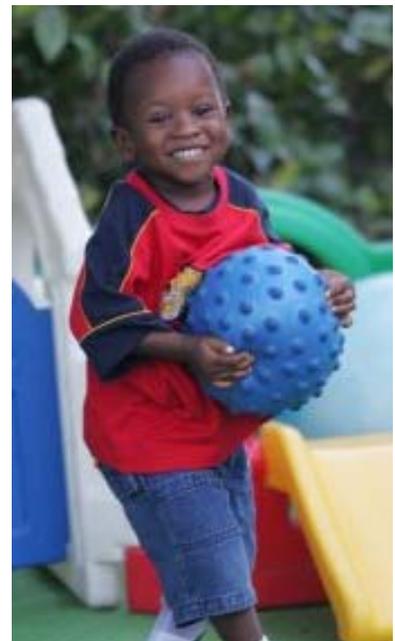
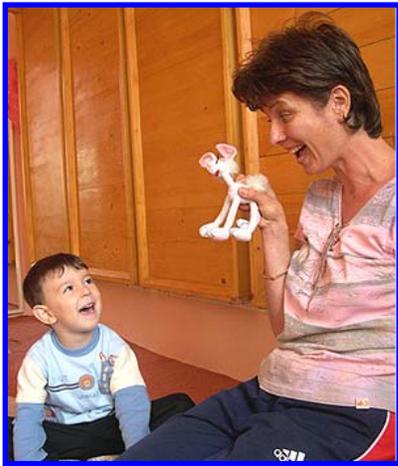


# Grandparents Raising Grandchildren with Disabilities In South Carolina



# Grandparents Raising Grandchildren with Disabilities

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# Guide to Developmental Disabilities

## **GUIDE TO DEVELOPMENTAL DISABILITIES**

### **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.

## **Mental Retardation (MR) or Intellectual Disability (ID)**

### **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

\* In South Carolina, the Department of Disabilities and Special Needs uses the following criteria:

Mild retardation:	IQ score from 53-70
Moderate retardation:	IQ score from 36-52
Severe retardation:	IQ score from 21-35
Profound retardation:	IQ score from 1-20

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 of the 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.

### **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

<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)

<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

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

## Autism Spectrum Disorders (ASDs)

### 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, cappuccino, 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.

### **Organizations**

Autism Society of America.

Tel: 301-657-0881 800-328-8476

[www.autism-society.org](http://www.autism-society.org)

South Carolina Autism Society

803-750-6988 or 800-438-4790

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

SC Dept. of Disabilities and Special Needs

Autism Division

(803) 898-9600

Toll Free: 1-888-376-4636)

[www.state.sc.us/ddsn](http://www.state.sc.us/ddsn)

## Cerebral Palsy

### 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).

### **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)

# Down Syndrome

## 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.

## Incidence

Approximately 4,000 children with Down syndrome are born in the U.S. each year, or about 1 in every 800 to 1,000 live births. Although parents of any age may have child with Down syndrome, the incidence is higher for women over 35. Most common forms of the syndrome do not usually occur more than once in a family.

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.

Besides having a distinct physical appearance, children with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are higher in those with Down syndrome, as are mild to moderate hearing loss and speech difficulty.

Approximately one third of babies born with Down syndrome have heart defects, most of which are now successfully correctable. Some individuals are born with gastrointestinal tract problems that can be surgically corrected.

Some people with Down syndrome also may have a condition known as Atlantoaxial

Instability, a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

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

### **Educational and Employment Implications**

Shortly after a diagnosis of Down syndrome is confirmed, parents should be encouraged to enroll their child in an infant development/early intervention program. These programs offer parents special instruction in teaching their child language, cognitive, self-help, and social skills, and specific exercises for gross and fine motor development. Research has shown that stimulation during early developmental stages improves the child's chances of developing to his or her fullest potential. Continuing education, positive public attitudes, and a stimulating home environment have also been found to promote the child's overall development.

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.

Because of the range of ability in children with Down syndrome it is important for families and all members of the school's education team to place few limitations on potential capabilities. It may be effective to emphasize concrete concepts rather than abstract ideas. Teaching tasks in a step-by-step manner with frequent reinforcement and consistent feedback has been proven successful. Improved public acceptance of persons with disabilities along with increased opportunities for adults with disabilities to live and work independently in the community, have expanded goals for individuals with Down syndrome. Independent Living Centers, group shared and supervised apartments and support services in the community have proven to be important resources for persons with disabilities.

### **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.

### **Organizations**

National Down Syndrome Society  
666 Broadway  
New York, NY 10012  
Telephone: 1-800-221-4602  
Fax: 212-979-2873  
Email: [info@ndss.org](mailto:info@ndss.org)  
Web: <http://www.ndss.org/>

National Down Syndrome Congress  
1370 Center Drive, Suite 102  
Atlanta, GA 30338  
800.232.6372; 770.604.9500  
E-mail: [info@ndscenter.org](mailto:info@ndscenter.org)  
Web address: [www.ndscenter.org](http://www.ndscenter.org)

The Arc of the United States (formerly the Association for Retarded Citizens of the United States)  
1010 Wayne Avenue, Suite 650  
Silver Spring, MD 20910  
301.565.3842  
E-mail: [info@thearc.org](mailto:info@thearc.org)  
Web address: [www.thearc.org](http://www.thearc.org)

SC Department of Disabilities and Special Needs (DDSN)  
Mental Retardation Division  
Phone: (803) 898-9600  
Toll Free: 1-888-376-4636

# Epilepsy

## 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 tests 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 settings. 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.

## Organizations

Epilepsy Foundation

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

<http://www.epilepsyfoundation.org>

800-1000-332-1000

Epilepsy Institute

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

<http://www.epilepsyinstitute.org>

Tel: 212-677-8550

Epilepsy Foundation of South Carolina  
(803) 798-8502  
epilepsyc@epilepsyc.org  
<http://www.epilepsyc.org/>

## **Fetal Alcohol Syndrome**

### **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 include 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.

### **Organizations**

#### **Fetal Alcohol Syndrome**

NCBDDD, CDC

1-800-CDC-INFO (232-4636)

Email: [cdcinfo@cdc.gov](mailto:cdcinfo@cdc.gov)

<http://www.cdc.gov/ncbddd/fas/>

## **Fragile X Syndrome**

### **What is it?**

Fragile X syndrome is the most common inherited form of Mental Retardation (ID) and learning disability. It results from a change, or mutation, in a single gene, which can be passed from one generation to the next. It is a sex-linked genetic abnormality in which the mother passes it on to her sons. 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 degree 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.

### **How many people have this condition?**

It affects approximately 1 in every 1,000 to 2,000 male individuals, and the female carrier frequency may be substantially higher. Males with this syndrome typically have a moderate to severe form of learning difficulties. Females may also be affected but generally have a milder form.

Approximately 15% to 20% of those with Fragile X Syndrome exhibit autistic-type behaviors, such as poor eye contact, hand-flapping or odd gesture movements, hand-biting, and poor sensory skills. Behavior problems and speech/language delay are common features of Fragile X Syndrome.

### **How do you diagnose it?**

This is usually by a pediatrician with support from a geneticist. Counseling will be offered and advice on management usually takes place in an educational setting

### **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 individual's 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 lives. 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.

### **Organizations**

National Fragile X Foundation

1-800-688-8765

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

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

## Hydrocephalus

### 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 "sunsetting"), 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.

**Organizations**

Hydrocephalus Association

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

<http://www.hydroassoc.org>

888-598-3789

National Hydrocephalus Foundation

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

<http://nhfonline.org>

888-857-3434

## Microcephaly

### 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.

### Organizations

The Arc of the United States

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

<http://www.thearc.org>

301-565-3842

March of Dimes Birth Defects Foundation

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

<http://www.marchofdimes.com>

888-663-4637

## Prader Willi Syndrome

### 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.

### **Organizations**

Prader-Willi Alliance

[www.prader-willi.org](http://www.prader-willi.org)

Prader-Willi Syndrome Association

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

toll free number 1-800-926-4797

## **Spina Bifida**

### **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.

### **Organizations**

Spina Bifida Association of America

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

<http://www.sbaa.org>

800-621-3141

## **DEAF/HARD OF HEARING**

**State Relay Service: Relay South Carolina-** <http://www.relaysouthcarolina.com>  
711 (V/TTY) or 1-800-676-3777 (V/TTY)

**South Carolina STS (Speech to Speech) Relay** - 877-735-7277 (toll free)

**SC State Library** - Dept. for the Blind and Physically Handicapped. Will send books, books on tape and a free player to those with disabilities  
<http://www.state.sc.us/scsl/scslweb/tbswelcome.html>  
803-898-5900 or 1-800-922-7818

**South Carolina Telecommunications Equipment Distribution Program (SC TEDP) -**  
1-877-225-8337 Voice or 1-877-889-8337 TTY  
<http://www.scsdb.k12.sc.us/TEDP/TEDP%20Instructions.htm>  
Provides telecommunications equipment at no cost to South Carolina residents with qualifying hearing, speech or dual sensory disabilities. Individuals experiencing difficulty with a standard telephone are encouraged to apply to receive free telephone equipment.

**Newsline® – Talking Books Services** - [www.state.sc.us/scsl/bph](http://www.state.sc.us/scsl/bph)  
1-803-734-8666 734-4611 or 1-800-922-7818

Newsline® readers have access to national papers such as The New York Times, The Los Angeles Times, The Chicago Tribune, USA Today, The Wall Street Journal, and several dozen more papers of local interest throughout the U. S. such as The Charlotte Observer.

**RID Searchable Databases** - <http://filemaker.rid.org/default.htm>

(Registry of Interpreters for the Deaf, Inc.) Search the database for interpreters or agencies by name, city, state, area code, or zip code to find professionals who provide sign language interpreting services for Deaf and Hard of Hearing persons. Only individuals and Interpreter Service Agencies that are members of Registry of Interpreters for the Deaf, Inc. are listed in the database.

**South Carolina Interpreter Locator** - <http://www.scadservices.org/scirt/terplocator.htm>  
(SC Interpreter Recruitment & Training (SCIRT) Project) Includes contact information for South Carolina interpreters for the deaf. The interpreters are listed by regions of the state.

**Miracle-Ear®** - [http://www.miracle-ear.com/resources/children\\_request.asp](http://www.miracle-ear.com/resources/children_request.asp)  
1-800-234-5422 Free information on Hearing Loss in Children.  
1-800-234-5423 For Hearing Aid Fitting Applications

To receive assistance through the Children's Foundation, the child must be:

- \*A resident of the United States.
- \*16 years old or younger and have a hearing loss that requires amplification.
- \*In possession of an audiogram and medical clearance dated within the last 6 months.
- \*In a family with an income level which does not allow the family to receive public support. \$20,000-\$45,000 gross.
- \*In a family committed to intervention, rehabilitation, and necessary follow-up services as the child grows.

## Early Intervention

## Early Intervention for Children with Special Needs

Children with special needs include those with physical or mental disabilities, emotional or behavioral problems, or considered at-risk for developing disabilities. Children who had prenatal exposure to drugs and alcohol are considered at risk. Prenatal (and often environmental) exposure to harmful substances and behaviors can result in the child being deprived of certain age-appropriate development steps. If you are concerned about your grandchild's development or are raising a child who has a disability, there are programs that can help you. Also, schools are a valuable resource for children with special needs. Children who have disabilities are mainstreamed into most classrooms. Ask about available programs at your grandchild's school.



Early intervention is for families with infants or toddlers ages birth through 3 years old who have concerns about how their child is developing. If you are concerned about grandchild's walking, talking, crawling, understanding, seeing or hearing, call BabyNet, South Carolina's early intervention program.

BabyNet is South Carolina's interagency system of early intervention services for families who have infants and toddlers, birth to three years of age, with developmental delays or conditions associated with developmental delays. Children may be eligible for BabyNet if they are learning or developing slowly. Eligible children are served regardless of family income or nationality.

BabyNet matches the special needs of infants and toddlers who have developmental delays with the professional resources available within the community. Services are provided in everyday routines, activities and places relevant to the life of the family. Anyone (a parent, doctor, caregiver, teacher or friend) can make a referral by calling the referral phone number listed below.

The following services are available to eligible South Carolina families who have children under age three with delays in development. Depending on each child's needs, BabyNet programs directly provide or offer access to 17 core early intervention services. The specific services a child receives is based on a custom-tailored plan for that child. The family plays a key role in working with staff to create this plan.

Assistive Technology - services and equipment, including adaptive assistive devices, designed or altered for special use by children with developmental delays.

Audiology - testing your child's hearing, making referrals for further auditory services, as needed.

Early Identification, Screening and Assessment - identifying your child's strengths, developmental needs, and your family's concerns.

Family Education - teaching your family about your child's delay and ways to help your child.

Health Services - helping your child benefit from other services including: clean

intermittent catheterization, tracheostomy care, tube feeding, changing dressings orostomy collection bags, and consultation with service providers concerning special health care needs.

Medical Services - diagnostic or evaluation services by a licensed physician who will assess your child's eligibility for BabyNet services. BabyNet programs do not pay for other medical services.

Nursing - health assessments, nursing care to prevent health problems or improve functioning, administration of medications, and regiments prescribed by a licensed physician.

Nutrition - services provided by a dietitian/nutritionist who evaluates your child's nutrition and needs.

Occupational Therapy - helping children learn skills needed for play and daily living, designing and providing adaptive and assistive devices.

Physical Therapy - identifying and preventing or reducing movement disabilities, includes designing and providing adaptive and assistive devices.

Psychological Services - counseling, analysis of your child's functioning, and interpretation of behavior.

Service Coordination - helping your child and family get services, providing information about BabyNet services, and finding other services in the community. A service coordinator works with your family to support your child's development and to arrange for services in and outside of your BabyNet program.

Social Work Services - assessing your child in the family setting, counseling, and social skill-building activities for your child.

Special Instruction - helping your child develop learning skills.

Speech-Language Therapy - helping your child understand language or learn to communicate, includes designing and providing assistive devices.

Transportation - arranging for someone to drive your child and family to and from early intervention services. This could include using a taxi or bus.

Vision Services - evaluation and assessment of vision, includes referral for medical or other professional services to train or restore visual functioning.

For more information on statewide early intervention services, contact the CareLine at 1-800-868-0404 or email: [babynet@dhec.sc.gov](mailto:babynet@dhec.sc.gov).

**The earlier you get help, the better.**

**Early intervention makes a difference!**

## Child Care

## Child Care

### ABC Special Needs Program



SC Child Care

The Child Care Services Division of the SC Department of Social Services places a high priority on serving families with children who have special needs. These are children who are under the age of 19 and have differing abilities and developmental delays such as Autism, Mental Retardation, Down Syndrome, or brain and spinal cord injuries.

A child may also be eligible if they are receiving physical therapy, occupational therapy, or speech therapy through their local county school district and have an “Individualized Education Plan” they are working on with their school. The ABC program offers a number of services to these families.

### Special Needs Child Care Vouchers

Families may qualify for special child care vouchers (slots), but only if the parent is employed, or is enrolled in a school or training program, or is also disabled. ABC vouchers are always intended to support working parents and their families. Parents who believe they are eligible must fill out an ABC Special Needs Child Care Application. Special Needs applications are available through certain agencies; the locations where an ABC Special Needs Application can be obtained are listed below:

- Local county Departments of Disabilities and Special Needs
- The South Carolina School for the Deaf & Blind
- The Babynet Office at the Dept. of Health and Environmental Control
- Children’s Rehabilitative Services at the county Dept. of Health and Environmental Control

Once the application is completed, the staff located at these agencies – usually an Early Interventionist, a Service Coordinator or a Referral Agent - will review the application to ensure that it is accurate and complete. All applications are forwarded to the ABC Special Needs Child Care Program located at the Department of Social Services. Parents will be notified about the status of their case within 2 weeks.

For questions regarding the ABC Special Needs Voucher program, call:  
Donna Casteen at (803) 898-9735 or email her at: [donna.casteen@dss.sc.gov](mailto:donna.casteen@dss.sc.gov).

### **Other Special Needs Resources**

The Center for Disability Resources at the USC School of Medicine/Pediatrics also offers training to child care providers that serve children with differing abilities. They consult with providers and offer them specialized technical assistance and training at no cost to the provider. They often go on-site to show providers how to do certain medical procedures; for example, they may show a provider how to perform blood sugar tests on kids with diabetes. They train all sorts of providers:

- family child care homes

- group child care homes

- child care centers

- faith-based providers

- families, friends, and neighbors caring for children in their homes

They will also assist grandparents looking for good childcare.

Call the USC Center for Disability Resources at: 803-935-5231.

## Special Education Considerations

## Individuals with Disabilities Education Act

The **Individuals with Disabilities Education Act** (IDEA) is a [United States federal law](#) that governs how states and public agencies provide early intervention, [special education](#), and related services to children with disabilities. It addresses the educational needs of children with disabilities from birth to the age of 21.<sup>[1]</sup>

The IDEA is considered to be a civil rights law. However, states are not required to participate. As an incentive and to assist states in complying with its requirements, IDEA makes funds available to states that adopt at least the minimum policies and procedures specified in the IDEA regarding the education of children with disabilities. Since its inception, all states have chosen to participate.

The IDEA was formerly known as the Education for All Handicapped Children Act but has grown considerably since. IDEA became a federal standard by an act of Congressional adoption in 1975 but has been amended many times since. The IDEA was most recently amended in 2004, which was a significant update.

In defining the purpose of special education, IDEA 2004 clarifies Congress' intended outcome for each child with a disability: students must be provided a [Free Appropriate Public Education \(FAPE\)](#) that prepares them for further education, employment and independent living.<sup>[2]</sup>

### Background

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Before the EHA statute was enacted in 1974, U.S. public schools educated only 1 out of 5 children with disabilities<sup>[3]</sup>. Until that time, many states had laws that explicitly excluded children with certain types of disabilities from attending public school, including children who were blind, deaf, and children labeled "emotionally disturbed" or "mentally retarded."<sup>[4]</sup> At the time the EHA was enacted, more than 1 million children in the U.S. had no access to the public school system.<sup>[5]</sup> Many of these children lived at state institutions where they received limited or no educational or rehabilitation services.<sup>[6]</sup> Another 3.5 million children attended school but were "warehoused" in segregated facilities and received little or no effective instruction.<sup>[7]</sup>

As of 2006, more than 6 million children in the U.S. receive special education services through IDEA.<sup>[8]</sup> Many states are still resistant to educating special needs children appropriately even though they continue to accept federal funding. The federal and state enforcement agencies do not use strong enforcement methods or penalties.

### Provisions of IDEA

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#### Eligibility for services

Having a disability does not automatically qualify a student for special education services under the IDEA. IDEA defines a "child with a disability" as a child . . . with [mental retardation](#), [hearing impairments](#) (including deafness), speech or language impairments, [visual impairments](#) (including blindness), [serious emotional disturbance](#) . . .

., orthopedic impairments, [autism](#), [traumatic brain injury](#), other health impairments, or specific learning disabilities; AND, who . . . [because of the condition] needs special education and related services."<sup>[9]</sup> Children with disabilities who qualify for special education are also automatically protected by Section 504 of the [Rehabilitation Act of 1973](#) and under the [Americans with Disabilities Act](#) (ADA). However, all modifications that can be provided under Section 504 or the ADA can be provided under the IDEA if included in the student's IEP.

Students with disabilities who do not qualify for special education services under the IDEA may qualify for accommodations or modifications under Section 504 and under the ADA. Their rights are protected by due process procedure requirements.

## **Individualized Education Program**

The act requires that [public schools](#) create an [Individualized Education Program](#) (IEP) for each student who is found to be eligible under the both the federal and state eligibility/disability standards. The IEP is the cornerstone of a student's educational program. It specifies the services to be provided and how often, describes the student's present levels of performance and how the student's disabilities affect academic performance, and specifies accommodations and modifications to be provided for the student.<sup>[10]</sup>

An IEP must be designed to meet the unique educational needs of that one child in the [Least Restrictive Environment](#) appropriate to the needs of that child. That is, the least restrictive environment in which the child learns. When a child qualifies for services, an IEP team is convened to design an education plan. In addition to the child's parents, the IEP team must include at least one of the child's regular education teachers, a special education teacher, someone who can interpret the educational implications of the child's evaluation, such as a school psychologist, and an administrator who has knowledge of the availability of services in the district and the authority to commit those services on behalf of the child. Parents are considered to be equal members of the IEP team along with the school staff. And of course, parents have fundamental rights as parents. Based on the full educational evaluation results, this team collaborates to write an IEP for the individual child, one that will provide a free, appropriate public education. The required content of an IEP is described in [Individualized Education Program](#). Alternatively, parents may prepare an IEP if the school's IEP is not fair to the child.

## **Related services**

The IDEA defines related services includes but is not limited to: transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education, and includes speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, early identification and assessment of disabilities in children, counseling services, including rehabilitation counseling, orientation and \*mobility services, and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling and training.<sup>[11]</sup>

## Free Appropriate Public Education

Guaranteed by the Individuals with Disabilities Education Act (IDEA), FAPE is defined as an educational program that is individualized to a specific child, designed to meet that child's unique needs, and from which the child receives educational benefit. To provide FAPE, schools must provide students with an "... education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living."<sup>[12]</sup>

Some of the criteria specified in various sections of the IDEA statute includes requirements that schools provide each disabled student an education that:

- Is designed to meet the unique needs of that one student
- Provides "...access to the general curriculum to meet the challenging expectations established for all children" (that is, it meets the approximate grade-level standards of the state educational agency)
- Is provided in accordance with the Individualized Education Plan (IEP) as defined in 1414(d)(3).<sup>[13]</sup>
- Results in educational benefit to the child.<sup>[14]</sup>

## Least Restrictive Environment

The U.S. Dept. Education, 2005a regulations implementing IDEA states: "...to the maximum extent appropriate, children with disabilities including children in public or private institutions or care facilities, are educated with children who are *nondisabled*; and special classes, separate schooling or other removal of children with disabilities from regular educational environment occurs only if the nature or severity of the disability is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."

Simply put, the LRE is the environment most like that of typical children in which the child with a disability can succeed academically (as measured by the specific goals in the student's IEP). This refers to the two questions decided upon in *Daniel R. R. v. State Board of Education*, 874 F.2D 1036 (5TH CIR. 1989).

This court, relying on *Roncker*, also developed a two- part test for determining if the LRE requirement is met. The test poses two questions:

1. Can an appropriate education in the general education classroom with the use of supplementary aids and services be achieved satisfactorily?
2. If a student is placed in a more restrictive setting, is the student "integrated" to the "maximum extent appropriate"? (Standard in AL, DE, GA, FL, LA, MS, NJ, PA, TX).<sup>[15]</sup>

Congress states a clear preference that the child be included in regular education activities as much as possible. Placement options include:<sup>[16]</sup>

- a regular classroom;
- a regular classroom with modifications and/or supplemental aids and services;
- a resource room for special education instruction with instruction in a regular classroom;
- a classroom for children with disabilities located in a regular school;
- day or residential special schools, where many or all students may have disabilities; and
- a home-, hospital-, or institution-based program.

### **Discipline of a child with a disability**

Pursuant to IDEA, discipline of a child with a disability must take that disability into account. For example, if a child with [Asperger syndrome](#) is sensitive to loud noises, and if the child runs out of a room filled with loud noises, any discipline of that child for running out of the room must take into account the sensitivity and whether appropriate accommodations were in place. According to the [United States Department of Education](#), for children with disabilities who have been suspended for 10 days total for each school year, including partial days, the local education agency (LEA) must hold a manifestation determination hearing within 10 school days of any decision to change the placement of a child with a disability because of a violation of a code of student conduct following either the Stay Put law which states that the child shall not be moved from his or her current placement or interim services in an alternative placement if the infraction was deemed to cause danger to other students. The LEA, the parent, and relevant members of the individualized education program (IEP) team (as determined by the parent and LEA) shall review all relevant information in the student's file, including the child's IEP, any teacher observations, and any relevant information provided by the parents to determine if the conduct in question was caused by, or had a direct and substantial relationship to, the child's disability; or the direct result of the LEA's failure to implement the IEP.

If the LEA, the parent, and relevant members of the IEP team make the determination that the conduct was a manifestation of the child's disability, the IEP team shall:

Conduct a functional behavioral assessment and implement a behavioral intervention plan for such child, provided that the LEA had not conducted such assessment prior to such determination before the behavior that resulted in a change in placement described in Section 615(k)(1)(C) or (G);

In the situation where a behavioral intervention plan has been developed, review the behavioral intervention plan if the child already has such a behavioral intervention plan, and modify it, as necessary, to address the behavior; and

Except as provided in Section 615(k)(1)(G), return the child to the placement from which the child was removed, unless the parent and the LEA agree to a change of placement as part of the modification of the behavior intervention plan.

## **Child Find**

Public school districts are responsible for identifying all students with disabilities within their districts, regardless of whether they are attending public schools, since private institutions may not be funded for providing accommodations under IDEA.

## **Procedural Safeguards**

IDEA includes a set of procedural safeguards designed to protect the rights of children with disabilities and their families, and to ensure that children with disabilities receive a FAPE. The procedural safeguards include the opportunity for parents to review their child's full educational records; full parent participation in identification and IEP team meetings; parent involvement in placement decisions; Prior Written Notice; the right of parents to request independent educational evaluations at public expense;; Notice of Procedural Safeguards;; Resolution Process; and objective mediation funded by the state education agency and impartial Due Process Hearings.<sup>[17]</sup> IDEA guarantees the following rights to parents:

- Right to be informed in writing of the Procedural Safeguards
- Right to review all educational records
- To be equal partners on the IEP team, along with the school staff
- To participate in all aspects of planning their child's education
- To file complaints with the state education agency
- Request mediation, or a due process hearing
- At this time, parents may present an alternative IEP and their witnesses (experts and others), to support their case.
- These hearings are Alternative Dispute Resolution (ADR) hearings and can be appealed. This is not a trial.

## **Early Intervention**

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Part C of the IDEA requires that infants and toddlers with disabilities receive early intervention services from birth through age 3. These services are provided according to an Individualized Family Service Plan (IFSP). In contrast, Part B of the IDEA requires that children with disabilities, from age 3 to 21, are provided a free appropriate public education.

## **Department of Education Regulations**

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In addition to the Federal law, the U.S. Department of Education publishes regulations that clarifies what the law means. States may add more provisions to further regulate how schools provide services, but they cannot reverse any provision specifically included in the federal statute.

### **Alignment with No Child Left Behind**

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The reauthorization of IDEA in 2004 revised the statute to align with the requirements of the No Child Left Behind Act (NCLB). NCLB allows financial incentives to states who improve their special education services and services for all students. States who do not improve must refund these incentives to the federal government, allow parents choice of schools for their children, and abide by other provisions. Some states are still reluctant to educate special education students and seek remedies through the courts. However, IDEA and NCLB are still the laws of the land to date.

## IDEA 2004 Summary

The Individuals with Disabilities Education Act (IDEA) is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities.

Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B.

This is a summary of some of the most critical changes affecting children with disabilities and their families in IDEA 2004, concentrating on the IEP process, due process and the discipline provisions. How these changes affect our children will depend, at least in part, on how the U.S. Department of Education interprets them through policies and regulations and how they are implemented at the state, district and school level. Most of these changes will be effective as of July 1, 2005.

A new provision in the Act authorizes the Secretary to issue only regulations necessary to secure compliance with the statute. This provision may limit the Secretary's authority to issue regulations that could be useful in clarifying ambiguities. A new section of the Act also suggests that states minimize the number of rules, regulations and policies to which the school districts are subject.

This law, as amended by the 2004 changes, will not provide mandatory full funding. Although the annual amounts now authorized (permitted) to be spent on IDEA would achieve full funding in six years, that assumes these amounts will actually be appropriated (spent), and explains why mandatory funding of IDEA is so important. In fact, two days after Congress passed the IDEA Conference Report with its "glide path to full funding" it appropriated significantly less funding for special education than it had just promised.

### IEP PROCESS

1. **Short-term objectives.** The long established obligation for IEP teams to spell out short-term objectives for meeting each child's measurable annual IEP goals no longer exists for most children. Such short-term objectives are only required for the very small percentage of children (generally less than 1% of students with disabilities) who are taking alternate assessments aligned to alternate achievement standards. The No Child Left Behind Act (NCLB) limits participation on these assessments to students with the most significant cognitive disabilities. NCLB also provides that both grade-level and alternate achievement standards should be aligned with state content standards. Parents should ensure that their child's academic IEP goals are also aligned with these standards. Short-term objectives are essential stepping stones toward these goals for all students with disabilities, not just a very small percentage.

In states that offer alternate assessments aligned to alternate achievement standards, it is the IEP team that determines whether a child fits the criteria for students with the most significant cognitive disabilities. Parents, as members of

the IEP team, may feel pressure to agree that their child fits these criteria in order to retain short-term objectives. Such pressure directly undermines the accountability provisions of NCLB.

Even if these short-term objectives are not mandated by law, all parents can still request their child's IEP team to identify them. IDEA 2004 still requires a description of how progress toward meeting will be measured and parents can contend that short-term objectives are the answer. Without short term objectives parents will have virtually no way of measuring whether their children are making progress in achieving their annual goals and will not be informed participants in their child's education. In addition, teachers will not have a guide as to the intervening steps that should be taken towards achieving these goals and when they should be taken. Teachers will also have great difficulty developing meaningful progress reports to the parents.

2. **IEP progress reports.** The progress the child is making toward meeting the annual goals must be reported, but there is no longer a reference to "the extent to which the progress is sufficient to attain the goal by the end of the year." This information seems especially important to parents and teachers if there is a shared commitment to help all children learn to high standards set for all. Parents may see progress all year only to realize in June that the progress was not sufficient to meet the goal.
3. **Transition information in IEP.** The amendments clarify that the transition process for a student with a disability now begins at age 16 and is not merely a plan for transition. Parents should request that the student's IEP, when appropriate, include a statement of inter-agency responsibilities and any needed linkages since this language is no longer in the statute.
4. **IEP attendance and participation.** A new section allows IEP team members to be excused from attendance if their area is not being discussed. When this section is read with new provisions allowing alternate means of meeting participation (e.g. conference calls), consolidation of reevaluation meetings and other IEP meetings, and a pilot program authorizing up to 15 states to use multi-year IEPs, the combined effect is a revolution in the traditional IEP meeting. Some say these are positive changes. Others are concerned that these provisions will limit cross fertilization of ideas and undermine the interdisciplinary nature of IEP meetings (team members each bring areas or "disciplines" of expertise to the table).

While written parental consent is required before these actions can occur, parents may find that they are under considerable pressure to provide their consent. At least once a year the parents should be able to get all the members of their child's team in one room, all sharing ideas for the benefit of the child. The potential richness of these conversations can not be anticipated in written reports submitted by excused members and conference calls do not allow for the same flow of ideas. You never know which IEP team member will turn the tide of a meeting.

5. **Pilot program for multi-year IEPs.** The Secretary of Education is authorized to approve proposals from up to 15 states to allow local school districts to offer, with

parental consent, a multi-year IEP, not to exceed 3 years. This option will limit parent participation in their child's education by not having a comprehensive annual IEP review, except in certain situations. Also, 3-year IEPs will contain multi-year goals which can be expected to be less specific and harder to measure than annual goals -especially when benchmarks and short-term objectives are no longer required for all but those students with the most significant cognitive disabilities. Another serious problem is that the required elements under IDEA for these multi-IEPs are not as inclusive as for annual IEPs. This is true with respect to statements on progress reports, accommodations, supplementary aids and services and more. While, the states may include these as required elements in the multi-year IEPs, IDEA does not mandate that they do so. Parents in these states will have to consent to the 3-year IEPs that must be reviewed at natural transition points by the IEP team. Therefore, it will be critical that parents are informed, knowledgeable and well prepared to deal with any pressure that may be put on them.

6. **Pilot program for paperwork reduction.** The Secretary of Education is authorized to grant waivers of statutory and regulatory requirements, for a period not to exceed 4 years, to 15 states proposing to reduce excessive paperwork and non-instructional time burdens. The Secretary is prohibited from waiving requirements related to civil rights or the right of a child to a free appropriate public education (FAPE). How this process is implemented is a matter of special concern to parents, who worry that many requirements in the IEP process which parents consider to be related to civil rights and FAPE, may be seen as contributors to the paperwork burden. Another significant concern is that "pilot" implies that this is the first step toward expanding these programs beyond the 15 states.
7. **IEP team transition.** Parents of a child transitioning from Part C services (early childhood) to part B services (school-age) can request an invitation to the initial IEP meeting be sent to representatives of the Part C system to assist with a smooth transition of services. This provision doesn't require a Part C representative to attend but it does encourage collaboration.
8. **Transfers between school districts.** Services comparable to those described in the IEP in effect before a child's transfer must be provided by the new school district. These services must continue until the previous IEP is adopted, or a new IEP is developed, adopted and implemented, in the case of a transfer in the same state or until a new IEP is developed, in the case of a transfer outside the state. This new provision will help parents of transferring students know what they can expect from their new schools.

## **DUE PROCESS**

1. **Procedural safeguards notice.** The procedural safeguards notice will be distributed only once a year except that a copy will be distributed upon initial referral, when a parent makes a request for an evaluation, when a due process complaint has been filed or if a parent requests a copy. The notice will no longer be automatically distributed with the IEP team notice or upon reevaluation. This is only a problem if parents are unaware of their rights, including the right to

request this notice if they need one.

2. **Statute of limitations.** Parents now have two years in which to exercise their due process rights after they knew or should have known that an IDEA violation has occurred. The interpretation of the language "should have known" will be critical.
3. **Due process complaint notice.** Parents who feel their child's educational rights are being compromised must file a complaint with the school district (with a copy to the state) identifying the name and contact information of the child, describing the nature of the problem with supporting facts and a proposed resolution. A new provision provides that the school district shall file a response within 10 days unless the district within 15 days notifies the state hearing officer that it is challenging the sufficiency of the parent's due process complaint notice. The State hearing officer has 5 more days to make a finding. In addition to the obvious delay, of particular concern is that the complexity of filing for due process may have a chilling effect on parents.
4. **Resolution session.** Parents must go through a mandatory "resolution session" before due process. The school district will convene a meeting with the parents and relevant members of the IEP team within 15 days of when the school district receives the parent's due process complaint. The school district has 30 days from the time the complaint is filed to resolve the complaint to the satisfaction of the parents, after which a due process hearing can occur. This provision may encourage school systems to wait until a due process complaint is filed before trying to resolve issues. Attorney's fees are not reimbursed for work related to the resolution session.
5. **Attorney's fees.** Parent's attorneys may be responsible for paying the school system attorney's fees if a cause of action in a due process hearing or court action is determined to be frivolous, unreasonable, or without foundation. Parents may be responsible for the school system's attorney fees if a cause of action was presented for any improper purpose, such as to harass or to cause unnecessary delay or needless increase in the cost of litigation. Obviously, parents should not file frivolous or improper causes of action, but it is important that school districts not use these changes in the law to intimidate parents. This could have a chilling effect on parents obtaining legal representation and filing valid complaints to improve their children's education.
6. **Qualifications for Hearing Officers.** A positive change is that there are now explicit qualification requirements for Hearing Officers.

## **DISCIPLINE**

1. **Stay put.** The right of a student with a disability to "stay put" in his/her current educational placement pending an appeal is eliminated for alleged violations of the school code that may result in a removal from the student's current educational placement for more than 10 days. Previously the law only denied "stay-put" rights to students with disabilities involved in drugs, weapons or other dangerous behavior or activity. The right to "stay put" while a parent challenges the manifestation determination or proposed placement is a critical element to

ensuring a student's continued free appropriate public education in the least restrictive environment.

Moving back and forth between the current placement and an interim alternative educational setting during an appeal can have a significant negative impact on achievement for children who already have difficulty adjusting to transitions. Parents must remain vigilant and ensure that their children continue to be provided the educational programming and services they need to make progress toward meeting their IEP goals. If this progress is negatively affected, the school may recommend a change to a more restrictive setting for the future. In addition, for purposes of reporting Adequate Yearly Progress under the No Child Left Behind Act, individual schools do not have to count children who are transferred to alternative settings and are, therefore, not in the same school for the full academic year. This could create an incentive for disciplinary actions against students with disabilities.

2. **Services to be received in interim alternative educational setting.** A child is entitled to receive programming and services necessary to enable him or her to receive a free appropriate public education consistent with section 612(a)(1) during the period in which he/she is in an interim alternative education setting. Under IDEA 2004, the student must be provided services to enable him or her to continue to participate in the general education curriculum and to progress toward meeting the goals in the IEP. The new provision replaced language requiring that a child in an interim alternative educational setting receive services and modifications, including those described in the student's current IEP which will enable the child to meet the goals in the IEP. The change in language cannot be interpreted as diluting any of these services that are consistent with the definition of FAPE because a student with a disability must continue to receive FAPE during the period of removal from his/her current educational placement.
3. **Manifestation Determination Review.** Before IDEA 2004, the burden was on the school district to show that the behavior resulting in a disciplinary action was not a manifestation of the child's disability before being allowed to apply the same disciplinary procedures as they use for non-disabled children. The burden of proof for the manifestation determination review has now been shifted to the parents who have to prove that the behavior was caused by or had a direct and substantial relationship to the disability. The language requiring the IEP team to consider whether the disability impaired the child's ability to control or to understand the impact and consequences of the behavior has been deleted. The language that gave the school an incentive to address behavior appropriately by requiring the IEP team to consider whether the IEP was appropriate has also been deleted.

Because the amendments to IDEA make it easier for schools to remove children for non-dangerous, non-weapon, non-drug related behaviors, and place the burden on parents to prove the connection between behavior and disability, parents will need to pay careful attention to the behavioral needs of their child in developing the IEP. Even if the child has not previously been subjected to disciplinary exclusion, parents may need to anticipate, to consider and spell out any concerns they may have about their child's possible emotional and

behavioral responses particularly when they are not provided the supports and services they may need.

4. **Special Circumstances.** Since 1997, IDEA had expressly authorized schools to unilaterally remove children to an interim alternative educational setting for as long as 45 days for offenses involving drugs and weapons -even if the behavior was a manifestation of the student's disability. In addition, a hearing officer could make the same decision if it was determined based on a preponderance of the evidence that keeping the child in his/her current placement was substantially likely to result in injury to the child or others. Although school authorities have always had the authority to respond to an emergency and to unilaterally remove any student with or without a disability who is causing serious bodily injury to another, now schools can also unilaterally remove children for 45 days for "inflicting serious bodily injury." This term is defined as involving a substantial risk of death; extreme physical pain; protracted and obvious disfigurement; or protracted loss or impairment of the function of a bodily member, organ, or mental faculty.

The hearing officer in determining whether to remove a child because maintaining his/her current placement is substantially likely to result in injury to self or others is no longer required to consider whether the school district's proposed change in placement is based on a preponderance of the evidence. In addition, the amended statute no longer requires the hearing officer to consider whether the school has made reasonable efforts to minimize the risk of harm, including the use of supplementary aids and services. These changes, to the degree they have the effect of punishing the child even if proper supports could have prevented the problem, arguably violate Section 504 of the Rehabilitation Act.

5. **45 day limit.** The 45 calendar day limit on the removal for these offenses has been changed to 45 school days, which is significantly longer [now 9 instead of 6 weeks of school at a critical time when students with disabilities are being held accountable for meeting high state standards.]
6. **Functional Behavioral Assessments.** The requirement for Functional Behavioral Assessments and Behavioral Intervention Plans are maintained in the discipline provisions.
7. **Case-by-case determination.** A paragraph has been added to the discipline provisions, which states that school personnel can consider any unique circumstances on a case-by-case basis when determining whether to change the placement of a child with a disability who violates a school code of conduct. This is a good provision for parents to quote when they are having trouble proving that their child's behavior is a manifestation of the disability. It serves to remind the school personnel that common sense should prevail and all circumstances should be considered.

### **Can grandparents attend IEP meetings?**

The South Carolina State Department of Education, Office of Parental and Community Partnerships works to increase parental/caregiver involvement in the education of children, to increase parent/caregiver-teacher contacts, and to further engage communities in increasing parental/caregiver involvement in education. The office considers the term “parent” to include any and all adults who play an important role in a child’s life, since other adults, such as grandparents, may carry the primary responsibility for a child’s education, development, and well-being. Office staff can connect you with local school district employees who work with parental involvement activities. Contact: (803) 734-1122.

## WHAT IS PRO-Parents?

Parents Reaching Out to Parents of South Carolina, Inc., is a private, non-profit organization which provides information and training about education to families of children with all types of disabilities.

PRO-Parents believes parents can be the best advocates for their children.

Experienced advisors assist parents to become more aware of their rights and responsibilities through telephone counseling, workshops and written material.

With confidence and knowledge, parents can then participate as equal partners with professionals on behalf of their children.

PRO-Parents also serves professionals in education and related fields throughout South Carolina.

### **Services**

#### **Workshops**

PRO-Parents provides training to parents of children with disabilities to prepare them to make decisions about their child's education: Regional Education Coordinators conduct free workshops around the state on several topics:

- Parents' rights and responsibilities under the law: An overview of the special education process.
- How to participate successfully in designing the Individualized Education Program (IEP) for your child.
- What does “inclusion” really mean? What constitutes the “least restrictive environment”?
- How to advocate effectively and work collaboratively with professionals.
- The laws: What are they and how do they differ? How do they protect my child with special needs?
- Transition: What help can I expect as my child prepares to leave school?
- Attention Deficit Disorder: Effective educational intervention.

## **Telephone Assistance**

- Telephone assistance provided by staff. Strategic planning with parents, IEP problem-solving consultation.
- Call the Columbia office for help - or ask for the number of the Regional Education Coordinator in your area.

## **Other Resources**

- Ask for written information about education issues; disabling conditions and needs; local and national support groups; all from PRO-Parents' comprehensive resource library.
- Newsletter - published four times each year.
- Presentation - which describe the organization and its service.

**PRO-Parents of SC  
652 Bush River Road  
Suite 203  
Columbia, SC 29210**

**Phone (local): (803) 772-5688  
Toll Free: 1-800-759-4776  
Fax: (803) 772-5341  
E-mail: [PROParents@proparents.org](mailto:PROParents@proparents.org)**

## School Transition Considerations

## **School Transition Considerations for Children with Special Needs**

The Individuals with Disabilities Education Improvement Act (IDEA 2004) was signed into law on December 3, 2004. Under IDEA, school districts are required to provide a free appropriate public education (FAPE) to all students with disabilities who have not reached age 22 and who have not earned a standard diploma or its equivalent. This requirement includes students who are eligible to receive or have received a special diploma, a certificate of completion, or a special certificate of completion, as well as students who have dropped out of school who wish to return. The IDEA 2004 regulations provide exceptions to the FAPE requirements for certain individuals with disabilities ages 18 through 21 who are convicted as adults and incarcerated in adult prisons.

Transition services for the student with a disability must be included in the student's IEP (Individualized Education Plan) by age 16. Transition services help students with disabilities and their families think about their life after high school. Transition services identify short-term and long-range goals for students. The transition plan should reflect the student's interests, preferences, accomplishments and skills, what they need to learn, and what they want to do.

The IEP/Transition Team is made up of the student, his/her parent(s), regular education teacher, special education teacher, representative(s) of the public agency(s) and other individuals with special knowledge or expertise regarding the student. In addition, representatives of any agency likely to be responsible for providing or paying for services for the student, such as the SC Department of Disabilities and Special Needs, SC Vocational Rehabilitation Department, SC Department of Mental Health, Commission for the Blind, etc., must be invited to attend. This team must consider postsecondary education/vocational training, employment, independent living, recreation/leisure activities, and community participation.

All education rights of the parents are transferred to the student upon reaching the age of majority of the state. In SC the age of majority is 18 years of age. At least one year before the student reaches 18, the IEP must contain a statement that the child's rights will be transferred to him or her. The student with a disability upon reaching the age of majority has the following rights:

- The right to know what his/her disability is and how it affects his/her ability to learn, live independently, and be a part of a life long learning system.
- The right to be provided information regarding assessment, services, and Individual Education Planning in a language and format that he/she can understand.
- The right to participate in his/her own Individual Education Plan (IEP) meetings.
- The right to have individuals who understand the student's disability serve on the student's IEP team.
- The right to accept or refuse services.
- The right to disagree with his/her IEP and receive help in writing a complaint, requesting mediation, or a due process hearing.

Contact your School District Special Education Coordinator or the School Guidance Counselor for additional information.

### Transition Timeline\*

Age Appropriate Consideration	Responsible Party
<ul style="list-style-type: none"> <li>Age of Majority Documentation Completed</li> </ul>	Student/Parent/IEP Team
<ul style="list-style-type: none"> <li>Review/Complete High School plan/vocational portfolio</li> </ul>	Student/Parent (if appropriate)/ IEP Team/Community Service Providers
<ul style="list-style-type: none"> <li>Complete school-based/community-based work experiences and/or career center training</li> </ul>	Student/Parent (if appropriate)/ IEP Team
<ul style="list-style-type: none"> <li>Secure housing if not living at home</li> </ul>	Student/Local DDSN Board/DDSN toll free @ 1-888-376-4636
<ul style="list-style-type: none"> <li>Secure appropriate transportation (own car, car-pooling, bus, cab, etc.)</li> </ul>	Student/IEP Team (if appropriate)
<ul style="list-style-type: none"> <li>Complete paperwork for post-secondary school training or apprenticeship</li> </ul>	Student/Parent/IEP Team (if appropriate)
<ul style="list-style-type: none"> <li>Connect with and self-disclose need for accommodations at post-secondary institution, if applicable</li> </ul>	Student/Parent/Appropriate Community Service Provider
<ul style="list-style-type: none"> <li>Register to Vote</li> </ul>	Local DMV office/DMV toll free @ 1-800-442-1368
<ul style="list-style-type: none"> <li>Register for draft (if male) within 30 days of 18<sup>th</sup> birthday (Those physically or mentally disabled confined to a residence, hospital or institution are exempt.)</li> </ul>	Local Post Office or register on-line @ <a href="http://www.sss.gov">www.sss.gov</a>
<ul style="list-style-type: none"> <li>Follow-up regarding eligibility determination for vocational rehabilitation services and participate in development of Individualized Plan for Employment for services while in school and after exiting school</li> </ul>	Student/Local SCVRD office/ SCVRD toll free @ 1-800-832-7526
<ul style="list-style-type: none"> <li>Explore Medicaid options – (DDSN – MR/RD &amp; HASCI waivers &amp; individual rehabilitation supports; CLTC – Community Choices, HIV/AIDS, &amp; Ventilator Dependent waivers)</li> </ul>	Student/Parent
<ul style="list-style-type: none"> <li>Check status regarding day service options (center-based day services, individual rehabilitation supports, employment and other service options)</li> </ul>	Student/Local DDSN Board/DDSN toll free @ 1-888-376-4636
<ul style="list-style-type: none"> <li>Learn how employment wages affect SSI and/or SSDI benefits</li> </ul>	Student/Parent/South Carolina Pathway Toward Employment (SCPTE) Regional Benefits Specialists: Northwest Region 1-866-439-4091 North Central Region 1-866-369-9311 Central Region 1-866-837-9260 Northeast Region 1-800-263-2217 Southwest Region 1-803-648-2858
<ul style="list-style-type: none"> <li>Explore post-secondary training and/or competitive employment opportunities</li> </ul>	Student/Local SCVRD office/SC Job Services offices/WIA One Stop Center toll free @ 1-800-436-8190
<ul style="list-style-type: none"> <li>Explore Adult Education options if Youth at Risk</li> </ul>	Student/Adult Education @ 1-803-734-8070 Literacy Council toll free @ 1-800-277-READ

Source: Links to Life: A Guide for Students and Parents to Access Resources from Educational and Community Service Providers, Tennant & Kuffel, July 2003

## Postsecondary Education Considerations

## **Students with Disabilities Preparing for Postsecondary Education**

Many high school students with disabilities will plan to continue their education upon graduation. Some will continue their education through a vocational school and others may attend a two-year and/or four-year university. If you are a student with a disability, you need to be informed of your rights and responsibilities. You also need to be informed of the postsecondary schools' responsibility for students with disabilities. Doing so will improve your chances of succeeding in school.

Beginning with the Individuals with Education Act of 1975 and most recently through the No Child Let Behind Act of 2001, the United States government has championed the right of people with disabilities and their families to get the most out of America's educational opportunities. [DisabilityInfo.gov](http://DisabilityInfo.gov) offers information on educational programs and resources available through the federal government, including the Individualized Education Programs; college opportunities; school-to-work transition and tools for educators.

### **Frequently Asked Questions Regarding Students with Disabilities and Postsecondary Education**

#### **1. What are the differences in my rights and responsibilities as a postsecondary student?**

Section 504 and Title II protect elementary, secondary, and postsecondary students from discrimination. The requirements of these laws differ after exiting high school. Section 504 requires a school district to provide a free appropriate public education (FAPE) to students with disabilities. School districts are required to identify a student's needs and provide any regular or special education and related aids and services necessary to meet those needs.

Postsecondary schools are not required to provide FAPE. Your postsecondary school is required to provide appropriate academic adjustments as necessary to ensure that it does not discriminate on the basis of disability. If your postsecondary school provides housing to non disabled students, then it must provide comparable, convenient and accessible housing to you at the same cost.

#### **2. May a postsecondary school deny my admission because I have a disability?**

A postsecondary school may not deny your admission simply because you have a disability. However, you must meet the essential requirements for admission.

#### **3. Do I have to tell a postsecondary school that I have a disability?**

No. It is up to you whether you tell them or not. However, if you want the school to provide academic adjustment, then you must let the school know you have a disability. If you want to ensure you are assigned to an accessible facility, then you will also need to let the school know that you have a disability.

#### **4. What must I do if I want an academic adjustment?**

You must inform the school that you have a disability and need an academic adjustment. Postsecondary schools are not required to identify you as having a disability or assess your needs.

Secondary schools usually provide information on the procedures and contacts for requesting an academic adjustment in their recruitment materials, catalogs, student handbooks, and/or their websites. Many schools also have staff available to assist students with disabilities. If you are unable to locate the procedures, ask a school official, such as an admissions officer or counselor.

### **5. When should I request an academic adjustment?**

You should request it as early as possible. Some adjustments take more time to provide than others. Follow your school's procedures to make sure that your school has enough time to review your request and provide an appropriate academic adjustment.

### **6. Do I have to prove that I have a disability to obtain an academic adjustment?**

Your school will probably require you to provide documentation that shows you have a current disability and need an academic adjustment.

### **7. What documentation should I provide?**

Some schools require more documentation than others. They may require you to provide documentation prepared by a physician, psychologist, or other diagnostician. The required documentation may include one or more of the following: a diagnosis of your current disability; the date of the diagnosis; how the diagnosis was reached; the credentials of the professional; how your disability affects a major life activity; and how the disability affects your school performance. The documentation should provide enough information for you and your school to decide what is an appropriate academic adjustment.

In general, your Individualized Education Plan (IEP) or Section 504 plan do not provide sufficient documentation because postsecondary education presents different demands. What you need to meet these demands may be different. In some cases, the nature of a disability may also change.

If the documentation you have does not meet the postsecondary school's requirements, a school official must tell you in a timely manner what you need to provide. You may need a new evaluation in order to provide the required documentation.

### **8. Who has to pay for a new evaluation?**

Neither your high school nor your postsecondary schools are required to conduct or pay for a new evaluation to document your disability and need for an academic adjustment. You may wish to contact the vocational rehabilitation department to see if they can provide assistance.

### **9. Is financial assistance available through the disability services office for students with disabilities?**

No. Check with the financial aid office at the school you will be attending. Some agencies that may provide support include Vocational Rehabilitation, Workers Compensation, the Veterans Administration, and Job Services.

**10. Once the school has received the necessary documentation from me, what should I expect?**

The school will review your request against the essential requirements for your program to help determine an appropriate academic adjustment. The school is not required to lower or waive essential requirements. If you request a specific adjustment, the school may offer an alternative if the alternative would also be effective. The school may also conduct its own evaluation of your disability and needs at its own expense. You should expect your school to work with you in an interactive process to identify an appropriate academic adjustment. Do not expect your postsecondary school to invite your parents to participate in the process or to develop an IEP for you.

**11. What if the academic adjustment we identified is not working?**

Let the school know as soon as you become aware that there is a problem. It may be too late to correct the problem if you wait until the course or activity is completed. You and your school should work together to resolve the problem.

**12. Can I receive a failing grade in a college class in which I am receiving academic adjustment?**

Yes. Adjustments ensure “access” not “success”.

**13. May a postsecondary school charge me for providing an academic adjustment?**

No. It may not charge students with disabilities more for participating in its programs or activities than it charges students without disabilities.

## **Services and Programs for Students with Disabilities at Secondary Institutions**

Services required by Section 504 and ADA are provided at no cost to students with disabilities. The college or university has the flexibility to select the specific accommodation or service it provides, as long as it is effective. Some examples of these could include:

- Allowing extra time to complete exams,
- Permitting exams to be individually proctored, read orally, dictated, or typed; and
- Providing modifications, substitutions, or waivers of courses, major fields of study, or degree requirements on a case-by-case basis.

Colleges and universities will have either an individual or an office on campus whose purpose is to coordinate support services and accommodations for students with disabilities. It is a good idea to establish communications with these service providers as early as possible in order to make arrangements for any accommodations or services you may require. Ask the admissions counselor where this office is located on campus.

### **Provision & Cost of Auxiliary Aids**

Postsecondary schools receiving federal financial assistance must provide effective auxiliary aids and services to students with disabilities in a timely manner to ensure effective participation. If the student is being evaluated to determine his/her eligibility under 504 or the ADA, the recipient must provide auxiliary aids in the interim.

The postsecondary student with a disability who is in need of auxiliary aids is obligated to provide notice of the disabling condition to the college and to assist it in identifying appropriate and effective aids. The student must identify the need and give adequate notice of the need to the appropriate representative of the college. The college may ask for supporting diagnostic test results and professional prescriptions for auxiliary aids. The college may also obtain its own professional determination of whether specific requested auxiliary aids are necessary.

Some of the various types of auxiliary aids and services may include:

- Taped texts
- Note takers
- Interpreters
- Readers
- Videotext displays
- Television enlargers
- Talking calculators
- Electronic readers
- Braille calculators, printers, or typewriters
- Telephone handset amplifiers
- Closed caption decoders
- Open and closed captioning
- Voice synthesizers
- Specialized gym equipment
- Calculators or keyboards with large buttons
- Reaching device for library use

- Assistive listening devices
- Assistive listening systems
- Telecommunications devices for deaf persons

Colleges are not required to provide the most sophisticated auxiliary aids available; however, the aids provided must effectively meet the needs of a student with a disability.

If an auxiliary aid is necessary for classroom or other appropriate (nonpersonal) use, the college must make it available, unless the provision of the aid would cause undue burden. A student with a disability may not be required to pay part or all of the costs of the aid or service. A college may not limit what it spends for auxiliary aids or services or refuse to provide auxiliary aids because it believes that other providers of these services exist, or condition its provision on availability of funds.

### **Personal Aids and Services**

Personal aids and services, including help in bathing, dressing, or other personal care, are not required to be provided by postsecondary institutions. Personal attendants and individually prescribed devices are the responsibility of the student who has a disability and not of the institution. For example, readers may be provided for classroom use but institutions are not required to provide readers for personal use or for help during individual study time.

### **Frequently Asked Questions About Auxiliary Aids & Services**

#### **1. What are an institution's requirements for providing auxiliary aids for library study?**

Libraries and some of the significant and basic materials must be made accessible by the recipient to students with disabilities. Students with disabilities must have appropriate auxiliary aids needed to locate and obtain library resources. The institution's library's basic index of holdings must be accessible.

Articles and materials that are library holdings and are required for course work must be accessible to all students enrolled in that course. If material is required for the class, then its text must be read for a blind student or provided in Braille or on tape. A student's actual study time and use of the articles are considered personal study time and the institution has no further obligation to provide additional auxiliary aids.

#### **2. What is an instructor objects to the use of an auxiliary or personal aid?**

An instructor may not forbid a student's use of an aid if that prohibition limits the student's participation in the school program.

#### **3. What if a student with a disability requires an auxiliary aid during an examination?**

A student may need an auxiliary aid or service in order to successfully complete a course exam. A student may be allowed to give oral rather than written answers. It

also may be possible for a student to present a tape containing the opal examination response.

**4. Can postsecondary institutions treat foreign students with disabilities who need auxiliary aids differently than American students?**

No. A postsecondary institution must provide to a foreign student with a disability the same type of auxiliary aids and services it would provide to an American student with a disability.

**5. Are institutions responsible for providing auxiliary services to students with disabilities in filling out financial aid and student employment applications, or other forms of necessary paperwork?**

Yes. If the student is requesting assistance is still in the process of being evaluated to determine eligibility for an auxiliary aid or service, help with this paperwork by the institution is mandated in the interim.

**6. Does a postsecondary institution have to provide auxiliary aids and services for a non-degree student?**

Yes. Students with disabilities who are auditing or who otherwise are not working for a degree must be provided auxiliary aids and services to the same extent as students who are in a degree-grating program.

**Financial Aid for Students with Disabilities**

The Heath Resource Center of the American Council on Education operates a national clearinghouse on postsecondary education for students with disabilities. Their on US federal student aid programs and other financial aid programs for students with disabilities. It also includes a list of 29 sponsors of scholarships specifically designated for students with disabilities.

Heath Resource Center  
2121 K Street, NW Suite 220  
Washington, DC 20037  
202-973-0904 or Toll Free 1-800-544-3284  
[www.heath-resource-center.org](http://www.heath-resource-center.org)

**Other Financial Considerations – Supplemental Security Income (SSI) & Plan for Achieving Self Support (PASS)**

Supplemental Security Income (SSI) pays monthly benefits to people with low incomes and limited assets who are 65 or older, blind, or have other disabilities. Children can qualify if they meet Social Security's definition of disability for SSI children and if their income and assets fall within the eligibility limits.

As its name implies, SSI supplements a person's income up to a certain level. The level varies from one state to another and may increase each year to reflect changes in cost-of-living.

Parent income and assets are considered when deciding if a child under 18 qualifies for SSI. This applies to children who live at home, or who are away at school but return home occasionally and are subject to parental control.

When a child turns 18, parent income and assets are no longer considered when determining eligibility for SSI. Therefore, a child who was not eligible for SSI before his or her 18th birthday may become eligible at age 18. |

The Social Security Administration may also approve a Plan for Achieving Self Support (PASS), in which a student is able to set aside income and resources that are being used toward a specific vocational goal (such as college tuition) and still receive SSI payments. However, a student needs to be aware that earnings from employment may affect SSI benefits.

For more information on SSI and PASS, contact your local Social Security Administration office or consult <http://www.ssa.gov/disability/>. You can also receive assistance from a local Benefits Specialist by consulting [www.scbpao-pathways.scvrd.net/](http://www.scbpao-pathways.scvrd.net/).

## Disability Resource Library - Delivered Right to Your Home

The Center for Disability Resource Library consists of books, videos, brochures, and audiotapes covering a variety of disability-related topics. The Library is located within the University of South Carolina, School of Medicine Library on Garners Ferry Road in Columbia.

### Library Hours

Monday - Friday: 8:00 am - 10:00 pm

Saturday: 8:00 am - 8:00 pm

Sunday: 1:00 pm - 10:00 pm

### Information Services

Reference librarians are available from 8:00 am to 5:00 pm, Monday - Friday.

Send requests to: [wilsons@gw.med.sc.edu](mailto:wilsons@gw.med.sc.edu) or (803) 733-1501 or on walk-in.

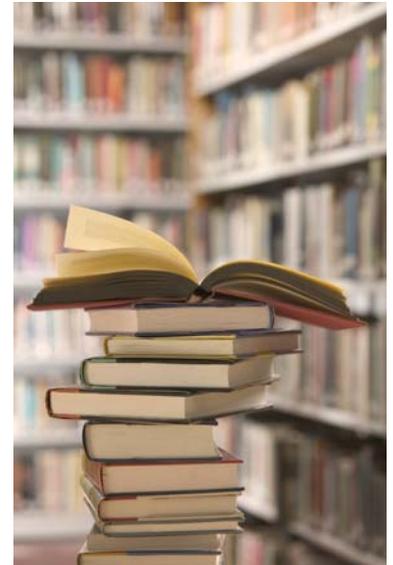
Books may be borrowed for a month. Videos may be borrowed for two weeks.

Materials can be mailed to your home or office.

Postage-paid return mailers are available for materials sent to South Carolina families. You may borrow multiple items at one time.

A courier is available to bring items to the Center for Disability Resources Monday-Friday.

Residents of states other than South Carolina may check out one item at a time, and are responsible for return postage.



Social Security Administration  
Benefits for Children  
Benefits for Adopted Children  
Benefits for Grandchildren  
Disabled Adult Child Benefits  
SSI & SSDI  
Work Incentives



## Social Security Benefits For Children

SSA Publication No. 05-10085, September 2004, ICN 468550

About 3.8 million children receive approximately \$1.6 billion each month because one or both of their parents are disabled, retired or deceased. Those dollars help to provide the necessities of life for family members and help to make it possible for those children to complete high school. When a parent becomes disabled or dies, Social Security benefits help to stabilize the family's financial future.

### Who can get child's benefits

Your child can get benefits if he or she is your biological child, adopted child or dependent stepchild. In some cases, your child also could be eligible for benefits on his or her grandparents' earnings.

To get benefits, a child must have:

- A parent(s) who is disabled or retired and entitled to Social Security benefits; or
- A parent who died after having worked long enough in a job where he or she paid Social Security taxes.

The child also must be:

- Unmarried;
- Younger than 18;
- 18-19 years old and a full-time student (no higher than grade 12); or 18 or older and disabled. (The disability must have started before age 22.)

### What you will need when you apply for child's benefits

When you apply for benefits for your child, you will need the child's birth certificate and the parent's and child's Social Security numbers. Depending on the type of benefit involved, other documents may be required. For example, if you are applying for survivors benefits for the child, you will need to furnish proof of the parent's death. If you are applying for benefits for a disabled child, you will need to furnish medical evidence to prove the disability. The Social Security representative who sees you will tell you what other documents you will need.

### Benefits can continue at age 18

Benefits stop when your child reaches age 18 unless your child is a student or disabled.

### If your child is a student

Three months before your child's 18th birthday, we will send you a notice that benefits will end at age 18 unless your child is a full-time student at a secondary ( or elementary) school. If your child is younger than 19 and still attending a secondary or elementary school, he or she must notify us by completing a statement of attendance that has been certified by a school official. The benefits then will usually continue until he or she graduates, or until two months after reaching age 19, whichever comes first.

### **If your child is disabled**

Benefits will continue at age 18 to a child who is disabled. Childhood disability benefits are also payable after attainment of age 18, if the disability began before age 22. (see Disabled Adult Child Benefits)

### **If you take care of a child**

If you are receiving benefits because you have a child in your care, the date your benefits will stop may be different than the child's.

If the child is not disabled, your benefits will end when he or she turns 16.

If the child is disabled, your benefits may continue if you exercise parental control and responsibility for a mentally disabled child or perform personal services for a child who is physically disabled. Before the child reaches 16, we will send you a notice describing the conditions under which your benefits may continue.

### **How much can a family get?**

Within a family, a child may receive up to one-half of the parent's full retirement or disability benefit, or 75 percent of the deceased parent's basic Social Security benefit. However, there is a limit to the amount of money that can be paid to a family. The family maximum payment is determined as part of every Social Security benefit computation and can be from 150 to 180 percent of the parent's full benefit amount. If the total amount payable to all family members exceeds this limit, each person's benefit is reduced proportionately (except the parent's) until the total equals the maximum allowable amount.

### **Contacting Social Security**

In addition to using the website, [www.ssa.gov](http://www.ssa.gov), you can call toll-free **1-800-772-1213**. Specific questions can be answered from 7 a.m. to 7 p.m., Monday through Friday. Information is provided by automated phone service 24 hours a day. (You can use the automated response system to leave a new address or request a replacement Medicare card.) If you are deaf or hard of hearing, you may call the TTY number, **1-800-325-0778**.

All calls are treated confidentially. Some telephone calls are monitored by a second Social Security representative to ensure you receive accurate and courteous service.

**Social Security Benefits for Adopted Child When Grandparent Retires**  
**Child Adoption Practices under Title II of the Social Security Act**  
**A-09-96-51001 - 8/29/97**

Dependency requirements under the Social Security Act (the Act) allow 1) grandparents receiving retirement benefits to adopt their minor grandchildren as dependents to obtain additional benefits; 2) the natural parents to become the adopted children's representative payee; and 3) the adopted grandchildren purportedly live with, and were supported by, their natural parents.

Section 10301 of the Omnibus Budget Reconciliation Act of 1989 amended section 202(d) of the Act by stating that a minor child (less than 18 years old) adopted after a worker becomes entitled to retirement or disability benefits would be eligible for child's benefits regardless of whether he or she was living with, and dependent on, the worker prior to the worker's entitlement. The legislative history showed that the congressional intent in enacting the amendments was to eliminate a disparity between the eligibility requirements for natural and adopted children.

Prior to the 1989 amendments, section 202(d) of the Act stated that a child adopted before a worker becomes entitled to retirement or disability benefits is eligible for child's insurance benefits. A child (other than the worker's natural or stepchild) adopted after a worker's entitlement is ineligible for Social Security benefits unless he or she was living with, and dependent upon, the worker for one-half or more of his or her support for the year prior to the worker's entitlement. In contrast, the natural child or stepchild of a disabled or retired worker is eligible for benefits regardless of when the relationship was established. Congressional intent behind enacting these dependency requirements was to prevent a beneficiary from adopting a child solely to supplement benefits.



## Benefits for Grandchildren

More and more parents are finding themselves raising grandchildren. Social Security will pay benefits to grandchildren if benefits are not payable on the work record of a parent.

### Grandchildren

If a child is not receiving benefits from a parent when the grandparent retires, becomes disabled, or dies, the grandchild may then be able to qualify for benefits if certain conditions are met. Generally, the biological parents of the child must be deceased or disabled, or the grandchild must be legally adopted by the grandparent.

In addition, the grandchild must have begun living with the grandparent before age 18 and received at least one half of his or her support from the grandparent for the year before the month the grandparent became entitled to retirement or disability insurance benefits, or died. Also, the natural parent(s) of the child must not be making regular contributions to his or her support.

If the grandchild was born during the one-year period, the grandparent must have lived with and provided at least one-half of the child's support for substantially all of the period from the date of birth to the month the grandparent became entitled to benefits.

The grandchild may qualify for benefits under these circumstances, even if he or she is a step-grandchild. However, if the grandparents are already receiving benefits, they would need to adopt the child for it to qualify for benefits.

Social Security has a toll-free number that operates from 7a.m. to 7p.m., Monday to Friday: **1-800-772-1213**. If you have a touch-tone phone, recorded information and services are available 24 hours a day, including weekends and holidays. People who are deaf or hard of hearing may call our toll-free "TTY" number, **1-800-325-0778**, between 7 a.m. and 7 p.m. on Monday through Friday. Please have your Social Security number handy when you call.

## **DISABLED ADULT CHILD BENEFITS**

### **Is your parent deceased or receiving retirement or disability benefits? - You may be eligible for disabled adult child benefits from Social Security**

An adult, who became disabled before age 22, may be eligible for child's benefits if his/her parent is deceased or receiving retirement or disability benefits. Social Security Administration (SSA) considers this a "child's" benefit because it is paid on a parent's Social Security earnings record. SSA makes the disability decision using the disability rules for adults.

The "adult child"—including an adopted child, or, in some cases, a stepchild, grandchild, or step grandchild—must be unmarried, age 18 or older, and have a disability that started before age 22.

You must make application to the Social Security Administration to receive these adult disabled child benefits. Once found eligible for these benefits, you will be notified by the Social Security Administration that you may continue to be eligible for Medicaid coverage under this group. You will need to contact your local Medicaid eligibility office for Medicaid continuation. Continued Medicaid eligibility is not automatic (see next section regarding Continuing Medicaid Coverage for the Disabled Adult Child.)

### **Frequently Asked Questions**

#### **What if the adult child never worked?**

It is not necessary that the adult child ever worked because benefits are paid on the parent's earnings record.

#### **What if the adult child is currently working?**

The adult child must not have been engaging in substantial gainful activity. This means, in 2008, working and earning more than \$940 a month. (This earnings amount increases each year.) Certain impairment-related work expenses may be excluded from these earnings, as may an unearned employer subsidy.

#### **What if the adult child is already receiving SSI benefits?**

An adult child already receiving SSI benefits should still check to see if benefits may be payable on a parent's earnings record. Higher benefits might be payable, and entitlement to Medicare may be possible.

#### **What if the adult child is already receiving disability benefits on his or her own record?**

An adult child already receiving disability benefits should still check to see if benefits may be payable on a parent's earnings record. It is possible for an individual disabled since childhood to attain insured status on his or her own record and be entitled to higher benefits on a parent's record.

#### **What if the parent never worked?**

No benefits would be payable on the record of a parent who never worked.

Can an application be completed online for disabled adult child's benefits?

At this time you cannot apply for child's benefits online. If you wish to file for benefits for a child or adult child, contact Social Security immediately at 1-800-772-1213, so that you do not lose any potential benefits.

### **How does SSA decide if an adult "child" is disabled for SSDI benefits?**

If a child is age 18 or older, SSA will evaluate his or her disability the same way it would evaluate the disability for any adult. SSA sends the application to the Disability Determination Services.

## **DISABLED ADULT CHILD BENEFITS & CONTINUING MEDICAID COVERAGE**

SSI disabled adult children who start receiving or receive an increase in disabled adult children benefits are allowed to keep their Medicaid coverage if they meet the following:

- Age 18 or older;
- Have lost eligibility for SSI and Medicaid because they started receiving or received an increase in disabled adult child benefits on or after July 1, 1987;
- Have become disabled or blind before reaching age 22;
- Would continue to be eligible for SSI if the disabled child benefits they started receiving or the increase and later increases they received on or after July 1, 1987 were not counted; and
- Meet financial and non-financial requirements of SSI.

## **DISABLED BENEFICIARIES & ELIGIBILITY FOR MEDICARE PART A COVERAGE**

The following disabled beneficiaries are entitled to Medicare Part A:

- Disabled Adult Child
- Disabled Wage Earner
- Disabled Widow

Any disabled beneficiary entitled to Medicare Part A may also have Part B for which he or she must pay the monthly premium (\$96.40 or higher if your income is above \$82,000 (single) or \$164,000 (couple) in 2008). Individuals who are eligible as a Qualified Medicare Beneficiary (QMB) do not pay this Medicare Part B premium.

### **Disabled Adult Child:**

A disabled child age 18 and over and entitled to child's benefits under the Social Security record of his/her retired/deceased/disabled parent may be eligible for Medicare after receiving benefits for 24 months. These Social Security benefits can begin no earlier than age 18; therefore, Medicare benefits do not begin before the month these individuals turn age 20.

### **Disabled Wage Earner:**

To be eligible for Social Security Administration (SSA) disability benefits, you must have worked and paid into the Social Security program (FICA tax) generally for five out of the last ten years prior to the onset of your disability. Medicare entitlement begins with the 25th month of entitlement to Social Security disability benefits (24-month qualifying period).

**Disabled Widow:**

A disabled widow age 50 or older and entitled to widow's benefits under her deceased husband's Social Security record may be eligible for Medicare after receiving SSA Disabled Widow's Benefits for 24 months.

**DISABLED ADULT CHILD & MEDICARE PART B**

Medicaid pays the Medicare Part B premiums, co-insurance amounts and deductibles for individuals who are aged (65+), blind or totally and permanently disabled who meet the following Qualified Medicare Beneficiary (QMB) criteria:

- Entitled to Medicare Part A
- Have countable income below 100% of the FPL (For 2007 - \$851/month for an individual or \$1,141/month for a couple)
- Have countable resources below \$4,000 for an individual or \$6,000 for a couple.

Several sources of income are not counted. Your child's SSI, for example, is not counted. Also, the first \$65 a month of your child's earned income, plus one-half of all remaining net earned income is not counted. In addition, \$20 in unearned or earned income is excluded.

If your adult child meets the QMB requirements, Medicaid can pay the following costs:

1. The monthly premium for Medicare Part B. In 2008, this premium is \$96.40 a month if your income is below \$82,000 (single) or \$164,000 (couple). The monthly premium increases as our income goes up (see rates below). (Medicare Part B helps pay for doctors' bills and other medical services. A person is enrolled in Part B when he or she enrolls in Part A, unless they state they don't want it. )
2. The monthly premium for Premium Hospital Insurance under Medicare Part A. Most individuals are eligible for free Part A. In 2008, those that aren't eligible for free Part A pay \$423 a month. (Medicare Part A is hospital insurance.)
3. Medicare Part A and B deductibles and coinsurance. (A deductible is an initial dollar amount which Medicare does not pay. Coinsurance is your share of expenses for covered services above the deductible.) See the next page for more details.

The following is a listing of Medicare premium, deductible, and coinsurance rates for 2008:

**Part A: (Hospital Insurance) Premium**

- Most people do not pay a monthly Part A premium because they or a spouse has 40 or more quarters of Medicare-covered employment.
- The Part A premium is \$423.00 per month for people who are not otherwise eligible for premium-free hospital insurance and have less than 30 quarters of Medicare-covered employment.

**Part B: (Medical Insurance) Premium**

\$96.40 per month if your income is below \$82,000 (single) or \$164,000 (couple)  
\$122.20 per month if your income is \$82,000 - \$102,000 (single) or \$164,000 - \$204,000 (couple)

\$160.90 per month if your income is \$102,000 - \$153,000 (single) or \$204,000 - \$306,000 (couple)  
\$199.70 per month if your income is \$153,000 - \$205,000 (single) or \$306,000 - \$410,000 (couple)  
\$238.40 per month if your income is above \$205,000 (single) or above \$410,000 (couple)

### **Medicare Deductible and Coinsurance Amounts for 2008:**

**Part A:** (pays for inpatient hospital, skilled nursing facility, and some home health care)  
For each benefit period Medicare pays all covered costs except the Medicare Part A deductible (2008 = \$1,024) during the first 60 days and coinsurance amounts for hospital stays that last beyond 60 days.

#### **For each benefit period you pay:**

- A total of \$1,024 for a hospital stay of 1-60 days.
- \$256 per day for days 61-90 of a hospital stay.
- \$512 per "lifetime reserve day" after day 90 each benefit period (up to 60 days over your lifetime)

#### **Skilled Nursing Facility Coinsurance**

- \$128.00 per day for days 21 through 100 each benefit period.

**Part B:** (covers Medicare eligible physician services, outpatient hospital services, certain home health services, durable medical equipment)

- \$135.00 per year. (Note: You pay 20% of the Medicare-approved amount for services after you meet the \$135.00 deductible.)

### **DISABLED ADULT CHILD & ELIGIBILITY FOR MEDICARE PART D COVERAGE**

Those adult disabled children who receive both Medicaid and Medicare benefits are referred to as "dual eligibles." Dual eligibles now receive prescription coverage through Medicare Part D. Dual eligibles in institutions (nursing facilities and intermediate care facilities for persons with mental retardation (ICF/MRs) are exempt from co-pays, premiums, and deductibles.

Dual eligibles, living in the community, pay limited co-pays of \$1 for generic drugs and \$3.10 for brand name drugs if their income is below 100% of the Federal Poverty Level (FPL) and \$2.15 for generic drugs and \$5.35 for brand name drugs if their income is above 100% of the FPL up to the out-of-pocket limit each year. They have no cost sharing above the annual catastrophic limit. Dual eligibles can also switch prescription drug plans at any time throughout the year.

## Social Security Administration

### Supplemental Security Income (SSI)

Social Security Administration pays monthly Supplemental Security Income (SSI) benefits to people with limited income and resources who are disabled, blind, or age 65 or older and a US citizen or national, or in one of certain categories of aliens. Blind or disabled children, as well as adults, can get SSI benefits. SSA pays SSI benefits on the first of the month for the entire month to meet basic needs for food, clothing, and shelter. Unlike Social Security benefits, SSI benefits are not based on your prior work or a family member's prior work.

For disability purposes in the SSI program, a child becomes an adult at age 18. Social Security Administration (SSA) uses different medical and nonmedical rules when deciding if an adult can get SSI disability payments. For example, **SSA does not count the income and resources of family members when deciding whether an adult meets the financial limits for SSI. SSA counts only the adult's income and resources.** SSA also uses the disability rules for adults when deciding whether an adult is disabled.

- If your child is already receiving SSI payments, SSA must review your child's medical condition when he or she turns age 18. SSA usually does this review during the one-year period that begins on your child's 18th birthday. SSA will use the adult disability rules to decide whether your 18-year-old child is disabled.
- If your child was not eligible for SSI before his or her 18th birthday because you and your spouse had too much income or resources, your child may become eligible for SSI at age 18.

#### What qualifies an adult as being "disabled?"

An individual age 18 and older is "disabled" if he or she has a medically determinable physical or mental impairment, which:

- results in the inability to engage in any substantial gainful activity; and
- can be expected to result in death; or
- has lasted or can be expected to last for a continuous period of not less than 12 months.

#### What is considered as income?

Income includes:

- money earned from work
- money received from other sources, such as Social Security, workers compensation, unemployment benefits, Department of Veterans' Affairs, friends or relatives, and
- free food or shelter

#### What items are counted as resources?

Resources are things you own such as:

- cash;
- bank accounts, stocks, US savings bonds;
- land;
- vehicles;
- personal property;
- life insurance; and
- anything else that could be converted to cash and used for food or shelter.
- deemed resources

The SSI limits for resources are \$2,000 for individuals and \$3,000 for couples.

For SSI, the following resources are not counted:

- the home you live in and the land it is on (we do not place a lien on your home);
- household goods and personal effects;
- your wedding and engagement rings;
- burial spaces for you or your immediate family;
- burial funds for you and your spouse, each valued at \$1,500 or less
- life insurance policies with a combined face value of \$1,500 or less;
- one vehicle, regardless of value, if it is used for transportation for you or a member of your household;
- retroactive SSI or Social Security benefits for up to nine months after you receive them (including payments received in installments);
- grants, scholarships, fellowships, or gifts set aside to pay educational expenses for nine months after receipt.

## Applying for Supplemental Security Income (SSI)

If you are applying for SSI, you can complete a large part of your application by visiting the SSA website at [www.socialsecurity.gov](http://www.socialsecurity.gov). You also can call SSA toll-free at **1-800-772-1213** to ask for an appointment with a Social Security representative.

Parents or guardians usually can apply for blind or disabled children under age 18. In some cases, other third parties can apply for children.

### What do I need to bring when I apply for SSI?

You should bring certain items when you apply. Even if you do not have all of the things listed below, apply anyway. The people in the Social Security office can help you get whatever is needed. Please bring:

- Your Social Security card or a record of your Social Security number;
- Your birth certificate or other proof of your age;
- Information about the home where you live, such as your mortgage or your lease and landlord's name;
- Payroll slips, bank books, insurance policies, burial fund records and other information about your income and the things you own;
- The names, addresses and telephone numbers of doctors, hospitals and clinics that you have been to, if you are applying for SSI because you are disabled or blind;
- Proof of U.S. citizenship or eligible noncitizen status.

You also should bring your checkbook or other papers that show your bank, credit union or savings and loan account number so SSA can have your benefits deposited directly into your account. Direct deposit protects benefits from loss, theft and mail delay. The money is always on time and ready to use without making a trip to the bank.

## **SSI & Employment Support Programs for Young People with Disabilities**

SSA has many ways to encourage young people who are receiving SSI payments and who want to go to work to do so.

Under SSI:

- When SSA figures your son/daughter's monthly SSI payment, SSA does not count most of his/her income. If your son/daughter is younger than age 22 and a student who regularly attends school, SSA excludes even more of his or her earnings each month. In 2007, students with disabilities younger than age 22 may exclude \$1,510 of their monthly earnings, with an annual limit of \$6,100, when counting their income for SSI purposes. These limits increase yearly.
- With a Plan to Achieve Self-Support (PASS), individuals who are age 15 or older can save some income and resources to pay for education and other things needed to be able to work. SSA does not count the saved income when SSA figures your son/daughter's income for SSI purposes. SSA does not count saved income and resources when they figure the amount of payment.
- Because of a medical condition(s), your son/daughter may need certain items and services in order to work, such as a personal assistant. When figuring your son/daughter's SSI payment, SSA will not count some or the entire amount paid for these items and services in your son/daughter's earnings.
- Your son/daughter older than age 15 may get help with rehabilitation and training.
- Medicaid coverage will continue even if your son/daughter's earnings are high enough to stop the monthly SSI payment, as long as the earnings are under a certain amount.

## **Supplemental Security Income (SSI) Work Incentives**

### **What is SSI?**

SSI stands for "Supplemental Security Income". Sometimes, SSI is also called "Title XVI (Title 16) benefits". SSI is a federal program administered by the Social Security Administration (SSA).

The SSI program provides a monthly cash benefit to some individuals who are age 65 or older, or who are blind, or who are disabled. The term "disabled" can also include children under age 18.

SSI is a "needs-based" program. This means that SSI is for those individuals who are older, blind, or disabled who have limited income and resources.

SSI is different from the "Social Security Disability Insurance" (SSDI) program. SSDI is an insurance program. It provides a monthly cash benefit to individuals who have worked and who become disabled. It is provided to workers who have made payments through their paychecks into the SSDI program and who become disabled.

People in South Carolina who receive SSI checks also are automatically eligible for "Medicaid" insurance. Medicaid is a medical insurance plan for individuals who meet certain income criteria and who may also be elderly or disabled.

SSI supplements any other income you receive to make sure that you receive a minimum monthly income to meet your basic expenses. Your monthly cash benefit is based on the Federal Benefit Rate (FBR) and the amount of income you receive from work, as well as any unearned income you may have from other sources.

### **How do I Know If I am Eligible for SSI?**

To be eligible for SSI:

- Your non-excluded resources must not exceed \$2,000 if you are an individual or \$3,000 if you are a couple.
- Your countable income must be less than the 2008 FBR amount of \$637 for an individual or \$956 for a couple; and
- Your "countable earnings" must not exceed the 2008 Substantial Gainful Activity (SGA) amount of \$940 per month. SGA is not a factor for people who meet the medical definition of blindness.

### **What Are SSI Work Incentives?**

The SSA wants people who receive SSI to work if they can. "SSI Work Incentives" help you to have more money each month by working than by not working. They offer incentives to people who work.

SSI Work Incentives can help you enter or reenter the workforce. They encourage you to go to work or to go to school for education or training for future employment. SSI Work incentives will give you some cash benefits while you try to move from

dependency on an SSI check to increased self-sufficiency. In many cases, this means that you **can** work and receive a portion of your SSI check!

SSI Work Incentives are rules that determine how your SSI benefits will be affected while you prepare for and go to work. There are several SSI Work Incentive benefits that might help you.

### **Earned Income Exclusion**

This work incentive is for all SSI recipients who work. It allows some of the money you earn ("earned income") to be excluded when figuring out how much your SSI check will be each month.

Your SSI benefits will be adjusted only after you reach a certain income level:

- **Up to \$85/month of your income has no impact on your SSI check.** All SSI recipients receive a "general income exclusion" of \$20, which applies to all income from any source. For recipients who are working, this is combined with an additional earned income exclusion of \$65, which applies to income from a job. If your only income besides SSI is the money from your job, then they do not count the first \$85 of your monthly earnings.
- **After that, your check is reduced 50 cents for every dollar you earn.** For example, if you work and earn \$685 in February, then your SSI benefit would only decrease by \$300.  $\{(685-85) \text{ divided by } 2\}$ . Therefore, you would end up with more money because you would have your paycheck based on \$685 and your SSI payment of \$337 ( $\$637-300$ ) are over \$1,000.

### **Student Earned Income Exclusion**

This work incentive is for SSI recipients who are students. It allows a person who is under 22 years of age, not married, not the "head of a household", and regularly attending school to exclude up to \$1550 per month of earnings (up to \$6,240 per year) without having those earnings decrease SSI cash benefits. This exclusion is applied before the general income and earned income exclusions described above. Earnings in excess of the monthly or yearly limits are not excludable.

The purpose of this exclusion is to encourage you either to work during the summer months or to participate in work programs during the school year.

### **Blind Work Expenses (BWE)**

This work incentive is for SSI recipients who are blind. It allows your work expenses, whether or not those expenses are related to your disability, to be excluded from your "earned income". Examples of these expenses include transportation to and from work, federal and state income taxes, union dues, cost of lunch at work, or translation of materials into Braille.

### **Other Income Reductions**

Two additional work incentives allow you to deduct additional money beyond the exclusions mentioned above, under specific circumstances.

## **Impairment Related Work Expenses (IRWE)**

This work incentive allows you to deduct from your earnings any expenses related to your impairment that are needed in order to work. These may include, for example, special transportation expenses. The expense cannot be an expense that a worker without a disability would also have, such as the purchase of a uniform. The expense cannot be an expense for which you are reimbursed by another source, such as Medicaid.

You may be able to increase your SSI benefit amount up to 50% of the cost of your disability-related work expenses by claiming these expenses as IRWEs. If you are blind, you may be able to increase your benefit amount by up to 100% for these and all of your work expense, whether they are disability-related or not by claiming them as Blind Work Expenses (BWE).

## **Plan for Achieving Self Support (PASS)**

This work incentive allows you to save for or set aside income or resources to use for work goals. PASS may be used to fund a broad range of expenses such as, for example, education, vocational training, or starting a business. You can also use a PASS to pay for other work related items, such as a personal attendant, job coach, an electric wheelchair, a computer or other assistive technology, occupational therapy, transportation expenses, or even a custom van.

A PASS can allow you to recover up to 100% of the income you spend or set aside by increasing your SSI check up to its maximum. Exactly how much your SSI benefit will be raised depends on your living situation, earned and unearned income, and the amount of the PASS. The PASS must be in writing and approved by the Social Security Administration. There is no limit to how long a PASS can remain in effect, but plans are reviewed every 12 months. You must have another source of income (e.g. income from a job or SSDI) to be eligible for a PASS.

## **Continued Medicaid Coverage (often referred to as "Section 1619b")**

The 1619 (b) incentive provides continued Medicaid coverage for SSI recipients when their earnings become too high to allow an SSI payment. To qualify for this incentive, you must:

- Have been eligible for an SSI cash payment for at least one month;
- Still meet the disability and non-disability requirements;
- Need Medicaid in order to work;
- Have gross earned income, which is below \$27,108; and
- Still meet all other eligibility rules, including the resources test.

## **Continued Eligibility for SSI Cash Payments**

Under Section 1619, a person who is eligible for continued Medicaid coverage under 1619(b) can begin receiving SSI cash payments without reapplying any time earnings drop below the break-even point. (The break-even point is the point at which after deducting your earned income you would receive an SSI payment). This means that

even if your SSI check drops to \$0 because of your earnings, you can restart it at any time if you lose your job or your income decreases.

## **Expedited Reinstatement of Benefits**

Individuals who no longer receive benefits because of earnings from work, but later find themselves unable to work because of their originally determined disability, have 60 months to request that their benefits be reinstated. No new application is needed, but income and resources must again meet the SSI eligibility criteria. You may receive temporary benefits, as well as Medicare and Medicaid, for up to six months while your case is being reviewed. If you are found not disabled, these benefits don't have to be repaid.

## **Strategies for Managing Your Work Incentives**

- Always report changes in your earnings to your local Social Security office. Otherwise, you risk being overpaid or underpaid in your monthly check, and could owe them a refund.
- Remember to make all SSA required reports in writing and keep copies of whatever they provide.
- Confirm your participation in Section 1619a and 1619b; the incentives, which allow continued eligibility for SSI and Medicaid. These should be automatic, but are not always.
- A PASS or IRWE must be approved by Social Security. You may find it helpful to get assistance in developing a PASS or IRWE.
- Contact or visit your local Social Security office and get to know the staff by name. Recognize that not all Social security staff understands these programs. Always be willing to ask questions or seek other advice. You can get the address, telephone number, and directions to your local SSA office on the Internet at [www.socialsecurity.gov/locator](http://www.socialsecurity.gov/locator).

## **For further information**

Information about SSI and work incentives is in the publication *Red Book - A Summary Guide to Employment Support for Individuals with Disabilities Under the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) Programs*. You can see the latest version of SSA's Red Book on Employment Support at: <http://www.ssa.gov/work/ResourcesToolkit/redbook.html>.

You can also get a copy free from your local office, or by calling the Social Administration's toll free number at **1-800-772-1213**. If you are deaf or hard of hearing, you may contact the TTY number at **1-800-325-0778**. SSA can answer specific questions between 7:00 a.m. and 7:00 p.m. on any business day. If you have a touch-tone telephone, recorded information and services are available 24 hours a day, including weekends and holidays.

The following web sites may also be helpful:

[www.socialsecurity.gov/work](http://www.socialsecurity.gov/work)

## **SSDI Work Incentives**

### **What is SSDI?**

SSDI stands for "Social Security Disability Insurance". SSDI is also called "Title II (Title 2) benefits". SSDI is an insurance program. SSDI benefits are provided to individuals who have worked and who become disabled. SSDI benefits are dependent on previous payments made into the system by a worker who has become disabled.

To receive SSDI benefits, you must: 1) meet the definition of disability, 2) be a person or family member covered under the law, and 3) have a sufficient work history.

### **How Do I Know if I am Eligible for SSDI?**

You will be considered disabled if you are unable to engage in any "substantial gainful activity (SGA)" because of a medically determinable physical or mental impairment that can be expected to result in death or that has lasted or that can be expected to last for a continuous period of not less than 12 months. If your impairment is other than blindness, earnings averaging over \$940 a month in 2008 generally demonstrate SGA. If you are blind, earnings averaging over \$1570 a month in 2008 generally demonstrate SGA.

You can receive SSDI benefits until you reach full retirement age. When you reach full retirement age, your disability benefits automatically convert to retirement benefits, but the amount remains the same. Certain members of your family may qualify for benefits based on your record. They include:

- Your spouse, if he or she is age 62 or older.
- Your spouse (who may be any age), if he or she is caring for a child of yours who is under 16 or disabled and also receiving checks.
- Your disabled widow or widower, who is age 50 or older. The disability must have started before your death or within seven years after your death. If your widow or widower caring for your children received Social Security checks, she or he is eligible if she or he becomes disabled before these payments end or within seven years after they end.
- Your unmarried son or daughter, who may be an adopted child (or in some cases, a stepchild or grandchild). The child must be under age 18 or younger than 19 if in high school full time.
- Your unmarried son or daughter, who is age 18 or older, if he or she has a disability that started before age 22. If a child with a disability under 18 is receiving benefits as a dependent of a retired, deceased or disabled worker, someone should contact Social Security to have his or her checks continued at age 18 on the basis of disability.

### **How Much Work History (Work Credits) are Required?**

To qualify for SSDI, you must have worked long enough and recently enough in a job that paid into the Social Security system. You can earn up to a maximum of four work credits per year, one for each quarter of the year you worked. The amount of earnings required for a credit increases each year as general wage levels increase. The number

of work credits you need for disability benefits depends on your age when you became disabled. Family members who qualify for benefits on your work record do not need work credits.

### **What is a Trial Work Period (TWP)?**

If you receive SSDI benefits, you are entitled to a Trial Work Period (TWP), which allows you to test your work skills while continuing to receive a full cash benefit. There is no limit to the amount of money you may earn during the TWP and still get your full cash benefit.

The TWP begins the first month in which you earn more than \$670 or work more than 80 self-employed hours in a month. The TWP continues until you accumulate 9 months in which you earned more than \$670 per month within a 60 consecutive month period. These 9 months do not have to be consecutive, but they must occur within a 60-month period. You are allowed only one TWP within any one period of disability.

### **What is an Extended Period of Eligibility (EPE)?**

The first month after your 9<sup>th</sup> TWP month, you begin your 36 month Extended Period of Eligibility (EPE). The EPE is a period of at least 36 months in which you are eligible to receive a SSDI check for any month your countable earnings are not "substantial". In 2008, earnings of \$940 per month or more (\$1,570 if you are blind) are considered substantial. If you have extra work expenses, your earnings could be substantially higher than \$940 before they affect your benefits (see SSDI Work Incentives below). No new application or disability decision is needed for you to receive a SSDI check during this period.

### **What is a Grace Period?**

During the EPE, the first month that you have earnings that exceed the SGA level will begin a 3-month Grace Period. You continue to receive your SSDI payment during these three months even though your earnings may continue to exceed SGA during the 2<sup>nd</sup> and 3<sup>rd</sup> months. After your Grace Period, your SSDI cash benefit will stop for any month in which earnings exceed the SGA level. Your SSDI benefits will convert to retirement insurance benefits when you reach full retirement age.

### **What is a Quick Benefit Restart?**

After your benefits stop because your earnings are substantial, you have five years during which you may request SSA to start your benefits immediately if you are unable to continue working because of your condition. You do not have to file a new application and you do not have to wait for your benefits to start while your medical condition is being reviewed to make sure you are still disabled.

### **What are SSDI Work Incentives?**

The SSA wants people who receive SSDI to work if they can. "SSDI Work Incentives" help you to have more money each month by working than by not working. They offer incentives to people who work.

SSDI incentives are rules that determine how your SSDI benefits will be affected if and when you go to work. They encourage you to go to work by protecting your SSDI cash benefits and/or your medical benefits until you can support yourself. SSDI Work Incentives encourage you to work or to seek education or training for future employment. There are several SSDI Work Incentive benefits that might help you.

### **Impairment Related Work Expense (IRWE)**

This work incentive allows you to deduct from your earnings any expenses related to your impairment that are needed in order for you to work. These may include, for example, special transportation expenses. The expense cannot be an expense that a worker without a disability would also have, such as the purchase of a uniform.

If SSA agrees that your work expenses are disability related, then the entire amount of your IRWE will be excluded from your earnings in determining whether or not your earnings exceed the Substantial Gainful Activity (SGA) amount of \$940 per month.

Here are some examples of disability-related work expenses likely to be deductible as IRWEs as long as they are work-related, reasonable and not reimbursed by another source:

- Attendant Care Services
- Transportation Costs
- Medical Devices
- Work-Related Equipment and Assistants
- Deductible Prosthesis
- Residential Modifications
- Routine Drugs and Medical Services
- Diagnostic Procedures
- Non-Medical Appliances and Devices

### **Plan for Achieving Self-Support (PASS)**

If you are a SSDI beneficiary whose benefit makes you ineligible for SSI, or if you have other unearned and/or earned income that is too high to make you eligible for at least \$1 of SSI cash benefit, then you may be able to become eligible for SSI (and Medicaid) by using a Plan for Achieving Self-Support (PASS). Under the PASS work incentive you can save for or set aside income or resources to pursue a feasible occupational goal. A PASS can be used to pay for training, education, work-related equipment, transportation, and new work expenses. Once you reach your occupational goal your PASS expires, and you may no longer be eligible for SSI. In some cases, you may be able to specify a new occupational goal to make you even more self-supporting. In such a case, you could write a new PASS and you may continue to be eligible for SSI and Medicaid until the new PASS has been completed.

### **Continued Medicare Coverage**

Most people with disabilities who work will continue to receive at least 93 consecutive months of free hospital and medical insurance coverage under Medicare following the last month of their nine-month trial work period. After that, they can buy Medicare Part A coverage by paying a monthly premium.

## **Expedited Reinstatement of Benefits**

Individuals who no longer receive benefits because of earnings from work, but later find themselves unable to work because of their originally determined disability, have 60 months to request that their benefits be reinstated. No new application is needed. If SSA approves your request for expedited reinstatement of your SSDI benefits, your eligible spouse and dependent children may also receive benefits. SSA can pay you for up to 12 months before your request if your condition kept you from working.

During the first 24 months you are eligible for benefits, we will not pay you for any month(s) you perform SGA, but your Medicare coverage will continue. Once you have received 24 months of benefits, which do not have to be in a row, you get a new trial work period and extended period of eligibility.

## **Blind Between the Ages of 54 and 65**

If you are blind between the ages of 54 and 65, then engaging in SGA will not affect your eligibility for SSDI as long as your skills and abilities are different from what they were before age 55 or before the onset of blindness, whichever is later.

You will not receive a cash benefit for months in which you engage in SGA, but you will not be terminated nor lose Medicaid eligibility because of SGA. If you receive your SSDI benefit only because of this provision, then you do not qualify for a TWP.

## **For further information**

Information about SSDI and work incentives is in the publication *Red Book A Summary Guide to Employment Support for Individuals with Disabilities Under the Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) Programs*. You can see the latest version of SSAs Red Book on Employment Support at: <http://www.ssa.gov/work/ResourcesToolkit/redbook.html>.

You can also get a copy free from your local office, or by calling the Social Administrations toll free number at **1-800-772-1213**. If you are deaf or hard of hearing, you may contact the TTY number at **1-800-325-0778**. SSA can answer specific questions between 7:00 a.m. and 7:00 p.m. on any business day. If you have a touch-tone telephone, recorded information and services are available 24 hours a day, including weekends and holidays.

# Medicaid Can Continue When SSI/SSDI Beneficiaries Go To Work

## SSI Recipients

### *Section 1619(b)*

Your Medicaid coverage can continue, even if your earnings alone or in combination with your other income become too high for an SSI cash payment. In addition, if your income decreases, then you may again be eligible for an SSI cash payment without having to reapply for benefits.

To qualify for continuing Medicaid coverage under 1619(b), you must:

- Be eligible for an SSI cash payment for at least one month
- Be disabled
- Have countable resources under the allowable limits of \$2,000 for an individual and \$3,000 for an eligible couple. (Your house and car are not counted as resources.)
- Need Medicaid in order to work
- Have gross earned income insufficient to replace SSI, Medicaid and publicly funded attendant care services. SSA uses a threshold amount to measure whether a persons earnings are high enough to replace his/her SSI and Medicaid benefits. The 2008 threshold amount used in SC is \$27,108. If you have gross earnings higher than the threshold amount for SC, then SSA can determine if you are eligible for a higher threshold amount.

## SSI Recipients and SSDI Beneficiaries

### *Medicaid for the Working Disabled*

If you are an SSI recipient and your earnings are above the 1619(b) threshold, you may be eligible to continue Medicaid coverage through the Working Disabled Program. In addition, SSDI beneficiaries who are working may be also be eligible for the Working Disabled program. This program provides Medicaid benefits to working disabled individuals whose net family income is less than 250% of the Federal Poverty Level.

### **To be eligible, you must:**

- Be a US citizen or lawful permanent resident alien
- Be a SC resident
- Be disabled according to the SSI definition of disability
- Be working (have earned income)
- Be under 65 years of age
- Have a Social Security number or verify that one has been applied for
- Have countable resources equal to or less than \$2,000 for an individual (Your home and car are not counted as resources)
- Have monthly countable unearned income equal to or less than the SSI Federal Benefit Rate of \$637 (2008 level). Unearned income refers to Social Security, Veterans Benefits, payments from annuities, etc.
- Assign rights to medical support

## To apply for the program, you will need:

- Proof of income
- Social Security number and medical records (if you have any at home)
- Award letters from Social Security, Veterans Administration Office, etc.

Applications may be filed out at Medicaid out-stationed locations such as county health departments, federally qualified rural health centers, most hospitals, and county eligibility offices. The hours of operation are usually Monday through Friday from 8:30 a.m. to 5:00 p.m.

## For further information

A benefits specialist through the South Carolina Pathways Toward Employment (SC PTE) or Walton Options can help you understand how your employment options affect your cash benefits and medical coverage. Services from the South Carolina Pathways Toward Employment and Walton Options are free of charge and can be reached as follows:

SC PTE:

**Anderson, Cherokee, Greenville, Oconee, Pickens, and Spartanburg** counties at 864-242-3531 ext. 315 or 866-439-4091 (toll free).

**Chester, Chesterfield, Clarendon, Darlington, Kershaw, Lancaster, Lee, Sumter, and York** counties at 803-432-1068 or 866-369-9311 (toll free).

**Berkeley, Dillon, Florence, Georgetown, Horry, Marion, Marlboro, and Williamsburg** counties at 843-564-2595 or 800-263-2217 (toll free).

**Calhoun, Fairfield, Laurens, Lexington, Newberry, Richland, and Union** counties at 803-935-5202 or 866-837-9260 (toll free).

WALTON OPTIONS:

**Abbeville, Aiken, Allendale, Bamberg, Barnwell, Beaufort, Charleston, Colleton, Dorchester, Edgefield, Greenwood, Hampton, Jasper, McCormick, Orangeburg, and Saluda** counties at 803-648-2858 or 803-279-9611 (TDD).

You can also contact your local Social Security office, or the Social Administrations toll free number at **1-800-772-1213**. If you are deaf or hard of hearing, you may contact the TTY number at **1-800-325-0778**. SSA can answer specific questions between 7:00 a.m. and 7:00 p.m. on any business day. If you have a touch-tone telephone, recorded information and services are available 24 hours a day, including weekends and holidays.

The following web sites may also be helpful:

[www.socialsecurity.gov/work](http://www.socialsecurity.gov/work)  
[www.workworld.org](http://www.workworld.org)

Health Insurance Considerations – Medicaid,  
Medicare & Private Health Insurance  
Medicaid versus Medicare  
Home and Community Based Waiver Services  
The Role Medicaid Plays in Services

## Health Insurance Considerations

### Medicaid

Federal and state governments share the cost of providing medical care for needy persons who have low income and limited resources through Medicaid. In SC, people who get SSI payments qualify for Medicaid.

### Medicare

Medicare is a federal health insurance program for people age 65 or older and for people who have been getting Social Security disability benefits for at least two years.

There are two exceptions to this rule. Your son/daughter can get Medicare if he or she:

- Has a chronic renal disease and needs a kidney transplant or maintenance dialysis; or
- Has Lou Gehrig's disease (amyotrophic lateral sclerosis).

An adult, who became disabled before age 22, may be eligible for child's benefits if his/her parent is deceased or receiving retirement or disability benefits. Social Security Administration (SSA) considers this a "child's" benefit because it is paid on a parent's Social Security earnings record. SSA makes the disability decision using the disability rules for adults. See "Is Your Parent Deceased or Receiving Retirement or Disability Benefits? – You may be Eligible for Disabled Adult Child Benefits from Social Security."

Individuals with both Medicare and Medicaid coverage are referred to as "dual eligibles."

### Private Health Insurance

If you have been covering your son/daughter with a disability on your private health insurance policy and you wish to continue this coverage, you and your son/daughter's physician will need to complete An Incapacitated Child Certification Form within 31 days of your son/daughter's 19<sup>th</sup> birthday or within 31 days of the date he/she is no longer a student. Your dependent son/daughter who is incapacitated must meet the following requirements to be covered:

- They must be covered at the time of incapacitation.
- They must be unmarried and must remain unmarried to continue eligibility.
- They must be incapable of self-sustaining employment because of mental illness, retardation or physical disability and must remain principally dependent (more than 50 percent) on the covered employee, retiree, survivor or COBRA subscriber for support and maintenance.

## Medicaid versus Medicare

### What is Medicaid?

**Medicaid** is South Carolina's grant-in-aid program by which the Federal and State governments share the costs of providing medical care for certain low-income individuals and families. Medicaid does not pay money to individuals; instead, it sends payments directly to the individual's health care providers.

**If individuals are eligible for Medicaid in SC, will they be Medicaid eligible if they move to another state? Will the services covered by Medicaid be the same from state to state?**

Medicaid coverage varies from state to state. Each state sets its own guidelines regarding eligibility and services. There are certain services that are mandatory (like hospital care, physician services, nursing home care, etc.) and certain services that are optional. Likewise, states are required to cover certain groups (mandatory groups) and states are given the option of covering other groups (optional groups). An individual who is eligible for Medicaid in South Carolina is not necessarily eligible if he/she moves to another state.

### What types of services does Medicaid in SC cover?

- Hospital Services
- Nursing Home Services
- Pharmaceutical Services
- Physician Services
- Home and Community Based Waiver Services
- Family Planning Services
- Dental services
- Hospice services
- Other medical services - vision care, laboratory and x-ray services, durable medical equipment, ambulance and medical transportation, podiatrist services, home health services, certain therapy services, and Rural Health Clinic Services

### What is Medicare?

**Medicare** is a health insurance program administered by the Federal government for eligible workers and retirees who are:

- 65 years of age and older,
- Under 65 years of age with certain disabilities\*, or
- Have End-Stage Renal Disease (ESRD or kidney failure) or Amyotrophic Lateral Sclerosis (ALS or Lou Gehrig's disease) of any age.

\* These individuals must wait for 29 months from the time the Social Security Administration determines they have a severe and permanent disability until they can begin to receive benefits.

## What benefits and services does Medicare provide?

<b>Medicare Consists of Multiple Parts</b>		
	<b>Mandatory or Voluntary</b>	<b>Type of Benefit</b>
<b>Part A</b>	Mandatory	Hospital insurance, including skilled nursing (not custodial or long-term care), some home care, and hospice services
<b>Part B</b>	Voluntary	Physician and outpatient services, some home care, durable medical equipment, and ambulance services
<b>Part C</b>	Voluntary	Alternative to receiving traditional Medicare. Beneficiaries enroll in a Medicare Advantage health plan
<b>Part D</b>	Voluntary	Prescription drug coverage
Parts A and B are referred to as "traditional Medicare."		

## Are Medicaid and Medicare the same?

No. In order to have Medicaid coverage, you must meet certain financial and non-financial eligibility requirements. There is no financial test for Medicare.

# **Medicaid Home and Community Based Services Waivers in SC**

## **What are Medicaid Home & Community Based Services Waivers?**

Home and community-based services (HCBS) waivers allow in-home and community care to be provided to certain Medicaid consumers so they can remain at home instead of in a nursing home, hospital, or institution.

## **How can Medicaid Home & Community Based Services help me stay at home?**

In addition to the usual Medicaid benefits like hospital stays, doctor visits and prescriptions, a Medicaid consumer enrolled in a home and community-based services waiver may be able to get extra services that make living at home possible. These extra services may include the following:

- Nursing
- Help with personal care and homemaking
- Temporary relief for your caregiver or family
- Adaptations to make your home more accessible for you

## **Are there different Home and Community Based Services Waivers in SC?**

Yes. There are currently six Medicaid waiver programs in SC administered by the SC Department of Health and Human Services (DHHS). The last three waiver programs listed are administered by DHHS, but operated by the Department of Disabilities and Special Needs (DDSN):

- Community Choices (formerly the Elderly/Disabled and SC Choice waivers)
- HIV/AIDS
- Mechanical Ventilator Dependent
- Mental Retardation/Related Disabilities (MR/RD)
- Head and Spinal Cord Injury (HASCI)
- Pervasive Developmental Disorder (PDD)

Each waiver program serves people who have a particular set of needs. The financial requirements are the same for each waiver. Other requirements and services differ by waiver. Look at the attached charts for information about the population served, point of entry, level of care required, and services offered for each waiver program.

# CLTC Area Office Addresses

## County Offices

Area 1 – Greenville  
620 North Main Street  
Greenville, SC 29601  
Telephone: 864-242-2211, 1-888-535-8523  
Fax: 864-242-2107  
[CLTCArea1@dhhs.state.sc.us](mailto:CLTCArea1@dhhs.state.sc.us)  
Counties Served: Greenville, Pickens

Area 2 – Spartanburg  
1411 W. O. Ezell Blvd., Suite 6  
Spartanburg, SC 29301  
Telephone: 864-587-4707, 1-888-551-3864  
Fax: 864-587-4716  
[CLTCArea2@dhhs.state.sc.us](mailto:CLTCArea2@dhhs.state.sc.us)  
Counties Served: Cherokee, Spartanburg, Union

Area 3 – Greenwood, IMS  
617 South Main Street  
P. O. Box 3088  
Greenwood, SC 29648  
Telephone: 864-223-8622, 1-800-628-3838  
Fax: 864-223-8607  
[CLTCArea3@dhhs.state.sc.us](mailto:CLTCArea3@dhhs.state.sc.us)  
Counties Served: Abbeville, Edgefield, Greenwood, Laurens, McCormick, Saluda

Area 4 – Rock Hill  
1890 Neely's Creek Road  
Rock Hill, SC 29732  
Telephone: 803-327-9061, 1-888-286-2078  
Fax: 803-327-9065  
[CLTCArea4@dhhs.state.sc.us](mailto:CLTCArea4@dhhs.state.sc.us)  
Counties Served: Chester, Lancaster, York

Area 5 – Columbia  
7499 Parklane Road, Suite 164  
Columbia, SC 29223  
Telephone: 803-741-0826, 1-888-847-0908  
Fax: 803-741-0830  
[CLTCArea5@dhhs.state.sc.us](mailto:CLTCArea5@dhhs.state.sc.us)  
Counties Served: Fairfield, Newberry, Lexington, Richland

Area 6 – Orangeburg  
1857 Joe S. Jeffords Highway  
Orangeburg, SC 29115  
Telephone: 803-536-0122, 1-888-218-4915  
Fax: 803-534-2358  
[CLTCArea6@dhhs.state.sc.us](mailto:CLTCArea6@dhhs.state.sc.us)  
Counties Served: Allendale, Bamberg, Calhoun, Orangeburg

Area 6A – Aiken Satellite Office  
2330 Woodside Executive Center  
Aiken, SC 29803  
Telephone: 803-641-7680, 1-888-364-3310  
Fax: 803-641-7682  
[CLTCArea6A@dhhs.state.sc.us](mailto:CLTCArea6A@dhhs.state.sc.us)  
Counties Served: Aiken, Barnwell

Area 7 – Sumter  
30 Wesmark Court  
Sumter, SC 29150  
Telephone: 803-905-1980, 1-888-761-5991  
Fax: 803-905-1987  
[CLTCArea7@dhhs.state.sc.us](mailto:CLTCArea7@dhhs.state.sc.us)  
Counties Served: Clarendon, Kershaw, Lee, Sumter

Area 8 – Florence  
201 Dozier Boulevard  
Florence, SC 29501  
Telephone: 843-667-8718, 1-888-798-8995  
Fax: 843-667-9354  
[CLTCArea8@dhhs.state.sc.us](mailto:CLTCArea8@dhhs.state.sc.us)  
Counties Served: Chesterfield, Darlington, Dillon, Florence, Marlboro

Area 9- Conway  
914 Norman Street  
P. O. Box 2150  
Conway, SC 29526  
Telephone: 843-248-7249, 1-888-539-8796  
Fax: 843-248-3809  
[CLTCArea9@dhhs.state.sc.us](mailto:CLTCArea9@dhhs.state.sc.us)  
Counties served: Georgetown, Horry, Marion, Williamsburg

Area 10 – Charleston  
4130 Faber Place Drive,  
Suite 303  
N. Charleston, SC 29405  
Telephone: (843) 529-0142 FAX: (843) 566-0171  
1-888-805-4397  
[CLTCArea10@dhhs.state.sc.us](mailto:CLTCArea10@dhhs.state.sc.us)  
Counties Served: Berkeley, Charleston, Dorchester

Area 10A - Point South Satellite  
10175 South Jacob Smart Blvd  
Ridgeland, SC 29936  
Telephone: 843-726-5353, 1-800-262-3329  
Beaufort Line: 843-521-9191  
Fax: 843-726-5113  
[CLTCArea10A@dhhs.state.sc.us](mailto:CLTCArea10A@dhhs.state.sc.us)  
Counties Served: Beaufort, Colleton, Hampton, Jasper

Area 11- Anderson, IMS  
3215 Mall Road, Suite H  
Anderson, SC 29621  
P. O. Box 5947  
Anderson, SC 29623-5947  
Telephone: 864-224-9452, 1-800-713-8003  
Fax: 864-225-0871  
[CLTCArea11@dhhs.state.sc.us](mailto:CLTCArea11@dhhs.state.sc.us)  
Counties Served: Anderson, Oconee

Contact Info
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Central office  
1801 Main St.  
P. O. Box 8206  
Columbia, SC 29202

803-898-2590

## **Local Disabilities and Special Needs Boards**

Burton Center Multi-County Board  
2350 Highway 72/221 East  
PO Box 3004  
Greenwood, SC 29648  
864-942-8900  
Abbeville, Edgefield, Greenwood, McCormick, & Saluda  
Counties

Aiken County Board of Disabilities  
PO Box 698  
1016 Vaucluse Road  
Aiken, SC 29802  
803-642-8800

Allendale/Barnwell Disabilities & Special Needs Board  
914 Barnwell Highway  
PO Box 556  
Barnwell, SC 29812  
803-584-5050  
Allendale & Barnwell Counties

Anderson Disabilities and Special Needs Board  
214 McGee Road  
Anderson, SC 29625  
864-260-4515

Bamberg County Disabilities & Special Needs Board  
16553 Heritage Highway  
Denmark, SC 29042  
803-793-5003

Beaufort County Disabilities & Special Needs Dept.  
1804 Old Shell Road  
PO Box 129  
Port Royal, SC 20035  
843-470-6300

Berkeley Citizens, Inc.  
1301 Old Highway 52 South  
PO Drawer 429  
Moncks Corner, SC 29461  
843-761-0300

Calhoun Disabilities and Special Needs Board  
78 Doodle Hill Road  
St. Matthews, SC 29135  
803-874-2664

Disabilities Board of Charleston County  
995 Morrison Drive  
PO Box 22708  
Charleston, SC 29413-2708  
843-805-5800

Cherokee Disabilities and Special Needs Board  
959 East O'Neal Street  
PO Box 340  
Gaffney, SC 29342-0340  
864-487-4190

Chester/Lancaster Disabilities & Special Needs Board  
1126 Camp Creek Road  
PO Box 577  
Lancaster, SC 29721  
803-285-4368  
Chester & Lancaster Counties

Chesterfield Disabilities and Special Needs Board  
1224 East Boulevard  
PO Drawer 151  
Chesterfield, SC 29709  
843-623-9016

Clarendon Disabilities and Special Needs Board  
312 Pine Street  
PO Drawer 40  
Manning, SC 29102  
803-435-2330

Colleton County Board of Disabilities  
119 Charles Street  
PO Box 1547  
Walterboro, SC 29488  
843-549-1732

Darlington Disabilities and Special Needs Board  
201 N Damascus Church Road  
Hartsville, SC 29550  
843-332-7252

Marion-Dillon Disabilities and Special Needs Board  
400 Martin Luther King Blvd  
PO Box 1082  
Marion, SC 29571  
843-423-4484  
Marion & Dillon Counties

Dorchester Disabilities and Special Needs Board  
2717 West 5<sup>th</sup> North Street  
PO Box 2950  
Summerville, SC 29484  
843-871-1285

Fairfield Disabilities and Special Needs Board  
410 West Washington Street  
PO Box 367  
Winnsboro, SC 29180  
803-635-2154

Florence Disabilities and Special Needs Board  
1211 National Cemetery Road  
PO Box 12810  
Florence, SC 29504  
843-667-5007

Georgetown Disabilities and Special Needs Board  
902 Highmarket Street  
PO Box 1471  
Georgetown, SC 29442  
843-546-8228

Greenville Disabilities and Special Needs Board  
1700 Ridge Road  
PO Box 17467  
Greenville, SC 29606-7467  
864-679-0220

Hampton Disabilities and Special Needs Board  
294 Hampton Road  
PO Box 128  
Hampton, SC 29924  
803-943-4818

Horry Disabilities and Special Needs Board  
250 Victory Lane  
Conway, SC 29526  
843-347-3010

Jasper Disabilities and Special Needs Board  
C/O JH Hill Ctr, Hwy 278 West  
PO Box 747  
Ridgeland, SC 29936  
843-726-4499

Kershaw Disabilities and Special Needs Board  
1619 Jefferson Davis Highway  
PO Box 310  
Camden, SC 29021  
803-432-4841

Laurens Disabilities and Special Needs Board  
1860 Highway 14  
PO Box 986  
Laurens, SC 29360  
864-682-2314 ext. 30

Lee Disabilities and Special Needs Board  
842 McCleod Road  
PO Box 468  
Bishopville, SC 29010  
803-484-9473

Richland-Lexington Disabilities and Special Needs  
420 Rivermont Drive  
Columbia, SC 29210  
803-252-5179  
Richland & Lexington Counties

Marlboro Disabilities and Special Needs Board  
109 Glen Street  
PO Box 1212  
Bennettsville, SC 29512  
843-479-1882

Newberry Disabilities and Special Needs Board  
115 Nance Street  
PO Box 856  
Newberry, SC 29108  
803-276-0078

Oconee Disabilities and Special Needs Board  
116 South Cove Road  
Seneca, SC 29672  
864-885-6055

Orangeburg Disabilities and Special Needs Board  
2785 Magnolia Street  
PO Box 1812  
Orangeburg, SC 29116  
803-536-1170

Pickens Disabilities and Special Needs Board  
1308 Griffin Mill Road  
PO Box 1308  
Easley, SC 29640  
864-859-5416

Charles Lea Center  
195 Burdette Street  
Spartanburg, SC 29307  
864-585-0322

Sumter Disabilities and Special Needs Board  
750 Electric Drive  
PO Box 2847  
Sumter, SC 29151-2847  
803-778-1669

Union Disabilities and Special Needs Board  
226 South Gadberry Street  
PO Box 903  
Union, SC 29379  
864-427-7700

Williamsburg Disabilities and Special Needs Board  
61 Greenlee Street  
Kingstree, SC 29556  
843-355-5481

York Disabilities and Special Needs Board  
7900 Park Place Road  
PO Box 30  
Rock Hill, SC 29731  
803-628-5999

## Community Long Term Care

A Division of the Department of Health and Human Services

The South Carolina Community Long Term Care Division has a variety of programs to serve individuals who want to work and/or live at home, need assistance, and are eligible for Medicaid. The statewide programs provide pre-admission screening, level of care determination, coordination of services, and case management or care advisement for eligible individuals seeking alternatives to institutional care. A summary of the programs is listed below.

	<b>Community Choices</b>	<b>HIV/AIDS Program</b>	<b>Mechanical Ventilator Program</b>
Population Served	Medicaid eligible, age 18 years or older, Nursing Facility level of care.	Medicaid eligible, diagnosed with HIV/AIDS and at risk of hospitalization, any age.	Medicaid eligible, age 21 years or older who meet skilled or intermediate level of care and who require mechanical ventilation.
Point of Entry	CLTC Area Office	CLTC Area Office	CLTC Area Office
Level of Care	Nursing Facility (NF)	At Risk of Hospitalization	Nursing Facility and Dependent on Mechanical Ventilation
Services	<ul style="list-style-type: none"> <li>• Case Management</li> <li>• Personal Care I &amp; II</li> <li>• Attendant Care</li> <li>• Companion</li> <li>• Environmental Modifications</li> <li>• Enhanced Environmental Modifications</li> <li>• Home Delivered Meals</li> <li>• Adult Day Health Care</li> <li>• Adult Day Health Care Nursing</li> <li>• Institutional Respite Care</li> <li>• Respite in CRCF</li> <li>• Personal Emergency Response System (PERS)</li> <li>• Incontinence Supplies</li> <li>• Nursing Home Transition Services</li> <li>• Chore Service (Opt. 4 ONLY)</li> <li>• Nutritional Supplements</li> <li>• Limited Durable Medical Equipment</li> </ul>	<ul style="list-style-type: none"> <li>• Case Management</li> <li>• Personal Care I &amp; II</li> <li>• Attendant Care</li> <li>• Companion</li> <li>• Environmental Modifications</li> <li>• Home Delivered Meals</li> <li>• Private Duty Nursing</li> <li>• Prescription Drugs</li> <li>• Limited Incontinence Supplies</li> <li>• Nutritional Supplements</li> <li>• Enhanced Environmental Modifications</li> </ul>	<ul style="list-style-type: none"> <li>• Personal Care I &amp; II</li> <li>• Attendant Care</li> <li>• Private Duty Nursing</li> <li>• Environmental Modifications</li> <li>• Specialized Medical Equipment &amp; Supplies</li> <li>• Institutional Respite Care</li> <li>• In-Home Respite Care</li> <li>• Personal Emergency Response System (PERS)</li> <li>• Prescription Drugs</li> <li>• Incontinence Supplies</li> <li>• Nutritional Supplies</li> <li>• Enhanced Environmental Modifications</li> </ul>
Waiting List	Yes	No	Yes

Revised 3/13/07

## Department of Disabilities and Special Needs (DDSN) Waiver Summaries

	<b>Mental Retardation or Related Disabilities (MR/RD) Program</b>	<b>Head and Spinal Cord Injuries (HASCI)</b>	<b>Pervasive Developmental Disorder (PDD) Waiver Program</b>
Population Served	Medicaid eligible, all ages, MR or related disabilities	Medicaid eligible with head <u>or</u> spinal Cord injuries <u>or</u> both <u>or</u> similar disabilities; ages 0-65	Medicaid eligible children, ages 3 through 10, who have been diagnosed with a PDD Including autism or Asperger's Syndrome and meet Level of Care criteria.
Point of Entry	Local Disabilities and Special Needs (DSN) Board	HASCI Division Information and Referral Service 1-866-867-3864 (toll free)	PDD Waiver Intake & Referral Toll Free Number 1-888-576-4658
Level of Care	ICF/MR	Nursing Facility or ICF/MR	ICF/MR
Services	<ul style="list-style-type: none"> <li>• Prevocational Services</li> <li>• Day Habilitation</li> <li>• Supported Employment</li> <li>• Personal Care I &amp; II</li> <li>• Residential Habilitation</li> <li>• Environmental Modifications</li> <li>• Private Vehicle Modifications</li> <li>• DME/Assistive Technology</li> <li>• Prescription Drugs</li> <li>• Respite Care</li> <li>• Audiology Services</li> <li>• Speech/Language Services</li> <li>• Adult Companion Services</li> <li>• Physical Therapy</li> <li>• Occupational Therapy</li> <li>• Psychological Services</li> <li>• Nursing Services</li> <li>• Adult Dental</li> <li>• Adult Vision</li> <li>• Adult Day Health Care</li> <li>• Behavior Support Services</li> <li>• Adult Day Health Care Nursing Services</li> <li>• Adult Attendant Care</li> </ul>	<ul style="list-style-type: none"> <li>• Prevocational Habilitation</li> <li>• Day Habilitation</li> <li>• Supported Employment</li> <li>• Attendant Care</li> <li>• Health Education for Consumer Directed Care</li> <li>• Peer Guidance for Consumer Directed Care</li> <li>• Residential Habilitation</li> <li>• Specialized Supplies and Modifications</li> <li>• Prescription Drugs</li> <li>• Respite Care</li> <li>• Communication Services</li> <li>• Personal Emergency Response System (PERS)</li> <li>• Physical Therapy</li> <li>• Occupational Therapy</li> <li>• Psychological Services</li> <li>• Behavior Support Services</li> <li>• Nursing Services</li> </ul>	<ul style="list-style-type: none"> <li>• Case Management</li> <li>• Early Intensive Behavioral Intervention</li> </ul>
Waiting List	Yes	Yes	Yes

Revised 3/13/07

## Moving a Special Needs Trust to a New State

## Moving a Special Needs Trust to a New State

Over the past several years you have navigated state and federal bureaucracies to ensure your child receives the maximum available resources. Along the way, he/she inherited money, or received a settlement in a personal injury matter requiring the establishment of a special needs trust to continue his/her eligibility for Supplemental Security Income (SSI), Medicaid and other government benefits

You might reasonably assume that his/her special needs trust, because it was established according to federal law, is transferable from one state to another, as is his/her eligibility for public benefits.

**What will change in the new state?** Although SSI eligibility is transferable, all states do not offer a supplementary payment. The amount of your child's SSI benefit may go up or down, depending on whether either your current state or the new state does have an SSI supplemental payment. You learn that your new state (as with most -- but not all -- states) makes acute-care Medicaid services available to anyone who receives SSI payments. However, eligibility for long term care Medicaid services is not automatically transferable and will require you to go through an entirely new application on your child's behalf. You cannot apply until he/she is officially a "resident" of the state to which you will be moving. For some Medicaid programs, he/she might even need to reside in the state for a specified duration before he/she qualifies.

All states do not treat special needs trusts similarly. You should confer with a local attorney in the new state, and locate a member of the Special Needs Alliance (<http://www.specialneedsalliance.com/locate-an-attorney.aspx>) there. In South Carolina, there is only one attorney listed with the Special Needs Alliance:

**Dennis J. Christensen, Esq., P.A.**  
[dennis@scelderlaw.com](mailto:dennis@scelderlaw.com)  
<http://www.scelderlaw.com>  
270 West Coleman Blvd., Ste. D  
Mt. Pleasant, SC 29464  
Tel: (843)971-1199  
Fax: (843)971-0096

Your new state may have a statute and regulations that set out additional requirements for a special needs trust. Failure to comply with those requirements will cause your child's trust to be treated as an available resource for Medicaid in the new state. Your child's trust will have to be amended to comply with the new state's laws and regulations.

**What can you do now?** How can you amend your child's special needs trust when it was set up as an irrevocable trust? The attorney in the new state suggests a draft of the required amendments or restate the trust entirely to conform with the laws of that state but that you should return to court in the state where it was originally established (or where the trustee operates) to obtain approval of any amendments. Will you need to continue to deal with the court in your current state? The new attorney recommends that you request a change in which state's law governs the trust, and ask the current court to approve transfer of control to the courts of your new state.

Medicaid has stringent requirements regarding determinations of medical necessity for services. Even if services are authorized, in many instances availability is limited because providers do not exist in the local marketplace.

You may still be able to maintain eligibility for SSI and acute coverage through Medicaid. You may also have medical coverage for dependents through an employer-sponsored group health insurance plan. In either case, basic coverage may include physician's visits, prescriptions, durable medical equipment, hospitalizations and other major medical expenses. The special needs trust might then be utilized to provide for long term care expenses such as attendant and respite care. If you decide to do without long term care assistance through Medicaid in the short term, you might still make the necessary changes to the trust at a later date should you decide to re-apply for Medicaid long term care services.

Make sure you enlist the assistance of an attorney with expertise in special needs planning and trust matters in the state to which you are contemplating moving.

Note: This information assumes that your child's special needs trust was "self-settled" -- that is, that it resulted from a court proceeding involving a personal injury action or inheritance. The description would have been similar if the money had been in a trust set up as part of an estate plan, or even a pooled trust arrangement. In either of those cases, however, the precise answers might be different, and the result either more or less comfortable for you to deal with. The primary point would not change: it is important to get information about Medicaid and other public benefits programs in the state to which you are contemplating moving **before** the move

*The Voice, The Official Newsletter of SNA*  
*Special Needs Alliance*  
March 2008 - Vol. 2, Issue 7

Applying for Services Through the  
Department of Disabilities and Special Needs  
(DDSN)

## **Applying for Services through the SC Department of Disabilities and Special Needs (DDSN) – Mental Retardation, Autism, or Related Disability**

DDSN provides services and supports to people with autism, mental retardation and related disabilities, traumatic brain injury and spinal cord injury. DDSN provides services to the majority of eligible individuals in their home communities through contracts with local service-provider agencies. Many of these agencies are called Disabilities and Special Needs (DSN) Boards and they serve every county in South Carolina. There are also other service providers available in certain locations around the state.

### Mental Retardation, Autism, or Related Disability

The Disabilities and Special Needs (DSN) Board in your county is the initial point of entry for all services funded by DDSN for people with severe, lifelong disabilities, with the exception of traumatic brain injury and spinal cord injury. A list of the county boards of disabilities and special needs can be found at:

<http://www.state.sc.us/ddsn/delivery/boards.htm>.

- A list of questions will be asked of you to determine if eligibility is probable. If your responses clearly rule out eligibility, your Disabilities and Special Needs Board will refer you to more appropriate agencies/resources. If your responses indicate you may be eligible, the DSN Board will provide you with a list of service coordination providers. The service coordination provider you choose will assign a service coordinator who will help you through the eligibility process.
- The service coordination provider will contact you to arrange a meeting during which the service coordinator will ask you to sign a service agreement and will begin collecting information needed to determine eligibility. Determining eligibility will be faster if you have all the information ready. Current and previous psychological information (within one year, if age 6 or under) adaptive measures, social information, medical reports and school records are needed.
- The DDSN Consumer Assessment Team or the Autism Division office will review the information collected by the service coordinator, and you will be notified whether or not the applicant was determined eligible for services.
- If records are available but found insufficient to determine eligibility further evaluation may be needed. The service coordinator will schedule an evaluation with an approved psychologist or the Autism Division office. The results will be used to determine eligibility and you will be notified of the eligibility determination.
- If records are not available the service coordinator will immediately schedule an evaluation with an approved psychologist or the Autism Division office. Once completed the results will be used to determine eligibility. The service coordinator will notify you of the eligibility determination upon completion.
- If you or your family members are not found to be eligible:
  - The reason(s) for the denial will be given with an explanation.
  - You will be given information on appeal procedures.

- You will be given the name of a contact person to assist you in filing an appeal, if desired.
- The service coordinator will refer you to other available resources.
- If you have new information that might impact the eligibility decision, the information should be given to your service coordinator, Disabilities and Special Needs Consumer Assessment Team and/or Autism Division office for reconsideration.

When records are available, determining your eligibility for services should take no more than three (3) months. If your eligibility is not determined within this time, you should contact your service coordinator or service coordination supervisor.

DDSN contracts with local Disabilities and Special Needs (DSN) Boards and other providers to provide an array of services. Services are provided based on the needs of the person, the appropriateness of the service to meet the need, and the availability of funding. Services may be limited by the availability of a service provider and/or the availability of a funding source for the service. Services and supports may be funded through the Mental Retardation/Related Disabilities (MR/RD) waiver, the Medicaid State Plan, and/or state funded Individual and Family Support Funding. The person must be Medicaid eligible to receive supports through the MR/RD waiver and/or the Medicaid State Plan. Those receiving services and supports through the MR/RD waiver must also meet the following eligibility requirements in addition to being Medicaid eligible:

- be assessed to have needs that can be met through the provision of waiver services;
- be allocated a waiver slot;
- choose to receive services through the waiver; and
- meet ICF/MR Level of Care criteria.

Services through the MR/RD waiver will be terminated if you:

- voluntarily withdraw or no longer wish to receive services funded by the MR/RD Waiver;
- no longer meet ICF/MR level of care criteria;
- are no longer eligible for Medicaid as determined by SC Department of Health and Human Services;
- are admitted to an ICF/MR or nursing facility;
- receive no waiver services for 30 days; or
- move out of the state.

## Types of Services & Supports Available for People with Mental Retardation, Autism, or Related Disabilities (MR/RD)

### Individual and Family Support Services for Adults:

- service coordination\*\*
- stipends for transportation \*\*\* (medical transportation \*\*)
- adult attendant care services\*
- adult companion services\*
- adult dental services\* (emergency dental services for recipients ages 21 and over \*\*)
- adult vision services\* (glasses for those who have had certain types of eye surgery \*\*)
- audiology services\* \*\*
- behavioral support services\*
- environmental modifications\*
- summer services \*\*\*
- personal care services\*
- nursing services\*
- occupational therapy services\* \*\*
- physical therapy services\* \*\*
- prescribed drugs\* \*\*
- private vehicle modifications\*
- psychological services\*\* (children only)
- respite care\* \*\*\*
- specialized medical equipment, supplies and assistive technology\* \*\*\*
- durable medical equipment \*\*
- speech-language pathology\* \*\*
- summer camps for adults \*\*\*
- rehabilitation support services \*\*
- facilitation/life planning \*\*\*

### Day Services for Adults:

- day habilitation \* \*\*\*
- prevocational services \* \*\*\*
- supported employment \* \*\*\*
- adult day health care \*

### Residential Services for Adults:

- intermediate care facilities for the mentally retarded (ICF/MR) – regional center setting and community setting \*\*
- residential habilitation – provided in community training homes, community residential care facilities, and supervised living settings) \* \*\*\*

Services Available Exclusively for People with Autism in Addition to the Services Listed Above:

- consultation for families, educators and service providers \*\*\*
- evaluations for service or treatment planning\*\*\*
- training for professionals and families\*\*\*
- Carolina Autism Resource and Evaluation Center provides in-depth assessments, treatment planning and planning for families\*\*\*

\* MR/RD waiver services

\*\* Medicaid State Plan Services

\*\*\* State funded services

## **Applying for Services through the SC Department of Disabilities and Special Needs (DDSN) - Traumatic Brain Injury, Spinal Cord Injury or a Similar Disability**

If you or a family member have a severe impairment as a result of traumatic brain injury, spinal cord injury, or both, or a similar disability:

- Contact the HASCI Division Information and Referral (I & R) Service at 1-866-867-3864 in Columbia, to be screened for referral to DDSN's Head and Spinal Cord Injury (HASCI) Division.
- If you are determined appropriate for formal consideration of eligibility, you will be referred by I & R to the nearest county DSN Board or approved service organization which provides HASCI Service Coordination. You have a choice in your service coordination provider.
- You will be contacted by a service coordinator to begin formal intake and eligibility determination procedures.
- If your condition or circumstances change significantly, contact I & R again and give them any updated information about your situation.

Information Needed to Determine Eligibility:

1. Medical records documenting a traumatic brain injury and/or spinal cord injury or any other condition.
2. Medical records pertaining to any other conditions.
3. Social information necessary to determine eligibility.
4. Completion of a functional limitations inventory by a HASCI Service Coordinator.

DDSN contracts with local Disabilities and Special Needs (DSN) Boards and other providers to provide an array of services. Services are provided based on the needs of the consumer, the appropriateness of the service to meet the need, and the availability of funding. Services may be limited by the availability of a service provider in a county, as well as the funding source for the service. Services and supports may be funded through the Head and Spinal Cord Injury (HASCI) waiver, the Medicaid State Plan, and/or state funded Individual and Family Support Funding. The individual must be Medicaid eligible to receive supports through the HASCI waiver and/or the Medicaid State Plan. Those individuals receiving services and supports through the HASCI waiver must also meet the following eligibility requirements in addition to being eligible for Medicaid or already covered by Medicaid:

- be eligible to receive services from the Head and Spinal Cord Injury Division of DDSN;
- request HASCI Waiver services through his/her HASCI service coordinator;
- require the degree of care that would be provided in a nursing facility or ICF/MR;
- have urgent circumstances affecting his/her health or functional status and which could be life-threatening;
- be dependent on others to provide or assist with critical health needs, basic activities of daily living or require daily monitoring or supervision to avoid institutionalization;

- need services not available from or adequate with existing resources, including family, private means and other agencies/programs to meet the basic needs of the individual to allow him/her to remain in the home;
- have adequate natural supports to live safely in a private home or other community setting with the type/amount of services available from the HASCI Waiver; and
- the cost of Medicaid HASCI Waiver and State Plan services must be less than or equal to the cost of institutional care.

Services through the HASCI waiver will be terminated if you:

- voluntarily withdraw or no longer wish to receive services funded by the HASCI Waiver;
- no longer meet nursing facility or ICF/MR level of care;
- no longer financially eligible for Medicaid as determined by SC Department of Health and Human Services;
- are admitted to a nursing facility or ICF/MR;
- receive no waiver services for 30 days; or
- move out of the state.

## Types of Services & Supports Available for People with Traumatic Brain Injury and/or Spinal Cord Injury or a Similar Disability

### Individual and Family Support Services for Adults:

- information and referral \*\*\*
- service coordination\*\*
- attendant care\*
- audiology services \*\*
- behavioral support services\*
- communication services\*
- emergency dental services for recipients ages 21 and over \*\*
- environmental modifications\*
- glasses for those who have had certain types of eye surgery \*\*
- health education for consumer directed care\*
- individualized summer services \*\*\*
- medical transportation \*\*
- occupational therapy services\* \*\*
- peer guidance for consumer directed care\*
- personal emergency response system\*
- personal care services\*
- private nursing services\*
- physical therapy services\* \*\*
- prescribed drugs\* \*\*
- private vehicle modifications\*
- psychological services\*\* (children only)
- respite care\* \*\*\*
- rehabilitation support services \*\*
- specialized supplies and modifications\* \*\*\*
- durable medical equipment

### Day Services for Adults:

- support employment services - job coach, enclaves, mobile work crews\*
- center-based pre-vocational, habilitation \* \*\*\*
- individual rehabilitation support services \*\*

### Residential Services for Adults:

- supervised living programs \*
- community training homes \*
- community residential care facilities \*
- community intermediate care facilities/mental retardation (ICF/MR) residencies \*
- regional residential centers \*\*
- nursing facilities \*\*

\* HASCI waiver services

\*\* Medicaid State Plan Services

\*\*\* State funded services

## **Local Disabilities and Special Needs Boards**

Burton Center Multi-County Board  
2350 Highway 72/221 East  
PO Box 3004  
Greenwood, SC 29648  
864-942-8900  
Abbeville, Edgefield, Greenwood, McCormick, & Saluda Counties

Aiken County Board of Disabilities  
PO Box 698  
1016 Vacluse Road  
Aiken, SC 29802  
803-642-8800

Allendale/Barnwell Disabilities & Special Needs Board  
914 Barnwell Highway  
PO Box 556  
Barnwell, SC 29812  
803-584-5050  
Allendale & Barnwell Counties

Anderson Disabilities and Special Needs Board  
214 McGee Road  
Anderson, SC 29625  
864-260-4515

Bamberg County Disabilities & Special Needs Board  
16553 Heritage Highway  
Denmark, SC 29042  
803-793-5003

Beaufort County Disabilities & Special Needs Dept.  
1804 Old Shell Road  
PO Box 129  
Port Royal, SC 20035  
843-470-6300

Berkeley Citizens, Inc.  
1301 Old Highway 52 South  
PO Drawer 429  
Moncks Corner, SC 29461  
843-761-0300

Calhoun Disabilities and Special Needs Board  
78 Doodle Hill Road  
St. Matthews, SC 29135  
803-874-2664

Disabilities Board of Charleston County  
995 Morrison Drive  
PO Box 22708  
Charleston, SC 29413-2708  
843-805-5800

Cherokee Disabilities and Special Needs Board  
959 East O'Neal Street  
PO Box 340  
Gaffney, SC 29342-0340  
864-487-4190

Chester/Lancaster Disabilities & Special Needs Board  
1126 Camp Creek Road  
PO Box 577  
Lancaster, SC 29721  
803-285-4368  
Chester & Lancaster Counties

Chesterfield Disabilities and Special Needs Board  
1224 East Boulevard  
PO Drawer 151  
Chesterfield, SC 29709  
843-623-9016

Clarendon Disabilities and Special Needs Board  
312 Pine Street  
PO Drawer 40  
Manning, SC 29102  
803-435-2330

Colleton County Board of Disabilities  
119 Charles Street  
PO Box 1547  
Walterboro, SC 29488  
843-549-1732

Darlington Disabilities and Special Needs Board  
201 N Damascus Church Road  
Hartsville, SC 29550  
843-332-7252

Marion-Dillon Disabilities and Special Needs Board  
400 Martin Luther King Blvd  
PO Box 1082  
Marion, SC 29571  
843-423-4484  
Marion & Dillon Counties

Dorchester Disabilities and Special Needs Board  
2717 West 5<sup>th</sup> North Street  
PO Box 2950  
Summerville, SC 29484  
843-871-1285

Fairfield Disabilities and Special Needs Board  
410 West Washington Street  
PO Box 367  
Winnsboro, SC 29180  
803-635-2154

Florence Disabilities and Special Needs Board  
1211 National Cemetery Road  
PO Box 12810  
Florence, SC 29504  
843-667-5007

Georgetown Disabilities and Special Needs Board  
902 Highmarket Street  
PO Box 1471  
Georgetown, SC 29442  
843-546-8228

Greenville Disabilities and Special Needs Board  
1700 Ridge Road  
PO Box 17467  
Greenville, SC 29606-7467  
864-679-0220

Hampton Disabilities and Special Needs Board  
294 Hampton Road  
PO Box 128  
Hampton, SC 29924  
803-943-4818

Horry Disabilities and Special Needs Board  
250 Victory Lane  
Conway, SC 29526  
843-347-3010

Jasper Disabilities and Special Needs Board  
C/O JH Hill Ctr, Hwy 278 West  
PO Box 747  
Ridgeland, SC 29936  
843-726-4499

Kershaw Disabilities and Special Needs Board  
1619 Jefferson Davis Highway  
PO Box 310  
Camden, SC 29021  
803-432-4841

Laurens Disabilities and Special Needs Board  
1860 Highway 14  
PO Box 986  
Laurens, SC 29360  
864-682-2314 ext. 30

Lee Disabilities and Special Needs Board  
842 McCleod Road  
PO Box 468  
Bishopville, SC 29010  
803-484-9473

Richland-Lexington Disabilities and Special Needs  
420 Rivermont Drive  
Columbia, SC 29210  
803-252-5179  
Richland & Lexington Counties

Marlboro Disabilities and Special Needs Board  
109 Glen Street  
PO Box 1212  
Bennettsville, SC 29512  
843-479-1882

Newberry Disabilities and Special Needs Board  
115 Nance Street  
PO Box 856  
Newberry, SC 29108  
803-276-0078

Oconee Disabilities and Special Needs Board  
116 South Cove Road  
Seneca, SC 29672  
864-885-6055

Orangeburg Disabilities and Special Needs Board  
2785 Magnolia Street  
PO Box 1812  
Orangeburg, SC 29116  
803-536-1170

Pickens Disabilities and Special Needs Board  
1308 Griffin Mill Road  
PO Box 1308  
Easley, SC 29640  
864-859-5416

Charles Lea Center  
195 Burdette Street  
Spartanburg, SC 29307  
864-585-0322

Sumter Disabilities and Special Needs Board  
750 Electric Drive  
PO Box 2847  
Sumter, SC 29151-2847  
803-778-1669

Union Disabilities and Special Needs Board  
226 South Gadberry Street  
PO Box 903  
Union, SC 29379  
864-427-7700

Williamsburg Disabilities and Special Needs Board  
61 Greenlee Street  
Kingstree, SC 29556  
843-355-5481

York Disabilities and Special Needs Board  
7900 Park Place Road  
PO Box 30  
Rock Hill, SC 29731  
803-628-5999

## Applying for Services Through Community Long Term Care (CLTC)

## **Applying for Services through Community Long Term Care (CLTC)**

Community Long Term Care (CLTC) offers a variety of programs to serve individuals who want to live at home, need assistance with their care, and are eligible for Medicaid.

The statewide program provides pre-admission assessment, level of care determination, coordination of services, and case management for eligible persons seeking alternatives to institutional care. The services are provided through the Medicaid program and are available for persons who meet requirements.

CLTC area offices are staffed by nurses and case managers. The nurses and case managers work with eligible persons and their families to plan, coordinate, and authorize needed services.

CLTC offers three programs for those who are Medicaid eligible: Community Choices – for those seniors and individuals 18 years or older who are unable to perform their own activities of daily living due to illness or disability (meet nursing facility level of care criteria); Mechanical Ventilator Dependent Program – for those individuals 21 years or older who are dependent upon mechanical ventilation; and the HIV/AIDS Program – for those who have HIV/AIDS and are considered to be at risk for hospitalization.

The Community Choices Program offers a full range of opportunities for participant direction, depending on the amount of risk and responsibility each participant wishes to assume. Participants may choose to receive all agency directed services; a mix of agency and participant directed services; or they may choose to direct their entire package of waiver services. Participants may choose to receive such services as attendant and companion care with employer authority only, or they may choose to exercise both employer and budget authority over attendant and companion care, in-home respite, and chore services. They may also choose to exercise budget authority and receive such services as home accessibility adaptations and appliances.

Participants may direct their own services if they have no communication or cognitive deficits which make them unable to make independent decisions in their own best interest. Participants may also choose a representative to act on their behalf if they are unable or unwilling to take on the additional risks and responsibilities of directing their own care.

The following services are available through the Community Choices Program:

- Case management
- Personal Care I - assistance with general household activities
- Personal Care II – assistance with activities such as bathing, dressing, preparing meals, housekeeping, and observing health signs
- Adult Day Health Care
- Respite
- Adult Attendant Care
- Adult Companion Care
- Chore Services
- Adult Day Health Care Nursing
- Home Delivered Meals

- Home Accessibility Adaptations and Appliances
- Specialized Medical Supplies and Equipment
- Personal Emergency Response System
- Nursing Home Transition Services

Referrals may be made by anyone with knowledge of the individual's needs and the permission of the person being referred. Many referrals come from family members, friends, clergy, home health nurses, physicians, and community agencies as well as persons with disabilities themselves.

If you would like to make a referral or apply for Long Term Care services through Community Long Term Care, please contact your local Health and Human Services Community Long Term Care office. The listing of each office can be found at: <http://www.dhhs.state.sc.us/dhhsnew/InsideDHHS/Bureaus/BureauofLongTermCareServices/other11262832003.asp>.

# CLTC Area Office Addresses

## County Offices

Area 1 – Greenville  
620 North Main Street  
Greenville, SC 29601  
Telephone: 864-242-2211, 1-888-535-8523  
Fax: 864-242-2107  
[CLTCArea1@dhhs.state.sc.us](mailto:CLTCArea1@dhhs.state.sc.us)  
Counties Served: Greenville, Pickens

Area 2 – Spartanburg  
1411 W. O. Ezell Blvd., Suite 6  
Spartanburg, SC 29301  
Telephone: 864-587-4707, 1-888-551-3864  
Fax: 864-587-4716  
[CLTCArea2@dhhs.state.sc.us](mailto:CLTCArea2@dhhs.state.sc.us)  
Counties Served: Cherokee, Spartanburg, Union

Area 3 – Greenwood, IMS  
617 South Main Street  
P. O. Box 3088  
Greenwood, SC 29648  
Telephone: 864-223-8622, 1-800-628-3838  
Fax: 864-223-8607  
[CLTCArea3@dhhs.state.sc.us](mailto:CLTCArea3@dhhs.state.sc.us)  
Counties Served: Abbeville, Edgefield, Greenwood, Laurens, McCormick, Saluda

Area 4 – Rock Hill  
1890 Neely's Creek Road  
Rock Hill, SC 29732  
Telephone: 803-327-9061, 1-888-286-2078  
Fax: 803-327-9065  
[CLTCArea4@dhhs.state.sc.us](mailto:CLTCArea4@dhhs.state.sc.us)  
Counties Served: Chester, Lancaster, York

Area 5 – Columbia  
7499 Parklane Road, Suite 164  
Columbia, SC 29223  
Telephone: 803-741-0826, 1-888-847-0908  
Fax: 803-741-0830  
[CLTCArea5@dhhs.state.sc.us](mailto:CLTCArea5@dhhs.state.sc.us)  
Counties Served: Fairfield, Newberry, Lexington, Richland

Area 6 – Orangeburg  
1857 Joe S. Jeffords Highway  
Orangeburg, SC 29115  
Telephone: 803-536-0122, 1-888-218-4915  
Fax: 803-534-2358  
[CLTCArea6@dhhs.state.sc.us](mailto:CLTCArea6@dhhs.state.sc.us)  
Counties Served: Allendale, Bamberg, Calhoun, Orangeburg

Area 6A – Aiken Satellite Office  
2330 Woodside Executive Center  
Aiken, SC 29803  
Telephone: 803-641-7680, 1-888-364-3310  
Fax: 803-641-7682  
[CLTCArea6A@dhhs.state.sc.us](mailto:CLTCArea6A@dhhs.state.sc.us)  
Counties Served: Aiken, Barnwell

Area 7 – Sumter  
30 Wesmark Court  
Sumter, SC 29150  
Telephone: 803-905-1980, 1-888-761-5991  
Fax: 803-905-1987  
[CLTCArea7@dhhs.state.sc.us](mailto:CLTCArea7@dhhs.state.sc.us)  
Counties Served: Clarendon, Kershaw, Lee, Sumter

Area 8 – Florence  
201 Dozier Boulevard  
Florence, SC 29501  
Telephone: 843-667-8718, 1-888-798-8995  
Fax: 843-667-9354  
[CLTCArea8@dhhs.state.sc.us](mailto:CLTCArea8@dhhs.state.sc.us)  
Counties Served: Chesterfield, Darlington, Dillon, Florence, Marlboro

Area 9- Conway  
914 Norman Street  
P. O. Box 2150  
Conway, SC 29526  
Telephone: 843-248-7249, 1-888-539-8796  
Fax: 843-248-3809  
[CLTCArea9@dhhs.state.sc.us](mailto:CLTCArea9@dhhs.state.sc.us)  
Counties served: Georgetown, Horry, Marion, Williamsburg

Area 10 – Charleston  
4130 Faber Place Drive,  
Suite 303  
N. Charleston, SC 29405  
Telephone: (843) 529-0142 FAX: (843) 566-0171  
1-888-805-4397  
[CLTCArea10@dhhs.state.sc.us](mailto:CLTCArea10@dhhs.state.sc.us)  
Counties Served: Berkeley, Charleston, Dorchester

Area 10A - Point South Satellite  
10175 South Jacob Smart Blvd  
Ridgeland, SC 29936  
Telephone: 843-726-5353, 1-800-262-3329  
Beaufort Line: 843-521-9191  
Fax: 843-726-5113  
[CLTCArea10A@dhhs.state.sc.us](mailto:CLTCArea10A@dhhs.state.sc.us)  
Counties Served: Beaufort, Colleton, Hampton, Jasper

Area 11- Anderson, IMS  
3215 Mall Road, Suite H  
Anderson, SC 29621  
P. O. Box 5947  
Anderson, SC 29623-5947  
Telephone: 864-224-9452, 1-800-713-8003  
Fax: 864-225-0871  
[CLTCArea11@dhhs.state.sc.us](mailto:CLTCArea11@dhhs.state.sc.us)  
Counties Served: Anderson, Oconee

Contact Info
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Central office  
1801 Main St.  
P. O. Box 8206  
Columbia, SC 29202

803-898-2590

## Services Of Other State Agencies & Non-Profit Organizations

# Protection and Advocacy for People with Disabilities, Inc. (P&A)

Established in 1977 as the protection and advocacy system for the State of South Carolina, P&A is a member of the National Disability Rights Network (NDRN) and is mandated by state and federal law to protect the rights of people with disabilities in South Carolina.

P&A is a private, non-profit South Carolina corporation governed by a volunteer board of directors. As required by federal law, P&A is independent of all agencies which provide treatment or other services to people with disabilities. Click here to learn more about P&A's [history](#).

## ■P&A's Mission

To protect the legal, civil, and human rights of people with disabilities in South Carolina by

- enabling individuals to advocate for themselves,
- speaking on their behalf when they have been discriminated against or denied a service to which they are entitled,
- and promoting policies and services which respect their choices.

## ■P&A's Vision

Protection and Advocacy for People with Disabilities, Inc. (P&A) is a resource where individuals in South Carolina obtain quality information and referral about disability rights, enabling people with disabilities to be effective self-advocates.

Outreach strategies assure full participation in P&A services for people with disabilities who are of rural or ethnic minority cultures.

There is full participation of students with disabilities in the public school system.

People with disabilities have equal access to places, services and goods that are available to the general public.

People with disabilities who are in confinement will receive quality services including treatment and habilitation, personal safety and liberty, basic life necessities, and integration opportunities. These services will be individualized and productive recognizing the dignity and autonomy of each person.

No one will have to live in an institution due to the lack of appropriate supports and services in the community.

## Our Services

P&A provides services to people with disabilities based on several factors.

### ■ Who P&A Serves

A person with a disability living anywhere in South Carolina who feels that he or she has been discriminated against because of the disability, or that he or she has been denied a service to which he or she is entitled, can call our toll free number

**(Voice) 1.866.ASK.PAPD  
(1.866.275.7273)**

**(TTY) 1.866.232.4525**

to speak with a P&A advocate. The advocate will immediately provide the caller with information and resources that will better equip the caller for self-advocacy. Individual case representation may only be provided to those people whose situations meet annually established case priorities. Due to our limited resources, funders require that every year P&A set priorities to determine the cases that we will accept.

### ■ Services P&A Provides

- **Information & Referral:** P&A advocates provide brief, written, or oral information about callers' problems and suggest ways to resolve the problems, including information about additional resources.
- **Case Representation:** This service is provided under P&A's annually-established priorities. Callers only become clients if they have met case selection criteria set annually by P&A.
- **Systemic Advocacy:** P&A efforts often result in changing laws, regulations, policies, practices or organizational structures to empower individuals with disabilities to achieve greater independence, productivity and inclusion within the community and the workforce.
- **Self-Advocacy Training, Education and Outreach:** P&A identifies disability communities that are in need of receiving self-advocacy training, education and outreach. Advocates conduct consumer focus groups, make presentations, and meet with community leaders as established in annual priorities.

## Contact Us or Other P&As

P&A's services are provided statewide. Services are NOT limited by age, race, sex, type of disability, income, residency, or religion. There are no fees for services. You can reach us by phone, e-mail, mail, or visiting. See details on next page.

***1. For information and/or assistance, contact the P&A Help Line at:***

1.866.275.7273 (Voice)

1.866.232.4525 (TTY) (Toll free in South Carolina)

OR

(803)782-0639 (Local and Out of State)

Voice and TTY Monday - Friday from 8:30 AM - 5:00 PM

I&R services are provided Monday - Friday from 8:30 AM - 4:30 PM

Voicemail messaging system in operation 24 hours

***2. To contact by e-mail:***

Although it is rare, occasionally emails are "lost" and either not received by us or by you. If you send us an email and do not receive a response within two working days, please contact us again. If possible, on the second attempt, please give us additional information such as a name and street address or telephone number.

[info@protectionandadvocacy-sc.org](mailto:info@protectionandadvocacy-sc.org)

***3. To contact by mail:***

Protection & Advocacy for People with Disabilities

3710 Landmark Drive, Suite 208

Columbia, SC 29204

***4. To visit an office:***

P&A has 4 offices located throughout the state of South Carolina.

**Central Office**

3710 Landmark Drive, Suite 208

Columbia, SC 29204

**Low Country Office**

1569 Sam Rittenberg Blvd.

Charleston, SC 29407

**Pee Dee Office**

2137 B Hoffmeyer Road

Florence, SC 29501

**Piedmont Office**

545 N. Pleasantburg Drive, Suite 106

Edgefield Building, Park Central

Greenville, SC 29607

**South Carolina Developmental Disabilities Council**  
**Office of the Governor**  
1205 Pendleton Street, Suite 450  
Columbia, South Carolina 29201  
803.734.0465  
803.734.1147 (TTY)

**What is the Developmental Disabilities Council?**



The South Carolina Developmental Disabilities Council was established in 1971 by Executive Order. The Council is comprised of 38 members appointed by the Governor. The membership includes individuals with developmental disabilities or their relatives, representatives of higher education, advocates, service providers, and state and local agencies.

The Council is federally funded under the Developmental Disabilities Act. The Council administers the basic State Grant Program and assures that the awards made through this program address the needs of persons with disabilities.

The Council encourages change by advocating and planning for better supports and services so that people with developmental disabilities will live in real homes, work at real jobs, learn real skills, and form friendships.

**The DD Council:**

- advocates for the independence,
- promotes the productivity, and
- fosters the integration of people who have developmental disabilities.

## DD Council Grants



The DD Council provides grants for programs that support inclusion into the community for individuals with disabilities.

Requests for grant applications are available beginning in January of each year. Grant proposals are due in early March, and grants are awarded on July 1.

If you would like more information about the DD Council grant process, please contact the Council at **(803) 734-0465** or **(803) 734-1147 (TTY)**.

### DD Council Priority Areas:

- Employment
- Health
- Quality Assurance
- Formal/Informal Community Supports

### What is a Developmental Disability?

- developmental disability is a severe chronic disability of a person which...
- is attributable to a mental or physical impairment or combination of mental and physical impairments;
- is apparent before the person reaches age 22;
- is likely to continue indefinitely;
- results in substantial functional limitations in three or more of the following areas of major activities:
  - self-care
  - learning
  - communication
  - economic self-sufficiency
  - self-direction
  - independent living
  - mobility
  - requires the need for lifelong individually planned coordinated services.

## **South Carolina Developmental Disabilities Council Committees**

- Executive Committee Rules
- State Plan
- Employment
- Formal/Informal Community Supports
- Quality Assurance
- Health

### **Mission**

The mission of the South Carolina Developmental Disabilities Council is to provide leadership in advocating, funding and implementing initiatives which recognize the inherent dignity of each individual, and promote independence, productivity, respect and inclusion for all persons with disabilities and their families. The State Plan will establish and advocate strategies to address a range of support systems for accessing opportunities for persons with disabilities and their families. The plan will include public/private agency collaboration and will be monitored and evaluated annually.

## Lieutenant Governor's Office on Aging

The Lt. Governor's Office on Aging administers federal funds received through the Older Americans Act and the State of South Carolina. These funds are distributed to ten regional Aging and Disability Resource Centers (ADRCs)/Area Agencies on Aging (AAAs) who then contract with local providers for services such as: home delivered and congregate meals, transportation, home care services, social adult day care services, respite and disease prevention/health promotion. Staff is also available to present informative educational programs to groups or staff of other agencies.



Services such as information and referral, family caregiver support, Long Term Care ombudsman, education and training, legal service, disaster planning and insurance counseling are provided at each of the ADRCs.

**Aging and Disability Resource Centers (ADRCs)** provide a single, coordinated system of information and access for seniors, caregivers and adults with disabilities seeking long term care by minimizing confusion, enhancing individual choice, and supporting informed decision-making. ADRCs make it easier for consumers to learn about and access existing services and supports that are available in their communities.



**Information, Referral, and Assistance (I/R&A) - SC Access**, [www.scaccesshelp.org](http://www.scaccesshelp.org), is an Internet based information resource designed to assist seniors, adults with disabilities, and their caregivers locate a variety of services in their area and provides educational material on numerous issues. Ten regional Information and Referral Specialists, located at the ADRCs, provide personal assistance by phone or in person.



**Family Caregiver Support Program (FCSP)** provides services to help the caregiver with information, planning, problem solving, caregiver training, support groups, finding ways to take a break from caregiving (respite) and other services designed to make caregiving a little easier, less stressful and more rewarding. The FCSP helps unpaid family caregivers of adults age 60 and over; caregivers of adults with Alzheimer's disease; grandparents (55 or older) raising a grandchild under 19; and grandparents caring for an adult grandchild with a disability.



**State Health Insurance Program (SHIP) or I-CARE (Insurance Counseling and Referral for Elders)** assists seniors and adults with disabilities in accessing health insurance coverage, including Medicaid and Medicare Parts A, B, C and D, the prescription drug program.



**Long Term Care Ombudsman Program** investigates complaints and advocates for residents' rights in nursing homes, assisted living and residential care facilities as well as facilities operated or contracted for operation by the Department of Disabilities and Special Needs (DDSN) or the Department of Mental Health (DMH). The **Friendly Visitor Program** recruits and trains volunteers to visit residents in facilities.



**Legal Services** may be available, (first come, first serve basis), for seniors who need legal assistance for NON-CRIMINAL situations including issues such as: Income Protection (bankruptcy, appeal denials of pension, etc.); Health Care (appeal disability or Medicare/Medicaid denial); Long Term Care (facility involuntary transfer, inappropriate discharge); Nutrition (if benefits denied and a legal appeal is required); Housing (eviction or discrimination issues); Protected Services (conservatorships); Guardianship (defending you from guardianship or ensuring the least restrictive guardianship); or Abuse, Neglect, or Exploitation.





**Veteran Directed Home and Community Based Services** is a program for veterans (of any age) at high risk of nursing home placement who wish to remain at home and are willing to participate in directing their care. Participants in the program are assessed for needed services and supports, a service plan and budget is developed, and assistance is given in selecting providers, purchasing services and directing their care. The pilot is in the Trident Region (*Charleston, Berkeley and Dorchester* counties) with statewide implementation being the ultimate goal.



**A scheme or scam may be** defined as any deception, pretense, false statement, false promise or misrepresentation made by a seller or advertiser of merchandise. Concealment, suppression, or failure to disclose a material fact may also be considered consumer fraud in certain instances. Merchandise is broadly defined to include any objects, wares, goods, commodities, real estate or services. To report a scheme or scam against a senior, please contact our office.



**Alzheimer's Resource Coordination Center (ARCC)** provides statewide coordination, service system development, information and referral, and caregiver support services to individuals with Alzheimer's disease and related disorders, their families and caregivers. The ARCC also provides technical assistance for the development of support groups and other local initiatives to serve individuals, families and caregivers and provides seed money to local communities to develop or strengthen programs or services to serve people with dementia and their caregivers.



**Geriatric Loan Forgiveness Program** provides funds to assist physicians in repaying student loans. In return, they agree to remain in South Carolina for five years and care for the state's ever increasing senior population.



**ElderCare Trust Fund** consists of monies received from a voluntary state income tax check-off. These funds are used to award seed grants to public and private nonprofit agencies and organizations to establish and administer innovative programs and activities that assist older South Carolinians to live with dignity and vitality in their communities.



**Permanent Improvement Program (PIP)** provides grants for permanent improvements of Senior Centers or the portion of the facility used for aging services. Grant proposals must provide evidence of need for proposed projects in the community and some match is required.



The **Better Choices Better Health** program uses a tested and proven method of helping people manage their chronic conditions and was developed by medical researchers at Stanford University. Small groups of classes are held once a week for 2 1/2 hours over a six week period. By attending all six classes, participants gain the knowledge and skills needed to help them live a healthier life.



The **A Matter of Balance Program** has also been proven to reduce the fear of falling in older adults. This fall prevention class is held twice a week for four weeks. Class locations can be found on the Lt. Governor's Office on Aging website.

## Aging & Disability Resource Centers

### What is an ADRC?

- A **visible and trusted place** in the community where you can get information and counseling on all available long term support options
- A **single point of entry** to public long term support services that **enables** people to make informed decisions and provides **streamlined access** to services
- A **partnership** between agencies to assist consumers and provide follow-up to ensure access to services

### What are the functions of an ADRC?

#### Awareness & Information

Public Education  
Information on Options

#### Assistance

Referral  
Crisis Intervention  
Options Counseling  
Benefits Counseling  
Planning for Future Needs  
Employment Options Counseling

#### Access

Eligibility Screening  
Private Pay Services  
Comprehensive Assessment  
Programmatic Eligibility Determination  
Medicaid Financial Eligibility Determination  
One-Stop Access to all public programs

### What are the benefits of an ADRC?

#### ADRCs:

- **make it easier** for older individuals and adults with physical disabilities to access health and social supports
- **help** persons stay healthy and active in their communities
- **support** families in their efforts to care for their loved ones at home and in the community
- **streamline** eligibility for seniors and adults with physical disabilities
- **simplify** the intake, eligibility and determination processes by integrating and coordinating the processes between programs and agencies
- **target** individuals who are at imminent risk of being institutionalized
- **ensure** that consumers understand their long term care options

### Who do ADRCs serve?

- People aged 60+
- Adults with physical disabilities (some ADRCs also serve adults with developmental disabilities)
- Family members, caregivers

## When and why were ADRCs begun?

ADRCs started as a grant-based program in March 2003, as a **first-ever partnership** between the Administration on Aging (AoA) and the Center for Medicare and Medicaid Services (CMS). The program was started so long term support resources for seniors and adults with disabilities would be integrated into a single coordinated system to minimize confusion, enhance individual choice, and support informed decision-making. **South Carolina was one of the first 12 successful grant applicants nationwide.** Now 43 states have ADRCs.

## Where are ADRCs located in SC?

### Current ADRCs and Service Areas

- **Lower Savannah:** Aiken, Allendale, Bamberg, Barnwell, Calhoun, Orangeburg  
803-649-7981 or 866-845-1550 toll free
- **Santee Lynches:** Clarendon, Lee, Kershaw, Sumter  
803- 775-738 or 800-948-1042 toll free
- **Appalachia:** Anderson, Oconee, Pickens, Greenville, Spartanburg, Cherokee  
864-242-9733 or 800-434-4036 toll-free
- **Trident:** Berkeley, Charleston, Dorchester  
843-554-2275 or 800-894-0415 toll-free
- **Pee Dee:** Chesterfield, Darlington, Dillon, Florence, Marlboro, Marion  
843-378-4501 or 866-505-3331 toll-free

## How do I reach an ADRC?

- **Visit** a physical location
- **Call** a local or toll free telephone number
- **Search** on-line: [www.SCAccesshelp.org](http://www.SCAccesshelp.org)

## What if I have additional questions?

For more information on ADRCs in South Carolina, you can contact the Lt. Governor's Office on Aging at (803) 734-9900 or toll free at 1 (800) 868-9095.

## SC Access

### What is it?

SC Access is a free information and referral program for seniors and adults with disabilities living in South Carolina. It includes a web-based search tool that can assist you in finding services, or you can get help by phone from trained Information and Referral Specialists.

### Who should use SC Access?

Anyone, including consumers, caregivers, family members and professionals, interested in finding services for seniors and adults with disabilities living in South Carolina should use it.

### What are the benefits of using SC Access?

You can find the services you need without leaving your home. You can go on-line or call an Information and Referral Specialist to find options. Other helpful features of SC Access are:

- **E-forms:** SC seniors can apply for Medicaid Long Term Care and GAPS pharmacy assistance on-line
- **Learn About:** Educational Information about programs, services, agencies and health conditions
- **Community Calendar:** Listing of meetings, training sessions and community events about senior and disability issues in South Carolina
- **Personal Care Worker Listing:** List of individuals interested in providing personal care services in the home

### Where do I find SC Access?

The SC Access web-site can be found at [www.scaccesshelp.org](http://www.scaccesshelp.org) or you can look on the back of this card to find the Regional Information and Referral Specialist closest to you.

### What if I have additional questions?

You can contact the SC Access program at the Lt. Governor's Office on Aging at (803) 734-9900 or toll free at 1(800)-868-9095. You can also contact an Information & Referral Specialist at the toll free numbers listed on the next page.

Call your local Information & Referral Specialist listed below to find options.

<b>COUNTY</b>	<b>LOCAL #</b>	<b>TOLL FREE #</b>
Abbeville	864-941-8061	800-922-7729
Aiken	803-649-7981	866-845-1550
Allendale	803-649-7981	866-845-1550
Anderson	864-242-9733	800-434-4036
Bamberg	803-649-7981	866-845-1550
Barnwell	803-649-7981	866-845-1550
Beaufort	843-726-5536	877-846-8148
Berkeley	843-554-2283	800-894-0415
Calhoun	803-649-7981	866-845-1550
Charleston	843-554-2283	800-894-0415
Cherokee	864-242-9733	800-434-4036
Chester	803-329-9670	800-662-8330
Chesterfield	843-383-8632	866-505-3331
Clarendon	803-775-7381	800-948-1042
Colleton	843-726-5536	877-846-8148
Darlington	843-383-8632	866-505-3331
Dillon	843-383-8632	866-505-3331
Dorchester	843-554-2283	800-894-0415
Edgefield	864-941-8061	800-922-7729
Fairfield	803-376-5390	866-394-4166
Florence	843-383-8632	866-505-3331
Georgetown	843-546-4231	888-302-7550
Greenville	864-242-9733	800-434-4036
Greenwood	864-941-8061	800-922-7729
Hampton	843-726-5536	877-846-8148
Horry	843-546-4231	888-302-7550
Jasper	843-726-5536	877-846-8148
Kershaw	803-775-7381	800-948-1042
Lancaster	803-329-9670	800-662-8330
Laurens	864-941-8061	800-922-7729
Lee	803-775-7381	800-948-1042
Lexington	803-376-5390	866-394-4166
Marion	843-383-8632	866-505-3331
Marlboro	843-383-8632	866-505-3331
McCormick	864-941-8061	800-922-7729
Newberry	803-376-5390	866-394-4166
Oconee	864-242-9733	800-434-4036
Orangeburg	803-649-7981	866-845-1550
Pickens	864-242-9733	800-434-4036
Richland	803-376-5390	866-394-4166
Saluda	864-941-8061	800-922-7729
Spartanburg	864-242-9733	800-434-4036
Sumter	803-775-7381	800-948-1042
Union	803-329-9670	800-662-8330
Williamsburg	843-546-4231	888-302-7550

York	803-329-9670	800-662-8330
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# Disability Related Acronyms and Glossary

## **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**

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 serve 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 South Carolina 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