

# Supplemental Guide for DEVELOPMENTAL DISABILITIES

## DEFINITION

## PREVENTION/SCREENING

## SPECIFIC CONDITIONS

Mental Retardation (Intellectual Disability - ID)\*  
Autism Spectrum Disorders  
Cerebral Palsy  
Down Syndrome  
Epilepsy  
Fetal Alcohol Syndrome  
Fragile X Syndrome  
Hydrocephalus  
Microcephaly  
Prader Willi Syndrome  
Spina Bifida

\* ID has been added to all mentions of Mental Retardation, in an effort to recognize that the terminology has changed from Mental Retardation to Intellectual Disability (ID) - as supported by the American Association on Mental Retardation that is now the American Association on Intellectual and developmental Disability (AAIDD).

## DISABILITY RELATED ACRONYMS AND GLOSSARY

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## DEFINITION

Developmental Disabilities are physical or mental impairments that begin before age 22, and alter or substantially inhibit a person's capacity to do at least three of the following:

1. Take care of themselves (dress, bathe, eat, and other daily tasks)
2. Speak and be understood clearly
3. Learn
4. Walk/ Move around
5. Make decisions
6. Live on their own
7. Earn and manage an income

Developmental delays can occur in all of the above mentioned areas of development or may just happen in one or more of the areas.

In addition to the above mentioned limitations, a DD diagnosis requires continuous need for individually planned and coordinated services.

Developmental Disability is a broad term used to describe growth delays in one or more developmental category, and therefore has no specific cause or cure. There are numerous

causes of developmental delay including early brain or birth injuries, genetic disorders and environmental factors.

Source: <http://www.acf.hhs.gov>

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## PREVENTION/SCREENING

What you need to know

List of disorders screened for in each state

### What you need to know

All states screen newborns for certain metabolic birth defects. (Metabolic refers to chemical changes that take place within living cells.) These conditions cannot be seen in the newborn, but can cause physical problems, Mental Retardation (ID) and, in some cases, death.

Many of the tests use a blood specimen taken before the baby leaves the hospital. The baby's heel is pricked to obtain a few drops of blood for laboratory analysis.

The March of Dimes recommends that all newborns be screened for at least 29 disorders including hearing loss.

### List of disorders screened for in each state (click link below)

<http://genes-r-us.uthscsa.edu/nbsdisorders.pdf>

Source: [www.marchofdimes.com](http://www.marchofdimes.com)

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## SPECIFIC CONDITIONS

### Mental Retardation (ID)

What is it?

What are the signs?

What causes Mental Retardation (ID)?

How is it diagnosed?

How does the DD definition compare with the definition of MR?

What about School?

Potential Services available in ESP

Organizations

Fact Sheet (PDF file)

### What is it?

Mental Retardation (ID) (MR) 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 Mental Retardation (ID) 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.

Mental Retardation (ID) is the most common developmental disorder- estimates are that as many as 3 out of every 100 people in the country have MR.

Mental Retardation (ID) is not a disease. You can't catch Mental Retardation (ID) from anyone. Mental Retardation (ID) is also not a type of mental illness, like depression. There is no cure for Mental Retardation (ID). However, most children with Mental Retardation (ID) can learn to do many things. It just takes them more time and effort than other children.

Mental Retardation (ID) is a developmental disability, but having a developmental disability does not mean the person has Mental Retardation (ID). *For instance, a person can have delayed functioning in motor skills and language caused, perhaps, by cerebral palsy but may have no delays in cognitive functioning. If a person does have Mental Retardation (ID) however, they will most likely experience delays in some areas of development.*

### **What are the signs?**

There are many signs of Mental Retardation (ID). For example, children with Mental Retardation (ID) 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.

### **What causes Mental Retardation (ID)?**

Doctors have found many causes of Mental Retardation (ID). The most common are:

- *Genetic conditions.* Sometimes Mental Retardation (ID) 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.* Mental Retardation (ID) 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 Mental Retardation (ID).
- *Problems at birth.* If a baby has problems during labor and birth, such as not getting enough oxygen, he or she may have Mental Retardation (ID).
- *Health problems.* Diseases like whooping cough, the measles, or meningitis can cause Mental Retardation (ID). Mental Retardation (ID) 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.

### **How is it diagnosed?**

Mental Retardation (ID) is diagnosed by looking at two main things. These are:

- **IQ or Intellectual Functioning** --the ability of a person's brain to learn, think, solve problems, and make sense of the world
- **Adaptive Behavior** --whether the person has the skills he or she needs to live independently

The average IQ score is 100. People scoring below 70 to 75 are thought to have Mental Retardation (ID). Using the IQ test score, people having Mental Retardation (ID) are categorized into one of four categories:

Mild retardation:	IQ score from 50-75
Moderate retardation:	IQ score from 35-55
Severe retardation:	IQ score from 20-40
Profound retardation:	IQ score from 20-25

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:

- communicating with others
- taking care of personal needs (ADLs)
- health and safety
- home living (IADLs)
- social skills (manners, getting along with others, etc.)
- reading, writing, and basic math
- skills necessary in the workplace

### **How does the DD definition compare with the definition of MR?**

The major differences are in the age of onset, the severity of limitations, and the fact that the developmental disability definition does not refer to an IQ requirement. Many individuals with MR will also meet the definition of developmental disability. However, it is estimated that at least half individuals with MR will not meet the functional limitation requirement in the DD definition. The DD definition requires substantial functional limitations in three or more areas of major life activity. The MR definition requires significant limitations in one area of adaptive behavior.

### **What about School?**

A child with Mental Retardation (ID) can do well in school but is likely to need individualized help. Fortunately, states are responsible for meeting the educational needs of children with disabilities.

For children up to age three, services are provided through an early intervention system. 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. It also describes the services the child will receive to address those needs. The IFSP will emphasize the unique needs of the family, so that parents and other family members will know how to help their young child with Mental Retardation (ID). Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income. In some states, early intervention services may be at no cost to parents.

For eligible school-aged children (including preschoolers), special education and related services are made available through the school system. 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.

Many children with Mental Retardation (ID) 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.

### **Tips for Parents**

- Learn about Mental Retardation (ID). The more you know, the more you can help yourself and your child.
- 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 Mental Retardation (ID). Parents can share practical advice and emotional support. Call National Dissemination Center for Children with Disabilities (NICHCY) at 1.800.695.0285 and ask how to find a parent group near you.
- Meet with the school and develop an educational plan 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.

### **Potential Services available in ESP**

**Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

**Consumer Services**

- t Non-Driver Identification
- t Personal Care Home Complaints
- t Voter Registration

**Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services
- t DD- Respite Services
- t DD- Counseling

**Elder Abuse/ Neglect**

- t Adult Protective Intervention
- t Institutional Abuse/ Neglect

**Financial Services**

- t Estate Planning

**Health Conditions/ Disease**

- t Developmental Delay

**Income Security**

- t Supplemental Security Income

**Information and Referral**

- t Disability Referrals

**Leisure/ Recreational**

- t Specialized Clubs/ Developmental Disabilities

**Medicaid Waiver/ Demonstration Programs**

- t Mental Retardation (ID) Waiver Program
- t Natural Support Waiver Program
- t Community Habilitation & Support Services Waiver Program
- t SOURCE

**Organizations/ Association**

- t MH/DD/AD Regional Offices

**Personal Care Homes**

- t Community Living Arrangements

**Organizations****The Arc of the United States**

1010 Wayne Avenue, Suite 650

Silver Spring, MD 20910

301.565.3842

[Info@thearc.org](mailto:Info@thearc.org) *E-mail*

[www.thearc.org](http://www.thearc.org) *Web*

[www.TheArcPub.com](http://www.TheArcPub.com) *Web (Publications)*

## **American Association on Mental Retardation (ID) (AAMR)**

444 North Capitol Street NW, Suite 846  
Washington, DC 20001-1512  
202.387.1968; 800.424.3688 (outside DC)  
[www.aamr.org](http://www.aamr.org) *Web*

## **Division on Developmental Disabilities**

The Council for Exceptional Children  
1110 North Glebe Road, Suite 300  
Arlington, VA 22201-5704  
888.232.7733; 703.620.3660  
866.915.5000 *TTY*  
[cec@cec.sped.org](mailto:cec@cec.sped.org) *E-mail*  
[www.dddcec.org](http://www.dddcec.org) *Web*

## **Fact Sheet on Mental Retardation (ID) (PDF file)**

Source: National Dissemination Center for Children with Disabilities  
<http://www.nichcy.org/pubs/factshe/fs8.pdf>

Source: <http://www.nlm.nih.gov>

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## **AUTISM Spectrum Disorders (ASDs)**

- What is it?
- What are the characteristics?
- What causes Autism Spectrum Disorders?
- What conditions are included?
- Potential Services available in ESP
- Organizations
- Fact Sheet (PDF file)

### **What is it?**

Autism spectrum disorders (ASDs) are a group of developmental disabilities caused by a problem with the brain. Scientists do not know yet exactly what causes this problem. ASDs can impact a person's functioning at different levels, from very mildly to severely. There is usually nothing about how a person with an ASD looks that sets them apart from other people, but they may communicate, interact, behave, and learn in ways that are different from most people. The thinking and learning abilities of people with ASDs can vary – from gifted to severely challenged.

Autism is one of five disorders that falls under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by “severe and pervasive impairment in several areas of development.”

The five disorders under PDD are:

- Autistic Disorder (most common type of ASD)
- Asperger's Disorder
- Childhood Disintegrative Disorder (CDD)

- Rett Syndrome
- PDD-Not Otherwise Specified (PDD-NOS)

### What are the characteristics?

As the name "autism spectrum disorder" says, ASDs cover a wide range of behaviors and abilities. People who have ASDs, like all people, differ greatly in the way they act and what they can do. No two people with ASDs will have the same symptoms. A symptom might be mild in one person and severe in another person. Some examples of the types of problems and behaviors a child or adult with an ASD might have follow.

**Social skills:** People with ASDs might not interact with others the way most people do, or they might not be interested in other people at all. People with ASDs might not make eye contact and might just want to be alone. They might have trouble understanding other people's feelings or talking about their own feelings. Children with ASDs might not like to be held or cuddled, or might cuddle only when they want to. Some people with ASDs might not seem to notice when other people try to talk to them. Others might be very interested in people, but not know how to talk, play, or relate to them.

**Speech, language, and communication:** About 40% of children with ASDs do not talk at all. Others have echolalia, which is when they repeat back something that was said to them. The repeated words might be said right away or at a later time. For example, if you ask someone with an ASD, "Do you want some juice?" he or she will repeat "Do you want some juice?" instead of answering your question. Or a person might repeat a television ad heard sometime in the past. People with ASDs might not understand gestures such as waving goodbye. They might say "I" when they mean "you", or vice versa. Their voices might sound flat and it might seem like they cannot control how loudly or softly they talk. People with ASDs might stand too close to the people they are talking to, or might stick with one topic of conversation for too long. Some people with ASDs can speak well and know a lot of words, but have a hard time listening to what other people say. They might talk a lot about something they really like, rather than have a back-and-forth conversation with someone.

**Repeated behaviors and routines:** People with ASDs might repeat actions over and over again. They might want to have routines where things stay the same so they know what to expect. They might have trouble if family routines change. For example, if a child is used to washing his or her face before dressing for bed, he or she might become very upset if asked to change the order and dress first and then wash.

### What Causes ASDs?

It is suspected that there may be multiple causes for ASD due to a complex interaction of genetic and environmental factors. Family studies have shed the most light on the genetic contribution to autism. Studies of twins have shown that in identical twins there is about a 75% rate of both twins having autism, while in non-identical twins this occurs about 3% of the time. The inheritance pattern is complex and suggests that a number of genes are involved.

For the majority of people with ASDs, the cause is not known; however, ASD tends to occur more frequently than expected among individuals who have certain other medical conditions, including Fragile X syndrome, tuberous sclerosis, congenital rubella syndrome, and untreated phenylketonuria (PKU). Some harmful substances ingested during pregnancy also have been associated with an increased risk of autism, specifically, the prescription drug thalidomide.

### **What conditions are included in ASDs?**

The five most common disorders are:

Autistic Disorder (most common type of ASD)

Asperger's Disorder

Childhood Disintegrative Disorder (CDD)

Rett's Disorder

Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)

### **Autistic Disorder**

Autistic disorder is one of the disabilities specifically defined in the Individuals with Disabilities Education Act (IDEA), the federal legislation under which children and youth with disabilities receive special education and related services. IDEA, which uses the term "autism," defines the disorder as "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, usually evident before age 3, that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences."

#### *Characteristics*

Some or all of the following characteristics may be observed in mild to severe forms:

- Communication problems (e.g., using and understanding language)
- Difficulty in relating to people, objects, and events
- Unusual play with toys and other objects
- Difficulty with changes in routine or familiar surroundings
- Repetitive body movements or behavior patterns.

Children with autism vary widely in abilities, intelligence, and behaviors. Some children do not speak; others have limited language that often includes repeated phrases or conversations. People with more advanced language skills tend to use a small range of topics and have difficulty with abstract concepts. Repetitive play skills, a limited range of interests, and impaired social skills are generally evident as well. Unusual responses to sensory information -- for example, loud noises, lights, certain textures of food or fabrics -- are also common.

Due to the similarity of behaviors associated with autism and pervasive developmental disorders (PDD), use of the term pervasive developmental disorder has caused some confusion among parents and professionals. However, the treatment and educational needs are similar for both diagnoses.

### **Asperger's Disorder**

Asperger's Disorder is a milder variant of Autistic Disorder. In Asperger's Disorder, affected individuals are characterized by social isolation and eccentric behavior in childhood. There are impairments in two-sided social interaction and non-verbal communication. Though grammatical, their speech is peculiar due to abnormalities of inflection and a repetitive pattern. Clumsiness is prominent both in their articulation and gross motor behavior. They usually have a circumscribed area of interest which usually leaves no space for more age appropriate, common interests. Some examples are cars, trains, French Literature, door knobs, hinges, cappucino, meteorology, astronomy or history.

### **Childhood Disintegrative Disorder**

Childhood disintegrative disorder is a condition occurring in 3 and 4-year-olds who have developed normally to age 2. Over several months, an affected child shows a loss of communication skills, has regression in nonverbal behaviors, and significant loss of previously-acquired skills. The condition is very similar to autistic disorder. The cause of childhood disintegrative disorder is unknown, but it has been linked to neurological problems.

Symptoms may include loss of social skills, loss of bowel and bladder control, loss of expressive or receptive language, loss of motor skills, lack of play, failure to develop peer relationships, impairment in nonverbal behaviors, delay or lack of spoken language and inability to start or sustain a conversation.

Treatment is the same for autistic disorder (autism) because of the similarity in the two disorders. Unfortunately, the prognosis for this disorder is limited. The loss of functioning will likely be permanent. However, to some degree, behaviors can be modified.

### **Rett Syndrome**

Rett syndrome is a childhood neurodevelopmental disorder characterized by normal early development followed by loss of purposeful use of the hands, distinctive hand movements, slowed brain and head growth, gait abnormalities, seizures, and Mental Retardation (ID). It affects females almost exclusively.

The course of Rett syndrome, including the age of onset and the severity of symptoms, varies from child to child. Before the symptoms begin, however, the child appears to grow and develop normally. Then, gradually, mental and physical symptoms appear. Hypotonia (loss of muscle tone) is usually the first symptom. As the syndrome progresses, the child loses purposeful use of her hands and the ability to speak. Other early symptoms may include problems crawling or walking and diminished eye contact. The loss of functional use of the hands is followed by compulsive hand movements such as wringing and washing. The onset of this period of regression is sometimes sudden. Another symptom, apraxia — the inability to perform motor functions — is perhaps the most severely disabling feature of Rett syndrome, interfering with every body movement, including eye gaze and speech.

Individuals with Rett syndrome often exhibit autistic-like behaviors in the early stages. Other symptoms may include toe walking; sleep problems; wide-based gait; teeth grinding and difficulty chewing; slowed growth; seizures; cognitive disabilities; and breathing difficulties while awake such as hyperventilation, apnea (breath holding), and air swallowing.

## **PDD-Not Otherwise Specified (PDD-NOS)**

Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) is a 'subthreshold' condition in which some - but not all - features of autism or another explicitly identified Pervasive Developmental Disorder are identified. PDD-NOS is often incorrectly referred to as simply "PDD." The term PDD refers to the class of conditions to which autism belongs. PDD is NOT itself a diagnosis, while PDD-NOS is a diagnosis. The term Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS; also referred to as "atypical personality development," "atypical PDD," or "atypical autism") is included in DSM-IV to encompass cases where there is marked impairment of social interaction, communication, and/or stereotyped behavior patterns or interest, but when full features for autism or another explicitly defined PDD are not met.

## **Potential Services available in ESP**

### **Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

### **Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services
- t DD- Respite Services
- t DD- Counseling

### **Health Conditions/ Disease**

- t Autism

### **Income Security**

- t Supplemental Security Income

### **Information and Referral**

- t Disability Referrals

### **Leisure/ Recreational**

- t Specialized Clubs/ Developmental Disabilities

### **Medicaid Waiver/ Demonstration Programs**

- t Family Support Waiver Program
- t Mental Retardation (ID) Waiver Program
- t Natural Support Waiver Program
- t Community Habilitation & Support Services Waiver Program
- t SOURCE

### **Organizations/ Association**

- t Organizations
- t MH/DD/AD Regional Offices

### **Personal Care Homes**

- t Community Living Arrangements

### **Support Groups**

- t Autism Support Group

## **Organizations**

## **Autism Society of America**

7910 Woodmont Ave.

Suite 300

Bethesda, MD 20814-3067

Tel: 301-657-0881 800-3AUTISM (328-8476)

Fax: 301-657-0869

<http://www.autism-society.org>

## **Fact Sheet on Autism Spectrum Disorders**

Source: Center for Disease Control

[http://www.cdc.gov/ncbddd/autism/actearly/pdf/parents\\_pdfs/AutismFactSheet.pdf](http://www.cdc.gov/ncbddd/autism/actearly/pdf/parents_pdfs/AutismFactSheet.pdf)

## **Fact Sheet for Autism/ Pervasive Developmental Disorder (PDF file)**

Source: National Dissemination Center for Children with Disabilities

<http://www.nichcy.org/pubs/factshe/fs1.pdf>

**Source:** [www.cdc.gov/ncbddd/autism/index.htm](http://www.cdc.gov/ncbddd/autism/index.htm)

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## **Cerebral Palsy**

[What is it?](#)

[What are the characteristics?](#)

[What causes Cerebral Palsy?](#)

[Potential Services available in ESP](#)

[Organizations](#)

[Fact Sheet \(PDF file\)](#)

## **What is it?**

Cerebral palsy refers to a group of disorders that affect a person's ability to move and to maintain balance and posture. It is due to a non-progressive brain abnormality, which means that it does not get worse over time, though the exact symptoms can change over a person's lifetime.

People with cerebral palsy have damage to the part of the brain that controls muscle tone. Muscle tone is the amount of resistance to movement in a muscle. It is what lets you keep your body in a certain posture or position.

For example, it lets you sit up straight and keep your head up. Changes in muscle tone let you move. For example, to bring your hand to your face, the tone in your biceps muscle at the front of your arm must increase while the tone in the triceps muscle at the back of your arm must decrease. The tone in different muscle groups must be balanced for you to move smoothly.

There are four main types of cerebral palsy - spastic, athetoid, ataxic, and mixed.

1. **Spastic:** People with spastic cerebral palsy have increased muscle tone. Their muscles are stiff. Their movements can be awkward. Seventy to eighty percent of people with cerebral palsy have spasticity. Spastic cerebral palsy is usually described further by what parts of the body are affected. In spastic diplegia, the main effect is found in both legs. In

spastic hemiplegia, one side of the person's body is affected. Spastic quadriplegia affects a person's whole body (face, trunk, legs, and arms).

2. **Athetoid or dyskinetic:** People with athetoid cerebral palsy have slow, writhing movements that they cannot control. The movements usually affect a person's hands, arms, feet, and legs. Sometimes the face and tongue are affected and the person has a hard time talking. Muscle tone can change from day to day and can vary even during a single day. Ten to twenty percent of people with cerebral palsy have the athetoid form of the condition.
3. **Ataxic:** People with ataxic cerebral palsy have problems with balance and depth perception. They might be unsteady when they walk. They might have a hard time with quick movements or movements that need a lot of control, like writing. They might have a hard time controlling their hands or arms when they reach for something. People with ataxic cerebral palsy can have increased or decreased muscle tone. Five to ten percent of people with cerebral palsy have ataxia.
4. **Mixed:** Some people have more than one type of cerebral palsy. The most common pattern is spasticity plus athetoid movements.

### **What are the characteristics?**

The symptoms of cerebral palsy vary from person to person. Symptoms can also change over time. A person with severe cerebral palsy might not be able to walk and might need lifelong care. A person with mild cerebral palsy, on the other hand, might walk a little awkwardly, but might not need any special help.

### **What causes Cerebral Palsy?**

Cerebral palsy is caused by brain damage that affects a child's ability to control his or her muscles. The part of the brain that is damaged determines what parts of the body are affected. There are many possible causes of the brain damage. Some causes affect how the child's brain develops during the first 6 months of pregnancy. These causes include genetic conditions and problems with the blood supply to the brain. Other causes of cerebral palsy happen after the brain has developed. These causes can occur during later pregnancy, delivery, or the first years of the child's life. They include bacterial meningitis and other infections, bleeding in the brain, lack of oxygen, severe jaundice, and head injury. Children who are born prematurely or who are very low birth weight (less than 1,500 grams or about 3 1/3 pounds) are more likely to have problems that might lead to cerebral palsy. However, children who are full term and normal birth weight can also have cerebral palsy. An individual with Cerebral palsy does not always have Mental Retardation (ID).

### **Potential Services available in ESP**

#### **Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

#### **Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services

t DD- Respite Services

t DD- Counseling

**Health Conditions/ Disease**

t Cerebral Palsy

**Health Supportive Services**

t Assistive Living Devices

t Daily Living Aids

t Durable Medical Equipment

t Specialized Clothing

**Income Security**

t Supplemental Security Income

**Information and Referral**

t Disability Referrals

**Leisure/ Recreational**

t Specialized Clubs/ Developmental Disabilities

**Medicaid Waiver/ Demonstration Programs**

t Community Care Services Program

t Independent Care Waiver Program

t Family Support Waiver Program

t Mental Retardation (ID) Waiver Program

t Natural Support Waiver Program

t Community Habilitation & Support Services Waiver Program

t SOURCE

**Organizations/ Association**

t MH/DD/AD Regional Offices

**Personal Care Homes**

t Community Living Arrangements

**Support Groups**

t Cerebral Palsy Support Group

**Organizations**

**United Cerebral Palsy Associations, Inc.**

1660 L Street, NW, Suite 700, Washington, DC 20036

202.776.0406; 202.973.7197 (TTY); 800.872.5827 (V/TTY)

[www.ucp.org](http://www.ucp.org)

**Easter Seals—National Office**

230 W. Monroe Street, Suite 1800, Chicago, IL 60606-4802

312.726.6200; 312.726.4258 (TTY); 800.221.6827

[www.easter-seals.org](http://www.easter-seals.org)

**Fact Sheet for Cerebral Palsy (PDF file)**

Source: National Dissemination Center for Children with Disabilities

<http://www.nichcy.org/pubs/factshe/fs2.pdf>

Source: <http://www.nlm.nih.gov>

## **Down Syndrome**

What is it?

Is there any treatment?

What is the prognosis?

Potential Services available in ESP

Organizations

Fact Sheet

### **What is it?**

Down syndrome is the most common and readily identifiable chromosomal condition associated with Mental Retardation (ID). It is caused by a chromosomal abnormality: for some unexplained 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.

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. 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;
- Short neck;
- Small head;
- Small oral cavity; and/or
- Short, high-pitched cries in infancy.

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

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 retardation may range from mild to severe, with the majority functioning in the mild to moderate range. Due to these individual differences, it is impossible to predict future achievements of children with Down syndrome.

### **Is there any treatment?**

There is no cure for Down syndrome, nor is there any prevention for the chromosomal accident that causes Down syndrome. However, recent studies suggest that some women who have had a baby with Down syndrome had an abnormality in how their bodies metabolize (process) the B vitamin folic acid. If confirmed, this finding may provide yet another reason why all women who might become pregnant should take a daily multivitamin containing 400 micrograms of

folic acid (which has been shown to reduce the risk of certain birth defects of the brain and spinal cord).

### **What is the prognosis?**

The prognosis in Down syndrome is quite variable, depending on the types of complications (heart defects, susceptibility to infections, development of leukemia) of each individual baby. The severity of the retardation can also vary significantly. Without the presence of heart defects, about 90% of children with Down syndrome live into their teens. People with Down syndrome appear to go through the normal physical changes of aging more rapidly, however. The average age of death for an individual with Down syndrome is about 50-55 years.

### **Potential Services available in ESP**

#### **Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

#### **Consumer Services**

- t Non-Driver Identification
- t Personal Care Home Complaints
- t Voter Registration

#### **Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services
- t DD- Respite Services
- t DD- Counseling

#### **Elder Abuse/ Neglect**

- t Adult Protective Intervention
- t Institutional Abuse/ Neglect

#### **Financial Services**

- t Estate Planning

#### **Health Centers/ Clinics**

- t Specialized Clinics

#### **Health Conditions/ Disease**

- t Developmental Delay

#### **Income Security**

- t Supplemental Security Income

#### **Information and Referral**

- t Disability Referrals

#### **Leisure/ Recreational**

- t Specialized Clubs/ Developmental Disabilities

#### **Medicaid Waiver/ Demonstration Programs**

- t Family Support Waiver Program
- t Mental Retardation (ID) Waiver Program
- t Natural Support Waiver Program
- t Community Habilitation & Support Services Waiver Program

t SOURCE

**Organizations/ Association**

t MH/DD/AD Regional Offices

**Personal Care Homes**

t Community Living Arrangements

**Support Groups**

t Down Syndrome Support Group

**Organizations**

**National Down Syndrome Society**

666 Broadway

New York, NY 10012

Telephone: 1-800-221-4602

Fax: 212-979-2873

Email: info@ndss.org

Web: <http://www.ndss.org/>

**Fact Sheet (PDF File)**

Source: National Dissemination Center for Children with Disabilities

<http://www.nichcy.org/pubs/factshe/fs4txt.htm>

New Parent Guide from the National Down Syndrome Society

<http://www.ndss.org/content.cfm?fuseaction=NwsEvt.Article&article=1558>

Source: <http://www.ndss.org>

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**Epilepsy**

What is it?

Is there any treatment?

What is the prognosis?

Potential Services available in ESP

Organizations

Fact Sheet (PDF file)

**What is it?**

Epilepsy is a brain disorder in which clusters of nerve cells, or neurons, in the brain sometimes signal abnormally. In epilepsy, the normal pattern of neuronal activity becomes disturbed, causing strange sensations, emotions, and behavior or sometimes convulsions, muscle spasms, and loss of consciousness. Epilepsy is a disorder with many possible causes. Anything that disturbs the normal pattern of neuron activity - from illness to brain damage to abnormal brain development - can lead to seizures. Epilepsy may develop because of an abnormality in brain wiring, an imbalance of nerve signaling chemicals called neurotransmitters, or some combination of these factors. Having a seizure does not necessarily mean that a person has epilepsy. Only when a person has had two or more seizures is he or she considered to have epilepsy. EEGs and brain scans are common diagnostic test for epilepsy.

### **Is there any treatment?**

Once epilepsy is diagnosed, it is important to begin treatment as soon as possible. For about 80 percent of those diagnosed with epilepsy, seizures can be controlled with modern medicines and surgical techniques. Some antiepileptic drugs can interfere with the effectiveness of oral contraceptives. In 1997, the FDA approved the vagus nerve stimulator for use in people with seizures that are not well-controlled by medication.

### **What is the prognosis?**

Most people with epilepsy lead outwardly normal lives. While epilepsy cannot currently be cured, for some people it does eventually go away. Most seizures do not cause brain damage. It is not uncommon for people with epilepsy, especially children, to develop behavioral and emotional problems, sometimes the consequence of embarrassment and frustration or bullying, teasing, or avoidance in school and other social setting. For many people with epilepsy, the risk of seizures restricts their independence (some states refuse drivers licenses to people with epilepsy) and recreational activities. People with epilepsy are at special risk for two life-threatening conditions: status epilepticus and sudden unexplained death. Most women with epilepsy can become pregnant, but they should discuss their epilepsy and the medications they are taking with their doctors. Women with epilepsy have a 90 percent or better chance of having a normal, healthy baby.

### **Potential Services Available in ESP**

#### **Health Conditions/ Disease**

t Epilepsy

#### **Organizations/ Associations**

t Organizations

#### **Support Groups**

t Epilepsy Support Group

### **Organizations**

#### **Epilepsy Foundation**

4351 Garden City Drive

Landover, MD 20785-7223

[postmaster@efa.org](mailto:postmaster@efa.org)

<http://www.epilepsyfoundation.org>

Tel: 301-459-3700 800-EFA- 1000 (332-1000)

Fax: 301-577-2684

#### **Epilepsy Institute**

257 Park Avenue South

New York, NY 10010

[website@epilepsyinstitute.org](mailto:website@epilepsyinstitute.org)

<http://www.epilepsyinstitute.org>

Tel: 212-677-8550

Fax: 212-677-5825

### **Fact Sheet for Epilepsy (PDF File)**

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## **Fetal Alcohol Syndrome**

[What is it?](#)

[What are the characteristics?](#)

[What is the prognosis?](#)

[Potential Services Available in ESP](#)

[Organizations](#)

[Fact Sheet \(PDF file\)](#)

### **What is it?**

Alcohol can cause a range of birth defects, the most serious being fetal alcohol syndrome (FAS). Children born with alcohol-related birth defects can have lifelong learning and behavior problems. Those born with FAS have physical abnormalities, mental impairment, and behavior problems. When present, Mental Retardation (ID) tends to be mild. Because scientists do not know exactly how much alcohol it takes to cause alcohol-related birth defects, it is best not to drink any alcohol during this time.

Fetal Alcohol Syndrome is 100% preventable—if a woman does not drink alcohol while she is pregnant.

### **What are the characteristics?**

Developmental abnormalities in infants born to alcoholic mothers, including characteristic facial appearance (microcephaly, maxillary hypoplasia, short palpebral fissures, and short upturned nose), growth deficiency, delayed intellectual development, motor retardation, joint abnormalities, poor coordination, and irritability. The pattern of abnormalities varies and may include additional oral, ocular, cardiac, urogenital, cutaneous, and other abnormalities.

### **What is the prognosis?**

These problems will last for an individual's whole life. People with severe problems may not be able to take care of themselves as adults. They may never be able to work.

### **Potential Services Available in ESP**

#### **Advocacy Assistance**

t Developmental Disabilities Advocacy Assistance

#### **Developmental Disabilities**

t DD- Adult Day Programs

t DD- Home Care Providers

t DD- Intake and Screening

t DD- Residential Options

t DD- Vocational Services

t DD- Respite Services

t DD- Counseling

#### **Health Conditions/ Disease**

- t Developmental Delay

**Income Security**

- t Supplemental Security Income

**Information and Referral**

- t Disability Referrals

**Leisure/ Recreational**

- t Specialized Clubs/ Developmental Disabilities

**Medicaid Waiver/ Demonstration Programs**

- t Community Care Services Program
- t Independent Care Waiver Program
- t Family Support Waiver Program
- t Mental Retardation (ID) Waiver Program
- t Natural Support Waiver Program
- t Community Habilitation & Support Services Waiver Program
- t SOURCE

**Organizations/ Association**

- t MH/DD/AD Regional Offices

**Personal Care Homes**

- t Community Living Arrangements

**Organizations**

**National Organization on Fetal Alcohol Syndrome**

<http://www.nofas.org/>

**Fact Sheet for Fetal Alcohol Syndrome (PDF file)**

Source: Centers for Disease Control

<http://www.cdc.gov/ncbddd/factsheets/FAS.pdf>

Source: <http://www.nlm.nih.gov>

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**Fragile X Syndrome**

What is it?

Is there any treatment?

What is the prognosis?

Potential Services Available in ESP

Organizations

Fact Sheet (PDF file)

**What is it?**

Fragile X syndrome is the most common inherited form of Mental Retardation (ID). It results from a change, or mutation, in a single gene, which can be passed from one generation to the next. Individuals with this disorder often have distinctive physical features, such as a long face, large prominent ears, poor eye contact, cluttered speech, poor pronunciation, hyperactivity, autistic features, macrocephaly (large head), prognathism (protruding jaw), nystagmus (jerky eye movements) and large testes. Individuals with this syndrome experience some degrees of

Mental Retardation (ID) along with speech and language delays. In addition, 15-20% may also exhibit behaviors associated with autism.

The most noticeable and consistent effect of Fragile X is on intelligence. More than 80 percent of males with Fragile X have an IQ (intelligence quotient) of 75 or less. The effect of Fragile X on intelligence is more variable in females. Some females have mental impairment, some have learning disabilities, and some have a normal IQ.

People with Fragile X syndrome also share certain medical problems as well as many common physical characteristics, such as large ears and a long face. In addition, having Fragile X is often associated with problems with sensation, emotion, and behavior.

### **Is there any treatment?**

At this time, there is no cure for fragile X syndrome. However, special education, speech and language therapy, occupational therapy and behavioral therapies are helpful in addressing many of the behavioral, and cognitive issues in fragile X syndrome. In addition, medical intervention including medications can be helpful for aggression, anxiety, hyperactivity and poor attention span. Because the impact of fragile X is so varied, it is important to do a careful evaluation of the individuals' abilities and difficulties to tailor a treatment plan to address specific needs.

### **What is the prognosis?**

Prognosis for this disease varies. Less affected individuals may be able to have a job and live on their own, while those experiencing severe retardation will need to be supervised for their entire life. These individuals may be able to live to 60 years of age. Those affected with the disease do have a capacity to learn, and can attend special schools that cater to their needs. They are generally very successful at these schools. Males affected with this disease generally can have a quality of life that is comparable to their healthy counterparts.

### **Potential Services Available in ESP**

#### **Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

#### **Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services
- t DD- Respite Services
- t DD- Counseling

#### **Health Conditions/ Disease**

- t Developmental Delay

#### **Income Security**

- t Supplemental Security Income

#### **Information and Referral**

- t Disability Referrals

#### **Leisure/ Recreational**

- t Specialized Clubs/ Developmental Disabilities

### **Medicaid Waiver/ Demonstration Programs**

- t Family Support Waiver Program
- t Mental Retardation (ID) Waiver Program
- t Natural Support Waiver Program
- t Community Habilitation & Support Services Waiver Program
- t SOURCE

### **Organizations/ Association**

- t MH/DD/AD Regional Offices

### **Personal Care Homes**

- t Community Living Arrangements

## **Organizations**

### **National Fragile X Foundation**

P.O. Box 190488

San Francisco, CA 94119-0488

Phone: 1-800-688-8765

Email: [NATLFX@FragileX.org](mailto:NATLFX@FragileX.org)

Web: [www.fragilex.org](http://www.fragilex.org)

### **Fact Sheet for Fragile X Syndrome**

Source: Explora Learning

<http://www.exploralearning.com/factsheets/fragilex.pdf>

Source: <http://www.fragilex.org>

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## **Hydrocephalus**

What is it?

Is there any treatment?

What is the prognosis?

Potential Services available in ESP

Organizations

Fact Sheet on Hydrocephalus (PDF file)

### **What is it?**

Hydrocephalus is a condition in which the primary characteristic is excessive accumulation of fluid in the brain. Although hydrocephalus was once known as "water on the brain," the "water" is actually cerebrospinal fluid (CSF) -- a clear fluid surrounding the brain and spinal cord. The excessive accumulation of CSF results in an abnormal dilation of the spaces in the brain called ventricles. This dilation causes potentially harmful pressure on the tissues of the brain.

Hydrocephalus may be congenital or acquired. Congenital hydrocephalus is present at birth and may be caused by genetic abnormalities or developmental disorders such as spina bifida and encephalocele. Acquired hydrocephalus develops at the time of birth or at some point afterward and can affect individuals of all ages.

Symptoms of hydrocephalus vary with age, disease progression, and individual differences in tolerance to CSF. In infancy, the most obvious indication of hydrocephalus is often the rapid increase in head circumference or an unusually large head size. In older children and adults, symptoms may include headache followed by vomiting, nausea, papilledema (swelling of the optic disk, which is part of the optic nerve), downward deviation of the eyes (called "sunseting"), problems with balance, poor coordination, gait disturbance, urinary incontinence, slowing or loss of development (in children), lethargy, drowsiness, irritability, or other changes in personality or cognition, including memory loss. Hydrocephalus is diagnosed through clinical neurological evaluation and by using cranial imaging techniques such as ultrasonography, computer tomography (CT), magnetic resonance imaging (MRI), or pressure-monitoring techniques.

### **Is there any treatment?**

Hydrocephalus is most often treated with the surgical placement of a shunt system. This system diverts the flow of cerebrospinal fluid (CSF) from a site within the central nervous system to another area of the body where it can be absorbed as part of the circulatory process. A limited number of patients can be treated with an alternative procedure called third ventriculostomy. In this procedure, a small hole is made in the floor of the third ventricle, allowing the CSF to bypass the obstruction and flow toward the site of resorption around the surface of the brain.

### **What is the prognosis?**

The prognosis for patients diagnosed with hydrocephalus is difficult to predict, although there is some correlation between the specific cause of hydrocephalus and the patient's outcome. Prognosis is further complicated by the presence of associated disorders, the timeliness of diagnosis, and the success of treatment. The symptoms of normal pressure hydrocephalus usually get worse over time if the condition is not treated, although some people may experience temporary improvements. If left untreated, progressive hydrocephalus is fatal, with rare exceptions. The parents of children with hydrocephalus should be aware that hydrocephalus poses risks to both cognitive and physical development. Treatment by an interdisciplinary team of medical professionals, rehabilitation specialists, and educational experts is critical to a positive outcome. Many children diagnosed with the disorder benefit from rehabilitation therapies and educational interventions, and go on to lead normal lives with few limitations.

### **Potential Services available in ESP**

#### **Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

#### **Consumer Services**

- t Non-Driver Identification
- t Personal Care Home Complaints
- t Voter Registration

#### **Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services

t DD- Respite Services

t DD- Counseling

**Elder Abuse/ Neglect**

t Adult Protective Intervention

t Institutional Abuse/ Neglect

**Financial Services**

t Estate Planning

**Health Conditions/ Disease**

t Developmental Delay

**Income Security**

t Supplemental Security Income

**Information and Referral**

t Disability Referrals

**Leisure/ Recreational**

t Specialized Clubs/ Developmental Disabilities

**Medicaid Waiver/ Demonstration Programs**

t Community Care Services Program

t Independent Care Waiver Program

t Family Support Waiver Program

t Mental Retardation (ID) Waiver Program

t Natural Support Waiver Program

t Community Habilitation & Support Services Waiver Program

t SOURCE

**Organizations/ Association**

t MH/DD/AD Regional Offices

**Personal Care Homes**

t Community Living Arrangements

**Organizations**

**Hydrocephalus Association**

870 Market Street

Suite 705

San Francisco, CA 94102

[info@hydroassoc.org](mailto:info@hydroassoc.org)

<http://www.hydroassoc.org>

Tel: 415-732-7040 888-598-3789

Fax: 415-732-7044

**National Hydrocephalus Foundation**

12413 Centralia Road

Lakewood, CA 90715-1623

[hydrobrat@earthlink.net](mailto:hydrobrat@earthlink.net)

<http://nhfonline.org>

Tel: 562-402-3523 888-857-3434

Fax: 562-924-6666

## **Fact Sheet on Hydrocephalus (PDF file)**

Source: International Hydranencephaly Support Group

<http://hydranencephaly.com/Brochures/hydranfactbrochure.pdf>

Source: <http://www.nlm.nih.gov/medlineplus/hydrocephalus.html>

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### **Microcephaly**

What is it?

Is there any treatment?

What is the prognosis?

Potential Services available in ESP

Organizations

### **What is Microcephaly?**

Microcephaly is a medical condition in which the circumference of the head is smaller than normal because the brain has not developed properly or has stopped growing. Microcephaly can be present at birth or it may develop in the first few years of life. It is most often caused by genetic abnormalities that interfere with the growth of the cerebral cortex during the early months of fetal development. It is associated with Down's syndrome, chromosomal syndromes, and neurometabolic syndromes. Babies may also be born with microcephaly if, during pregnancy, their mother abused drugs or alcohol, became infected with a cytomegalovirus, rubella (German measles), or varicella (chicken pox) virus, was exposed to certain toxic chemicals, or had untreated phenylketonuria (PKU). Babies born with microcephaly will have a smaller than normal head that will fail to grow as they progress through infancy. Depending on the severity of the accompanying syndrome, children with microcephaly may have Mental Retardation (ID), delayed motor functions and speech, facial distortions, dwarfism or short stature, hyperactivity, seizures, difficulties with coordination and balance, and other brain or neurological abnormalities. Some children with microcephaly will have normal intelligence and a head that will grow bigger, but they will track below the normal growth curves for head circumference.

### **Is there any treatment?**

There is no treatment for microcephaly that can return a child's head to a normal size or shape. Treatment focuses on ways to decrease the impact of the associated deformities and neurological disabilities. Children with microcephaly and developmental delays are usually evaluated by a pediatric neurologist and followed by a medical management team. Early childhood intervention programs that involve physical, speech, and occupational therapists help to maximize abilities and minimize dysfunction. Medications are often used to control seizures, hyperactivity, and neuromuscular symptoms. Genetic counseling may help families understand the risk for microcephaly in subsequent pregnancies

### **What is the prognosis?**

Some children will only have mild disability. Others, especially if they are otherwise growing and developing normally, will have normal intelligence and continue to develop and meet regular age-appropriate milestones.

### **Potential Services available in ESP**

**Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

**Consumer Services**

- t Non-Driver Identification
- t Personal Care Home Complaints
- t Voter Registration

**Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services
- t DD- Respite Services
- t DD- Counseling

**Elder Abuse/ Neglect**

- t Adult Protective Intervention
- t Institutional Abuse/ Neglect

**Financial Services**

- t Estate Planning

**Health Conditions/ Disease**

- t Developmental Delay

**Income Security**

- t Supplemental Security Income

**Information and Referral**

- t Disability Referrals

**Leisure/ Recreational**

- t Specialized Clubs/ Developmental Disabilities

**Medicaid Waiver/ Demonstration Programs**

- t Community Care Services Program
- t Independent Care Waiver Program
- t Family Support Waiver Program
- t Mental Retardation (ID) Waiver Program
- t Natural Support Waiver Program
- t Community Habilitation & Support Services Waiver Program
- t SOURCE

**Organizations/ Association**

- t MH/DD/AD Regional Offices

**Personal Care Homes**

- t Community Living Arrangements

**Organizations****The Arc of the United States**

1010 Wayne Avenue

Suite 650

Silver Spring, MD 20910

[Info@thearc.org](mailto:Info@thearc.org)

<http://www.thearc.org>

Tel: 301-565-3842

Fax: 301-565-3843 or -5342

### **March of Dimes Birth Defects Foundation**

1275 Mamaroneck Avenue

White Plains, NY 10605

[askus@marchofdimes.com](mailto:askus@marchofdimes.com)

<http://www.marchofdimes.com>

Tel: 914-428-7100 888-MODIMES (663-4637)

Fax: 914-428-8203

Source: <http://www.nlm.nih.gov/medlineplus/microcephaly.html>

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### **Prader Willi Syndrome (PWS)**

[What is it?](#)

[What are the characteristics?](#)

[Is there any treatment?](#)

[What is the prognosis?](#)

[What causes PWS?](#)

[Potential Services available in ESP](#)

[Organizations](#)

[Fact Sheet \(PDF file\)](#)

### **What is it?**

Prader-Willi syndrome is a genetic disorder characterized in infancy by:

- diminished muscle tone (hypotonia);
- feeding difficulties;
- failure to grow and gain weight (failure to thrive); and
- excessive appetite in early childhood.

Affected children have an intense craving for food and will do almost anything to get it. This results in uncontrollable weight gain. Morbid obesity (the degree of obesity that seriously affects health) may lead to respiratory failure with hypoxia (low blood oxygen levels), right-sided heart failure (cor pulmonale), and death.

All individuals with Prader-Willi syndrome have some cognitive impairment that ranges from borderline normal with learning disabilities to mild Mental Retardation (ID). Behavior problems are common and can include temper tantrums, obsessive/compulsive behavior, and skin picking.

Severe obesity is the primary medical problem, but there are numerous major health concerns for individuals with Prader Willi, such as:

- Obesity-related problems—including diabetes, high blood pressure, chronic venous insufficiency (leading to ulcers in legs and feet), cellulitis, and hypoventilation
- Strabismus (crossed eyes) may require surgical correction
- Scoliosis

- Osteoporosis can occur earlier than usual and can cause fractures
- Sleep disturbances and sleep apnea
- Bedwetting
- Dental problems—including soft tooth enamel, thick saliva, poor oral hygiene, teeth grinding

### **Is it possible for people with PWS to lead typical lives?**

People with PWS can accomplish many of the things their "typical" peers do -- attend school, enjoy community activities, get jobs, and even move away from home. However, they need a lot of help. School children with PWS are likely to need special education and related services, such as speech and occupational therapy. In community, work and residential settings, adolescents and adults often need special assistance to learn and carry out responsibilities and to get along with others. In all settings, people with PWS need around-the-clock food supervision. As adults, most affected individuals do best in a special group home for people with PWS, where food access can be restricted without interfering with those who do not need such restriction. Although in the past many died in adolescence or young adulthood, it is thought that prevention of obesity will allow a person with PWS to live a normal lifespan.

### **How is Prader-Willi treated?**

There is no cure for PWS at this time. There are lots of health problems that need to be treated, though. With early diagnosis and a proactive approach, these kids' health, growth, and development can thrive.

- Weight management is a major task of parents of kids with PWS. These kids need a balanced, low calorie diet with vitamin and calcium supplements, along with plenty of exercise. You will probably need to restrict access to food by locking your cabinets and refrigerator. No medication or surgical intervention has been found to eliminate the need for strict dieting.
- Growth hormone is a common medication used in PWS. It increases muscle mass and function, may allow for a higher daily calorie intake, and helps kids grow taller. The brochure, A Comprehensive Team Approach to the Management of PWS is available in English, German and Greek. It discusses the use of Growth Hormone to treat PWS. Please note that the pharmaceutical company that produces growth hormone medication funded this brochure.
- Sex hormone replacement can lead to more normal physical development in puberty.
- Behavioral management—daily routines, structure, firm rules and limits, and positive rewards work best. Psychotropic medications may help with obsessive-compulsive symptoms and mood swings as a last resort if behavior management programs do not work.
- Physical and occupational therapy help promote motor development along with growth hormone. Speech and language therapy may help with speech delays. Early intervention and special education can help your child reach their full potential.

### **What causes Prader-Willi Syndrome?**

Prader-Willi syndrome occurs when the genes in a specific region of chromosome 15 do not function. The abnormal genes usually result from random errors in development, but are sometimes inherited.

## **Potential Services available in ESP**

### **Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

### **Consumer Services**

- t Non-Driver Identification
- t Personal Care Home Complaints
- t Voter Registration

### **Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services
- t DD- Respite Services
- t DD- Counseling

### **Elder Abuse/ Neglect**

- t Adult Protective Intervention
- t Institutional Abuse/ Neglect

### **Financial Services**

- t Estate Planning

### **Health Conditions/ Disease**

- t Developmental Delay

### **Income Security**

- t Supplemental Security Income

### **Information and Referral**

- t Disability Referrals

### **Leisure/ Recreational**

- t Specialized Clubs/ Developmental Disabilities

### **Medicaid Waiver/ Demonstration Programs**

- t Family Support Waiver Program
- t Mental Retardation (ID) Waiver Program
- t Natural Support Waiver Program
- t Community Habilitation & Support Services Waiver Program
- t SOURCE

### **Nutrition Services**

- t Nutrition Education Programs

### **Organizations/ Association**

- t MH/DD/AD Regional Offices

### **Personal Care Homes**

- t Community Living Arrangements

## **Organizations**

## Prader-Willi Alliance

www.prader-willi.org

## Prader-Willi Syndrome Association

www.pwsausa.org

toll free number 1-800-926-4797

## Fact Sheet on Prader Willi Syndrome (PDF file)

Source: Prader Willi Syndrome Association

<https://www103.sslldomain.com/pwsausa/AwarenessWeek/GA-01A.pdf>

Sources: [www.pwsausa.org](http://www.pwsausa.org)

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## Spina Bifida

What is it?

Is there any treatment?

What is the prognosis?

Potential Services available in ESP

Organizations

Fact Sheet (PDF file)

## What is it?

Spina bifida (SB) is a neural tube defect (a disorder involving incomplete development of the brain, spinal cord, and/or their protective coverings) caused by the failure of the fetus's spine to close properly during the first month of pregnancy. Infants born with SB sometimes have an open lesion on their spine where significant damage to the nerves and spinal cord has occurred. Although the spinal opening can be surgically repaired shortly after birth, the nerve damage is permanent, resulting in varying degrees of paralysis of the lower limbs. Even when there is no lesion present there may be improperly formed or missing vertebrae and accompanying nerve damage. In addition to physical and mobility difficulties, most individuals have some form of learning disability.

The three most common types of SB are:

1. **Myelomeningocele-** The severest form, in which the spinal cord and its protective covering (the meninges) protrude from an opening in the spine which causes nerve damage and more severe disabilities;
2. **Meningocele-** The spinal cord develops normally but the meninges protrude from a spinal opening. There is usually no nerve damage. Individuals may suffer minor disabilities, but new problems can develop later in life.
3. **Occulta-** The mildest form, in which one or more vertebrae are malformed and covered by a layer of skin. There may be no motor or sensory impairments evident at birth. Subtle, progressive neurologic deterioration often becomes evident in later childhood or adulthood. In many instances, spina bifida occulta is so mild that there is no disturbance of spinal function at all. Occulta can be diagnosed at any age.

SB may also cause bowel and bladder complications, and many children with SB have hydrocephalus (excessive accumulation of cerebrospinal fluid in the brain).

### **Is there any treatment?**

There is no cure for SB because the nerve tissue cannot be replaced or repaired. Treatment for the variety of effects of SB may include surgery, medication, and physiotherapy. Many individuals with SB will need assistive devices such as braces, crutches, or wheelchairs. Ongoing therapy, medical care, and/or surgical treatments may be necessary to prevent and manage complications throughout the individual's life. Surgery to close the newborn's spinal opening is generally performed within 24 hours after birth to minimize the risk of infection and to preserve existing function in the spinal cord.

### **What is the prognosis?**

The prognosis for individuals with SB depends on the number and severity of abnormalities. Prognosis is poorest for those with complete paralysis, hydrocephalus, and other congenital defects. With proper care, most children with SB live well into adulthood.

Thanks to new medical treatments and technology, most people born with Spina Bifida can expect to live a normal life. People with Spina Bifida have many special challenges because of their birth defect, but their condition does not define who they are. People with Spina Bifida have careers, get married and have children just like people who don't have Spina Bifida.

### **Potential Services Available in ESP**

#### **Advocacy Assistance**

- t Developmental Disabilities Advocacy Assistance

#### **Developmental Disabilities**

- t DD- Adult Day Programs
- t DD- Home Care Providers
- t DD- Intake and Screening
- t DD- Residential Options
- t DD- Vocational Services
- t DD- Respite Services
- t DD- Counseling

#### **Health Centers/ Clinics**

- t Continence Clinics

#### **Health Conditions/ Disease**

- t Spina Bifida

#### **Income Security**

- t Supplemental Security Income

#### **Information and Referral**

- t Disability Referrals

#### **Leisure/ Recreational**

- t Specialized Clubs/ Developmental Disabilities

#### **Medicaid Waiver/ Demonstration Programs**

- t Community Care Services Program
- t Independent Care Waiver Program

- t Family Support Waiver Program
- t Mental Retardation (ID) Waiver Program
- t Natural Support Waiver Program
- t Community Habilitation & Support Services Waiver Program
- t SOURCE

**Organizations/ Association**

- t Organizations
- t MH/DD/AD Regional Offices

**Personal Care Homes**

- t Community Living Arrangements

**Organizations**

**Spina Bifida Association of America**

4590 MacArthur Blvd. NW

Suite 250

Washington, DC 20007-4266

[sbaa@sbaa.org](mailto:sbaa@sbaa.org)

<http://www.sbaa.org>

Tel: 202-944-3285 800-621-3141

Fax: 202-944-3295

**Fact Sheet on Spina Bifida (PDF file)**

Source: National Dissemination Center for Children with Disabilities

<http://www.nichcy.org/pubs/factshe/fs12.pdf>

Source :[http://www.ninds.nih.gov/disorders/spina\\_bifida/spina\\_bifida.htm](http://www.ninds.nih.gov/disorders/spina_bifida/spina_bifida.htm)

**DISABILITY RELATED ACRONYMS AND GLOSSARY**

**ADA- Americans with Disabilities Act**

The ADA protects people with disabilities from discrimination in employment, government services, and public accommodations.

**ADL- Activities of Daily Living**

Basic living skills including personal care and hygiene, cooking, housekeeping and money management.

**AT- Assistive Technology**

Technology that assists individuals to participate in activities as independently as possible. This can include “low-tech” items (i.e., timers, organizational tools, calculators) as well as more advanced technology (i.e., wheelchairs, computers, communication boards).

**CRP- Community Rehabilitation Provider**

A community-based agency, typically private and non-profit, that provides employment services to adults with disabilities. The majority of funding for most CRPs comes from government agencies and funding sources.

### **Deaf-Blindness**

Deaf-blindness, or dual sensory impairment, is a combination of both visual and hearing impairments. An individual with deaf-blindness can experience severe communication, educational, and other developmental problems. A person with deaf-blindness cannot be accommodated by services focusing solely on visual impairments or solely on hearing impairments, so services must be specifically designed to assist individuals with deaf-blindness.

### **DD-Developmental Delays**

Developmental delays refer to conditions which represent a significant delay in the process of child development. The delays may involve cognitive, physical, communicative, social/emotional, and adaptive areas of development. Without special intervention, these delays may affect the educational performance of the child.

### **DD-Developmental Disabilities**

A developmental disability is a severe and long lasting disability which is the result of a mental and/or physical impairment, occurs before age 22, is likely to continue indefinitely, reflects the person's need for specialized services and/or treatment, and results in substantial functional limitations in three or more areas. The areas include: self-care, self-direction, economic self-sufficiency, independent living, learning, receptive and expressive language, and mobility.

### **Employment Specialist**

A staff member from a community agency who helps people with disabilities obtain employment. This term is sometimes used interchangeably with the term “job coach”.

### **Enclaves**

A group of individuals with disabilities who work in a community business with ongoing support and possibly supervision provided by rehabilitation agency staff.

### **Functional Vocational Assessment**

Identifies an individual’s vocational interests and skills through the performance of job tasks in a variety of actual work environments in the community. Also known as a situational assessment.

### **IDEA- Individuals with Disabilities Education Act**

The federal law that mandates a “free appropriate public education” to all “eligible” children with disabilities (including mental, physical, and emotional disabilities) who, because of their disability, require special instruction in order to learn.

### **IEP- Individualized Education Program (school)**

A plan, mandated by IDEA, that states the goals and services for a student for a period of up to, but for no longer than, one year (it is rewritten each year to reflect changes in the educational program).

**IL- Independent Living**

The concept of independent living involves the belief that individuals with disabilities have the same rights and responsibilities as other people in society. Thus, services provided to the public should be accessible to persons with disabilities, and systems of support should be made available to help individuals with disabilities live within the community and lead more independent lives.

**ILC- Independent Living Centers**

ILCs are community based, not-for-profit, non-residential organizations that provide advocacy, peer counseling, independent living skills training, and information & referral to persons of any age with any type of disability.

**ISP- Individual Support Plan (adult service provider)**

A formal plan that assesses an individual's needs for supports; identifies and chooses the natural, generic, and specialized supports that will meet those needs; and plans for the outcome that will enhance the individual's quality of life.

**ITP - Individualized Transition Plan**

The Individualized Transition Plan is the part of a person's IEP that identifies the long range goals of the person in respect to life after school. Transition services are a coordinated set of activities that are designed to help a student with disabilities move from school to life after school. The person's life after school may include: post secondary education, vocational training, integrated employment, continuing and adult education, independent living, participation in the community, and other activities. The ITP indicates how the individual will be supported or helped to participate in his/her preferred activities and achieve his/her goals.

**LD- Learning Disabilities**

Learning disabilities is a broad term used to refer to disorders that affect a person's ability to interpret what they see or hear and link information from different parts of the brain. These disorders usually manifest as problems with reading, writing, reasoning, or mathematics. Learning disabilities are neurological, lifelong disorders, but can often be overcome through appropriate intervention and support.

**MR- Mental Retardation (ID)**

A developmental disability characterized by slower learning and more concrete thought processes.

**Natural Supports**

Natural, supportive relationships that are fostered and developed among individuals with disabilities and non-disabled co-workers, classmates, activity participants, neighbors etc. An emphasis in recent years in the disability field has been on using these relationships to support an individual with a disability, rather than relying on paid staff for assistance and support.

**Paraplegia**

Paraplegia is paralysis of the legs and lower part of the body. Paraplegia often involves loss of sensation as well as loss of movement. It is usually caused by injury or disease in the lower spinal cord, or brain disorders, such as cerebral palsy.

**Person-Centered Planning**

A planning process that focuses on the individual and his/her interests, strengths, and needs. Emphasis is placed on the planning process being controlled by the individual with a disability, with involvement by individuals of their choice from their personal network. There are numerous models of this type of planning available.

**OSEP- Office of Special Education Programs**

The federal agency that oversees special education services for children and youth with disabilities from birth through age 21. OSEP is a division of OSERS.

**OSERS- U.S. Office of Special Education and Rehabilitation Services**

A federal agency that supports programs that assist in educating children with special needs; provides for the rehabilitation of youth and adults with disabilities; and supports research to improve the lives of individuals with disabilities.

**PASS- Plans for Achieving Self Support**

A Social Security Work Incentive that can be used to help reduce the impact of earned income on SSI benefits. A PASS allows a person with a disability to set aside income and/or resources towards a work goal for a specified period of time (i.e., a person could set aside money for education or vocational training).

**P&A- Protection and Advocacy**

Federally-funded organizations, located in every state, that protect the legal rights of people with disabilities.

**Quadriplegia**

Quadriplegia is the paralysis of all four limbs. (see paraplegia)

**Reasonable Accommodation**

Change in an environment to meet the access needs of an individual in accordance with the Americans with Disabilities Act.

**RSA- Rehabilitation Services Administration**

A federal agency that oversees programs that help individuals with physical or mental disabilities to obtain employment through the provision of such supports as counseling, medical and psychological services, and job training. RSA is the main funding agency for state Vocational Rehabilitation programs. RSA is a division of OSERS.

**SE- Supported Employment**

The provision of ongoing supports from an external source (e.g., a community rehabilitation provider or state agency) to an individual in a paid, community-based setting, where the majority of the workers do not have disabilities, directed at teaching the tasks of that specific job as they occur, and identifying supports for the individual within the workplace.

**SpEd- Special Education**

Education services for children and youth with disabilities.

**SLS - Supported Living Services**

is an opportunity to support individuals with developmental disabilities based on the needs and preferences of the individual. Key concepts of Supported Living Services (SLS) include individual choice, involvement and the availability of supports to assist individuals to access and participate in typical activities and functions of community life. Supported Living Services can provide supports to an individual in the family home and can also provide opportunities for adults to move into their own homes. Supported Living services, unlike traditional 24 hour supervision models, offers an array of supports to choose from to assist individuals in being as independent as possible. SLS is designed to use a variety of natural non paid supports and generic community services, available to all individuals who qualify, augmenting the paid supports provided. Supported Living is not able to provide all of the supports a person necessarily needs, but is able to assist and supplement some of those needs.

**UAP- University Affiliated Program**

A federally-funded program whose mission is to service as a liaison between academic expertise and institutions of higher learning and service delivery systems so as to positively affect the lives of individuals with developmental disabilities and their families by increasing their independence, productivity, and integration into communities. The University of Georgia is a UAP.

**VR- Vocational Rehabilitation**

The process of assisting individuals with disabilities to obtain and maintain employment through diverse services tailored to meet the needs of each individual. Each state has a public VR agency.

Source: Institute for Community Inclusion