cell division called nondisjunction. Prior to or at conception, a pair of 21st chromosomes in either the sperm or the egg fails to separate. As the embryo develops, the extra chromosome is replicated in every cell of the body. This error in cell division is responsible for 95 percent of all cases of Down syndrome.

Down syndrome also encompasses two other genetic conditions: mosaicism and translocation. Mosaicism occurs when nondisjunction of chromosome 21 takes place in one of the initial cell divisions after fertilization causing a person to have 46 chromosomes in some of their cells and 47 in others. The least common form of Down syndrome, mosaicism accounts for only 1 to 2 percent of all cases. Translocation, which accounts for 3 to 4 percent of cases of Down syndrome, occurs when part of chromosome 21 breaks off during cell division and attaches to another chromosome, usually chromosome 14. While the total number of chromosomes in the cells remains 46, the presence of an extra part of chromosome 21 causes the characteristics of Down syndrome.

The cause of the extra full or partial chromosome is still unknown. What we do know is that it is not caused by environmental factors or anything the mother does before or during her pregnancy. Maternal age is the only factor that has been linked to an increased chance of having a baby with Down syndrome resulting from nondisjunction. A 35-year-old woman has a one in 350 chance of conceiving a child with Down syndrome. By age 45, the incidence has increased to one in 30. However, because younger women have higher fertility rates, 80 percent of babies with Down syndrome are born to women under the age of 35. Once a woman has given birth to a baby with Down syndrome, the chance of having a second child with Down syndrome is about 1 in 100, although age may also be a factor.

Maternal age, however, is not linked to the chance of having a baby with translocation. Most cases are sporadic, chance events, but in about one third of translocation cases, one parent is a carrier of a translocated chromosome. For this reason, the chance of translocation in a second pregnancy is higher than that seen in nondisjunction.

How does behavioral development differ in children with Down syndrome as compared to their peers?

The behavioral challenges that we see in children with Down syndrome are not all that different from those we see in typically developing children; they may occur at a later age and last a little longer. For example, temper tantrums are fairly common in 2- and 3-year-olds. A child with Down syndrome may have temper tantrums that begin at 3 or 4 years of age. The behavior itself is really no different, neither are the techniques you would use to intervene.

It's also important to know the child's language skills. Many of the behavioral concerns in children with Down syndrome are related to their frustration with communication. We often find that we can successfully address behavioral issues by helping children find verbal and/or non-verbal ways to express themselves and communicate more effectively.

What are some common behavioral concerns in children with Down syndrome?

One behavior is temper tantrums, which are common to all children. Because the child with Down syndrome often has communication difficulties, temper outbursts can be more difficult to manage, particularly when out in public.

Another big concern is the child wandering off - not because they're angry or running away, but rather, because they simply like to explore the neighborhood. Parents will report that their 6- or 7-year-old goes out of the gate and over to the neighbor's house, but because the parents do not know where the child is, it's a very scary thing. The primary goal of intervention is to keep the child safe by doing things such as making sure that there are good locks on the door and using alarms. Wandering is such a common concern that Joan Medlen, editor of *Disability Solutions*, dedicated a whole issue to the topic.

Another challenging behavior is the child who throws himself down on the ground when he does not want to do something. This can occur in the grocery store, at home, in the classroom, or in the middle of the street. It is different from the temper tantrums because the child is not mad; he's simply saying, "I'm not going." This stubborn, oppositional behavior can happen at any age. When children are 2 or 3 years old, it is easy to pick them up and carry them, but when they are nine or ten, this is much more difficult to manage. It can also be dangerous behavior if it occurs in the middle of a street, it is important for parents to get help with how to manage this type of behavior before it gets out of control.

What are some behavioral concerns in teens and adults?

Often in teens and young adults there are problems with withdrawn and depressed behavior. They stop wanting to go to their jobs or participate in recreational activities, and there may be sleep problems. There are so many transitions and changes happening in their lives - for example, school is ending, they are looking for jobs, and siblings are often leaving home. They can have the feeling of, "Gee, I'm 18 or 19 - I should be on my own and I'm not. I'm still living at home with my mom and dad." At this age the adolescent is dealing with social skills and sexual uncertainties.

How should coaches/volunteers approach behavior issues with Down syndrome individuals?

The first step is to be aware of medical problems as some behavior problems can be directly related to medical issue. The child may have hearing loss, vision problems, a thyroid condition, sleep apnea or celiac disease. All of these things can initially present as a change in behavior. Also, parents should update information considering psychological or emotional stressors that may be impacting behavior, such as depression, anxiety, changes at home, a sibling moving away, or parents going through a divorce.

Evaluate the ABC's of behavior: the antecedent - what precedes the behavior - the behavior itself, and the consequences of the behavior. It is important to look at both positive and negative consequences. It is always preferable to use positive consequences to reward appropriate behavior. That is something we often forget to do. We should be reinforcing the behavior, saying things like "I really like what you're doing now."

A lot of acting out behavior is actually done to get attention, so when we use positive consequences to reinforce good behavior we can decrease negative behavior. Sometimes, however, there must be negative consequences, like "time outs" or, in the case of an older child, taking away privileges, for inappropriate behavior. It's important to remember that, particularly for younger kids, the consequence has to be delivered when the behavior happens. For example, it is often difficult for a child to make the connection between something they did wrong at school and the consequence they get for it at home.

What advice would you give coaches/volunteers who feel overwhelmed because of behavioral issues?

Remember that they cannot work on all the challenging behaviors at the same time. There may be five or six different concerns, but you have to target a specific behavior on which to focus your energy. As we develop skills around managing that particular behavior, they will find that those skills carry over to management of the other behaviors.

It is important to remember that the challenging behaviors we see in children with Down syndrome are behaviors that are seen in all children. They may occur at a later chronological age and last a bit longer.

Behavior Guidelines for School Age

Common concerns:

- o Temper tantrums
- o Aggression
- o Oppositional
- o Attention deficit disorder
- o Autism
- o Depression/withdrawn
- o Anxiety
- o Transitions

Information needed:

- o Developmental age
- o Behavior techniques used in school and at home
- o Health problems including vision and hearing status

Recommendations:

- o Discuss concerns with parents
- o Behavior questionnaires
- o Develop behavior plan

Behavior Guidelines Adults

Common Concerns:

- o Transitions from school to work
- o Depression
- o Self-talk
- o Loss of skills (?Alzheimer's)

Information needed:

- o Health status including vision and hearing
- o Living situation (home, group home, apartment)
- o Work status
- o Family structure (sibs leaving home, elderly parents, death of parent)

Recommendations:

- o Discuss with parents
- o Vision and hearing evaluations
- o Counseling with person familiar in working with people with special needs
- o Encourage independent skills

Cerebral Palsy Fact Sheet

What is Cerebral Palsy?

The term cerebral palsy refers to any one of a number of neurological disorders that appear in infancy or early childhood and permanently affect body movement and muscle coordination but don't worsen over time. Even though cerebral palsy affects muscle movement, it isn't caused by problems in the muscles or nerves. It is caused by abnormalities in parts of the brain that control muscle movements. The majority of children with cerebral palsy are born with it, although it may not be detected until months or years later. The early signs of cerebral palsy usually appear before a child reaches 3 years of age. The most common are a lack of muscle coordination when performing voluntary movements (ataxia); stiff or tight muscles and exaggerated reflexes (spasticity); walking with one foot or leg dragging, walking on the toes, a crouched gait, or a "scissored" gait; and muscle tone that is either too stiff or too floppy. A small number of children have cerebral palsy as the result of brain damage in the first few months or years of life, brain infections such as bacterial meningitis or viral encephalitis, or head injury from a motor vehicle accident, a fall, or child abuse.

Is there any treatment?

Cerebral palsy can't be cured, but treatment will often improve a child's capabilities. Many children go on to enjoy near-normal adult lives if their disabilities are properly managed. In general, the earlier treatment begins the better chance children have of overcoming developmental disabilities or learning new ways to accomplish the tasks that challenge them. Treatment may include physical and occupational therapy, speech therapy, drugs to control seizures, relax muscle spasms, and alleviate pain; surgery to correct anatomical abnormalities or release tight muscles; braces and other orthotic devices; wheelchairs and rolling walkers; and communication aids such as computers with attached voice synthesizers.

What is the prognosis?

Cerebral palsy doesn't always cause profound disabilities. While one child with severe cerebral palsy might be unable to walk and need extensive, lifelong care, another with mild cerebral palsy might be only slightly awkward and require no special assistance. Supportive treatments, medications, and surgery can help many individuals improve their motor skills and ability to communicate with the world.

What research is being done?

Researchers are investigating the roles of mishaps early in brain development, including genetic defects, which are sometimes responsible for the brain malformations and abnormalities that result in cerebral palsy. Scientists are also looking at traumatic events in newborn babies' brains, such as bleeding, epileptic seizures, and breathing and circulation problems, which can cause the abnormal release of chemicals that trigger the kind of damage that causes cerebral palsy. To make sure children are getting the right kinds of therapies, studies are also being done that evaluate both experimental treatments and treatments already in use so that physicians and parents have valid information to help them choose the best therapy.

Autism Fact Sheet

What is autism?

Autism (sometimes called “classical autism”) is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs). Autism is characterized by impaired social interaction, problems with verbal and nonverbal communication, and unusual, repetitive, or severely limited activities and interests. Other ASDs include Asperger syndrome, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS). Experts estimate that three to six children out of every 1,000 will have autism. Males are four times more likely to have autism than females.

What are some common signs of autism?

There are three distinctive behaviors that characterize autism. Autistic children have difficulties with social interaction, problems with verbal and nonverbal communication, and repetitive behaviors or narrow, obsessive interests. These behaviors can range in impact from mild to disabling. The hallmark feature of autism is impaired social interaction. Parents are usually the first to notice symptoms of autism in their child. As early as infancy, a baby with autism may be unresponsive to people or focus intently on one item to the exclusion of others for long periods of time. A child with autism may appear to develop normally and then withdraw and become indifferent to social engagement. Children with autism may fail to respond to their name and often avoid eye contact with other people. They have difficulty interpreting what others are thinking or feeling because they can't understand social cues, such as tone of voice or facial expressions, and don't watch other people's faces for clues about appropriate behavior. They lack empathy. Many children with autism engage in repetitive movements such as rocking and twirling, or in self-abusive behavior such as biting or head-banging. They also tend to start speaking later than other children and may refer to themselves by name instead of “I” or “me.” Children with autism don't know how to play interactively with other children. Some speak in a sing-song voice about a narrow range of favorite topics, with little regard for the interests of the person to whom they are speaking. Many children with autism have a reduced sensitivity to pain, but are abnormally sensitive to sound, touch, or other sensory stimulation. These unusual reactions may contribute to behavioral symptoms such as a resistance to being cuddled or hugged. Children with autism appear to have a higher than normal risk for certain co-existing conditions, including fragile X syndrome (which causes mental retardation), tuberous sclerosis (in which tumors grow on the brain), epileptic seizures, Tourette syndrome, learning disabilities, and attention deficit disorder. For reasons that are still unclear, about 20 to 30 percent of children with autism develop epilepsy by the time they reach adulthood. While people with schizophrenia may show some autistic-like behavior, their symptoms usually do not appear until the late teens or early adulthood. Most people with schizophrenia also have hallucinations and delusions, which are not found in autism.

What causes autism?

Scientists aren't certain what causes autism, but it's likely that both genetics and environment play a role. Researchers have identified a number of genes associated with the disorder. Studies of people with autism have found irregularities in several regions of the brain. Other studies suggest that people with autism have abnormal levels of serotonin or other neurotransmitters in the brain. These abnormalities suggest that autism could result from the disruption of normal brain development early in fetal development caused by defects in genes that control brain growth and that regulate how neurons communicate with each other. While these findings are intriguing, they are preliminary and require further study. The theory that parental practices are responsible for autism has now been disproved.

What role does inheritance play?

Recent studies strongly suggest that some people have a genetic predisposition to autism. In families with one autistic child, the risk of having a second child with the disorder is approximately 5 percent, or one in 20. This is greater than the risk for the general population. Researchers are looking for clues about which genes contribute to this increased susceptibility. In some cases, parents and other relatives of an autistic child show mild impairments in social and communicative skills or engage in repetitive behaviors. Evidence also suggests that some emotional disorders, such as manic depression, occur more frequently than average in the families of people with autism.

Do symptoms of autism change over time?

For many children, autism symptoms improve with treatment and with age. Some children with autism grow up to lead normal or near-normal lives. Children whose language skills regress early in life, usually before the age of 3, appear to be at risk of developing epilepsy or seizure-like brain activity. During adolescence, some children with autism may become depressed or experience behavioral problems.

Tips for working with Individuals with Autism

- Make sure directions are given step-by-step, verbally, visually, and by providing physical supports or prompts, as needed by the student. Individuals with autism spectrum disorders often have trouble interpreting facial expressions, body language, and tone of voice. Be as concrete and explicit as possible in your instructions and feedback to the student.
- Find out what the individuals strengths and interests are and emphasize them. Tap into those avenues and create opportunities for success. Give positive feedback and lots of opportunities for practice.
- Build opportunities for the individual to have social/collaborative interactions. Provide support, structure, and lots of feedback.
- If behavior is a significant issue for the individual, seek help from parents to understand the meanings of the behaviors and to develop a unified, positive approach to resolving them.
- Have consistent routines and schedules. When you know a change in routine will occur prepare the individual by telling him/her what is going to be different and what to expect or do.
- Work together with the individual's parents to create and implement a plan tailored to meet the individual's needs. Regularly share information about how the individual is doing at practice.

Intellectual Disability Fact Sheet

An intellectual disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18. A complete and accurate understanding of an intellectual disability involves realizing that an intellectual disability refers to a particular state of functioning that begins in childhood, has many dimensions, and is affected positively by individualized supports. As a model of functioning, it includes the contexts and environment within which the person functions and interacts and requires a multidimensional and ecological approach that reflects the interaction of the individual with the environment, and the outcomes of that interaction with regards to independence, relationships, societal contributions, participation in school and community, and personal well being.

Five assumptions essential to the application of intellectual disabilities:

1. Evaluate limitations in present functioning within the context of the individual's age, peers and culture.
2. Take into account the individual's cultural and linguistic differences as well as communication, sensory, motor, and behavioral factors
3. Recognize that within an individual limitations often coexist with strengths.
4. Describe limitations so that an individualized plan of needed supports can be developed.
5. Provide appropriate personalized supports to improve the functioning of a person with an intellectual disability?

Definitions:

Disability: A disability refers to personal limitations that represent a substantial disadvantage when attempting to function in society. A disability should be considered within the context of the environment, personal factors, and the need for individualized supports.

Intelligence: Intelligence refers to a general mental capability. It involves the ability to reason, plan, solve problems, think abstractly, comprehend complex ideas, learn quickly, and learn from experience. Although not perfect, intelligence is represented by Intelligent Quotient (IQ) scores obtained from standardized tests given by a trained professional. In regard to the intellectual criterion for the diagnosis of an intellectual disability, an intellectual disability is generally thought to be present if an individual has an IQ test score of approximately 70 or below. An obtained IQ score must always be considered in light of its standard error of measurement, appropriateness, and consistency with administration guidelines. Since the standard error of measurement for most IQ tests is approximately 5, the ceiling may go up to 75. This represents a score approximately 2 standard deviations below the mean, considering the standard error of measurement. It is important to remember, however, that an IQ score is only one aspect in determining if a person has an intellectual disability. Significant limitations in adaptive behavior skills and evidence that the disability was present before age 18 are two additional elements that are critical in determining if a person has an intellectual disability.

Adaptive Behavior: Adaptive behavior is the collection of conceptual, social, and practical skills that people have learned so they can function in their everyday lives. Significant limitations in adaptive behavior impact a person's daily life and affect the ability to respond to a particular situation or to the environment.

Limitations in adaptive behavior can be determined by using standardized tests that are normed on the general population including people with disabilities and people without disabilities. On these standardized measures, significant limitations in adaptive behavior are operationally defined as performance that is at least 2 standard deviations below the mean of either (a) one of the following three types of adaptive behavior: conceptual, social, or practical, or (b) an overall score on a standardized measure of conceptual, social, and practical skills.

Conceptual Skills	Social Skills	Practical Skills
Receptive and expressive language Reading and writing Money concepts Self-directions	Interpersonal Responsibility Self-esteem Gullibility (likelihood of being tricked or manipulated) Naiveté Follows rules Obeys laws Avoids victimization	Personal activities of daily living such as eating, dressing, mobility and toileting. Instrumental activities of daily living such as preparing meals, taking medication, using the telephone, managing money, using transportation and doing housekeeping activities. Occupational skills Maintaining a safe environment

What are the causes of Intellectual Disabilities?

The causes of intellectual disabilities can be divided into biomedical, social, behavioral, and educational risk factors that interact during the life of an individual and/or across generations from parent to child. Biomedical factors are related to biologic processes, such as genetic disorders or nutrition. Social factors are related to social and family interaction, such as child stimulation and adult responsiveness. Behavioral factors are related to harmful behaviors, such as maternal substance abuse. And educational factors are related to the availability of family and educational supports that promote mental development and increases in adaptive skills. Also, factors present during one generation can influence the outcomes of the next generation. By understanding inter-generational causes, appropriate supports can be used to prevent and reverse the effects of risk factors.

Concept of Supports (Recommended by AAIDD)

The concept of supports originated about 15 years ago and it has revolutionized the way habilitation and education services are provided to persons with intellectual disabilities. Rather than mold individuals into pre-existing diagnostic categories and force them into existing models of service, the supports approach evaluates the specific needs of the individual and then suggests strategies, services and supports that will optimize individual functioning. The supports approach also recognizes that individual needs and circumstances will change over time.

Supports are defined as the resources and individual strategies necessary to promote the development, education, interests, and personal well-being of a person with intellectual disabilities. Supports can be provided by a parent, friend, teacher, psychologist, doctor or by any appropriate person or agency.

Why are supports important?

Providing individualized supports can improve personal functioning, promote self-determination and societal inclusion, and improve personal well-being of a person with intellectual disabilities. Focusing on supports as the way to improve education, employment, recreation, and living environments is an important part of person-centered approaches to providing supports to people with mental retardation.

What are some specific examples of supports areas and support activities?

Human Development Activities

- Providing physical development opportunities that include eye-hand coordination, fine motor skills, and gross motor activities
- Providing cognitive development opportunities such as using words and images to represent the world and reasoning logically about concrete events
- Providing social and emotional developmental activities to foster trust, autonomy, and initiative

Teaching and Education Activities

- Interacting with trainers and teachers and fellow trainees and students
- Participating in making decisions on training and educational activities
- Learning and using problem-solving strategies
- Using technology for learning
- Learning and using functional academics (reading signs, counting change, etc.)
- Learning and using self-determination skills

Home Living Activities

- Using the restroom/toilet
- Laundering and taking care of clothes
- Preparing and eating food
- Housekeeping and cleaning
- Dressing
- Bathing and taking care of personal hygiene and grooming needs
- Operating home appliances and technology
- Participating in leisure activities within the home

Community Living Activities

- Using transportation
- Participating in recreation and leisure activities
- Going to visit friends and family
- Shopping and purchasing goods
- Interacting with community members
- Using public buildings and settings

Employment Activities

- Learning and using specific job skills
- Interacting with co-workers
- Interacting with supervisors
- Completing work-related tasks with speed and quality
- Changing job assignments
- Accessing and obtaining crisis intervention and assistance

Health and Safety Activities

- Accessing and obtaining therapy services
- Taking medication
- Avoiding health and safety hazards
- Communicating with health care providers
- Accessing emergency services
- Maintaining a nutritious diet
- Maintaining physical health
- Maintaining mental health/emotional well-being

Behavioral Activities

- Learning specific skills or behaviors
- Learning and making appropriate decisions
- Accessing and obtaining mental health treatments
- Accessing and obtaining substance abuse treatments
- Incorporating personal preferences into daily activities
- Maintaining socially appropriate behavior in public
- Controlling anger and aggression