



South Carolina Autism Society

Together We Can Solve the Puzzle

INFORMATION ON AUTISM SPECTRUM DISORDERS

Developed by:
South Carolina Autism Society
Autism Division - SC Department of Disabilities & Special Needs

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1. What is Autism?

Autism is a developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects functioning of the brain, autism and its associated behaviors occur in approximately 1 of every 150 people.

Autism interferes with the normal development of the brain in the areas of reasoning, social interaction and communication skills. Children and adults with autism typically have deficiencies in verbal and non-verbal communication, social interactions and leisure or play activities. The disorder makes it hard for them to communicate with others and relate to the outside world. They may exhibit repeated body movements (hand flapping, rocking, etc.), have unusual responses to people or attachments to objects and resist changes in routines. In some cases, aggressive and/or self-injurious behavior may occur.

Autism is four to five times more prevalent in boys than girls and knows no racial, ethnic or social boundaries. Family income, lifestyle and level of education do not affect the chance of occurrence.

It is conservatively estimated that nearly 1.5 million people in the United States (approximately 25,000 people in South Carolina) have some form of autism. Its prevalence rate now places it as the third most common developmental disability – more common than Down syndrome. Yet the majority of the public, including some professionals in the medical, educational and vocational fields, are still unaware of how autism affects behavior. Progress is being made in developing more effective teaching methods and other interventions for people

Is There More Than One Type of Autism?

Autism is often referred to as a spectrum disorder, meaning that the symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit any combination of these behaviors with any degree of severity. Two children with a diagnosis of autism can act very differently from one another.

A diagnosis of autism is based on the standards set forth in a diagnostic handbook, the Diagnostic and Statistical Manual, now in its fourth edition (DSM-IV -TR-2000). Several autism-related disorders are grouped under the broad heading "Pervasive Developmental Disorder" or PDD. They include autism, PDD-NOS (pervasive developmental disorder, not otherwise specified) and Asperger's disorder. These diagnoses are often used differently by professionals to describe individuals who manifest some, but not all, of the characteristics associated with autism.

The diagnosis of autism is made when a specified number of characteristics listed in the DSM-IV are present in ranges inappropriate for the child's age. By comparison, a diagnosis of PDD-NOS may be made when a child exhibits fewer symptoms than in autism, although those symptoms may be exactly the same as those in a child with an autism diagnosis. Asperger's disorder tends to involve symptoms more markedly different than those seen in autism, although there are some similarities.

Most professionals will agree that there is no standard "type" or "typical" person with autism. Parents may hear more than one label applied to the

same child: for example, autistic-like, communication disorder with autistic tendencies, or high functioning or low functioning autism. These labels don't describe differences between the children as much as they may indicate differences in the professionals' training, vocabulary and exposure to autism.

The presence of autism can sometimes be difficult to diagnose. Each diagnosis relies on perceptive observations of the child, ideally across several settings (home, school, clinic, etc.), by professionals with a knowledge of autism. Some professionals believe the distinction between autism and PDD-NOS is not significant. Some may believe they are "sparing" the parents by giving a diagnosis of PDD-NOS rather than autism. Many professionals still argue whether Asperger's is truly a form of autism. It's important to understand that whatever the type of autism diagnosis, these children are likely to benefit from similar approaches to education and treatment.

What Causes Autism?

Medical researchers are exploring different explanations for the various forms of autism. Although no one cause of autism is known, current research links autism to biological or neurological differences in the brain. Scans such as the MRI (Magnetic Resonance Imaging) and PET (Positron Emission Tomography) shows abnormalities in the structure of the brain, with significant differences within the cerebellum, including the size and number of Purkinje cells. In some families there appears to be a pattern of autism or related disabilities. This suggests there is a genetic basis to the

disorder, although no one gene has been directly linked to autism. In all likelihood, research will show that several genes are involved.

Several previous theories about the cause of autism have been proven false. Autism is not a mental illness. Children with autism are not unruly kids who choose not to behave. Autism is not caused by bad parenting. Furthermore, no known psychological factors in the development of the child have been shown to cause autism.

How is Autism Diagnosed?

There are no medical tests for diagnosing autism. An accurate diagnosis must be based on observations of the child's communication, behavior and developmental levels. However, because many of the behaviors associated with autism occur with other disorders, a doctor may order a variety of medical tests to rule out other possible causes.

Diagnosis may be difficult for a practitioner with limited training or exposure to autism because the characteristics of the disorder vary so much. Locating a medical specialist or a diagnostician who has experience with autism is most important. Ideally a child should be evaluated by a multidisciplinary team, which may include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant or other professionals knowledgeable about autism. Several diagnostic tools have been developed over the past few years to help professionals make an accurate autism diagnosis:

CHAT:

Checklist for Autism in Toddlers

CARS:

Childhood Autism Rating Scale

PIA:

Parent Interviews for Autism

GARS:

Gilliam Autism Rating Scale

BRIAC:

Behavior Rating Instrument for Autistic and other Atypical Children

DSM IV:

Diagnostic and Statistical Manual, edition IV (1994)

ADI-R:

Autism Diagnostic Interview – Revised

ADOS-G:

Autism Diagnostic Observation Schedule - Generic

A brief observation in a single setting cannot present a true picture of an individual's abilities and behaviors. At first glance, the person with autism may appear to have mental retardation, a behavior disorder or problems with hearing. It is important to distinguish autism from other conditions because an accurate

Diagnosis can provide the basis for building an appropriate and effective educational and treatment program.

What are the Symptoms?

What are people with autism like? Children with autism may appear relatively normal in their development until the age of 24 to 30 months, when parents notice delays in language, play or social interaction. Below is a list of some common characteristics, although no one individual will necessarily have all of them. The range of symptoms and degree of severity will be different in each person.

Communication Skills

- Language develops slowly or not at all
- Use of words without attaching the usual meaning to them
- Communicates with gestures instead of words
- Short attention span
- Echolalia (repeating words or phrases in place of normal language)
- Not responsive to verbal cues; acts as if deaf
- Difficulty in expressing needs; uses gestures or pointing instead of words

Social Interaction

- Spends time alone rather than with others
- Acts as if has little interest in making friends
- Less responsive to social cues such as eye contact or smiles
- Difficulty in mixing with other children
- Inappropriate laughing and giggling
- Little or no eye contact
- Seems to prefer to be alone; aloof manner
- May not want cuddling or act cuddly

Sensory Impairment

- Unusual reactions to physical sensations, such as being overly sensitive to touch or less than normally responsive to pain
- Sight, hearing, touch, smell and taste may be affected to lesser or greater degrees
- May exhibit self-stimulating behaviors, such as hand flapping or rocking
- May avoid cuddling or may seek it
- Apparent insensitivity to pain

Play

- Lack of spontaneous or imaginative play
- Does not imitate the actions of others
- Doesn't initiate pretend games
- Sustained odd play
- May spin objects inappropriately
- Inappropriate attachment to objects
- Noticeable physical over-activity or extreme under-activity

Behaviors

- May be overactive or very passive
- Throws frequent tantrums for no apparent reason
- May persevere on (repeatedly focus on or use) a single item, idea, person, phrase or word
- Apparent lack of common sense
- May show aggressive or violent behavior or injure self
- Insistence on sameness; resists changes in routine

- No real fear of dangers
- Unresponsive to normal teaching methods
- Uneven gross/fine motor skills (may not kick ball but can stack blocks)

There are great differences between individual people who have autism. Traits vary greatly from person to person. The degree of intensity of traits also can vary significantly from person to person. For example, someone who is mildly affected may exhibit only slight delays in language but have great challenges with social interactions. Another person may have average or above average verbal, memory or spatial skills but appear to lack imagination or have difficulty joining in a game of softball with others. More severely affected individuals may need greater assistance in handling day to day activities like crossing streets or making purchases. The supervision a person with autism needs will vary according to the intensity and combination of their traits. Supervision requirements will vary from close monitoring to independent living.

Contrary to popular belief, many children and adults with autism make eye contact, show affection, smile, and laugh and express a variety of emotions, although in varying degrees. Like other children, they respond to their environment in positive and negative ways. The autism seems to make it more difficult for them to control how their bodies and minds respond to situations and stimuli. They live normal life spans and their behaviors that are associated with autism may change over time. Some behaviors may become less problematic or even disappear over the years.

People with autism are more likely than non-autistic individuals to have other disorders that affect the functioning of the brain, such as epilepsy,

mental retardation or genetic disorders like Fragile X syndrome. About two-thirds of those diagnosed with autism will test in the range of mental retardation. (Many parents and some experts question the validity of such test scores, pointing out that children and adults with autism may not communicate well enough to assure accurate test results.) Approximately 25 to 30 percent may develop seizures at some time during their lives. There is no single seizure profile for individuals with autism.

2. Glossary of Terms

AAPEP – The abbreviation for the Adolescent and Adult Psychoeducational Profile. *See Adolescent and Adult Psychoeducational Profile.*

ABA – The abbreviation for Applied Behavior Analysis. *See Applied Behavior Analysis.*

ADA – The abbreviation for Americans with Disabilities Act. *See Americans with Disabilities Act.*

Adaptive Behavior – The ability to adjust to new situations and to apply familiar or new skills to those situations. For example, a two-year-old is displaying his ability to adapt when he says, “Mine!” to the child who is attempting to take his toy. A five-year-old shows adaptive behavior when he is able to use the same table manners he uses at home at a friend’s house.

ADI-R – Autism Diagnostic Interview-Revised, a tool for diagnosing autism.

Adolescent and Adult Psychoeducational Profile – An assessment tool designed for adolescents and adults with autism or other similar communicative disorders. Its purpose is to evaluate the person’s current and potential skills in areas that are important for functioning in the home, community and vocational setting.

ADOS-G – Autism Diagnostic Observation Schedule-General, a diagnostic tool for autism.

Advocate – An individual who represents or speaks out on behalf of another person’s interests (as in a parent on behalf of his or her child).

Americans with Disabilities Act (ADA) – Federal civil rights law protecting individuals with disabilities. Enacted in 1990.

Annual Goal – A statement of the desired outcome of early intervention services or education for a specific child and his family. For example, an annual goal might be for the child to develop mobility skills. Annual goals for early intervention are selected by the child’s parents and the child’s early intervention multidisciplinary team. They are stated on the *Individualized Family Service Plan*. Annual goals for education also are developed by a team that includes the child’s parents, and are

stated in the Individual Education Plan (IEP). Objectives may also be stated to provide developmentally appropriate activities and measurement of progress toward attainment of the goal. Objectives are more specific and measurable, such as, “(child’s name) will creep forward on his hands and knees for 10 feet” and “will walk forward with both hands held for 15 feet.”

Antibody – A protein produced by the body which combats antigens (such as those found in viruses, bacteria, and other microorganisms). Also known as immunoglobulin.

Applied Behavior Analysis (ABA) – Applied Behavior Analysis (ABA) is not a particular treatment or therapy. ABA is the name of a professional field that uses principles of learning to increase performance of socially desirable behaviors. It always relies upon the collection of objective data to measure performance and the effectiveness of an intervention. ABA is used in industry, business and education as well as in the field of disabilities. The term “ABA” is sometimes used to refer to a one-on-one therapy that is named discrete trial training. Some educational professionals as well as parents will use the term ABA when referring to discrete trial training. *See Discrete Trial Training.*

Arc – A national organization, formerly known as the Association for Retarded Citizens, which provides advocacy services to individuals with mental retardation and their families and publishes information about mental retardation. The Arc has local and state branches throughout the United States.

ASA – The abbreviation for Autism Society of America. *See Autism Society of America.*

Asperger’s Disorder – Condition found in the DSM-IV-TR manual under Pervasive Developmental Disorders. The essential features are severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests and activities. Additional criteria are listed in the DSM-IV-TR.

Assistive Technology – Special items or equipment used to increase, maintain or improve one’s functioning abilities. The term covers items such as computers, pencil holders, specialized switches and calculators.

Attention Deficit Hyperactivity Disorder (ADHD) – A group of symptoms believed to be caused by slight abnormalities in the brain. These symptoms include a developmentally inappropriate lack of ability to attend (such as difficulty with listening to and following directions), impulsivity, distractibility, clumsiness *and* hyperactivity. ADHD occurs in as many as three percent of children, with onset prior to four years of age in about 50 percent of cases.

Audiologist – A specialist who determines the presence and type of hearing impairment. An audiologist conducts hearing tests and makes recommendations for hearing aids.

Audiology – The study of hearing and hearing disorders.

Audiometric Testing – Tests to measure the ability to hear sounds of varying frequency (pitch) and intensity (loudness), thereby revealing any hearing impairment. Results are then recorded on an *audiogram*. Also known as audiometry.

Augmentative Communication – Any method of communicating without speech, such as by signs, gestures, picture boards, or electronic or non-electronic devices. These methods can help individuals who are unable to use speech or who need to supplement their speech to communicate effectively.

Autism – Autism is a developmental disability that typically appears during the first three years of life. The result of a neurological disorder that affects functioning of the brain, autism and its associated behaviors occur in approximately 1 in every 166 individuals. It is important to note that some children with mental retardation, fragile X syndrome, psychiatric disorders, sensory deficits such as vision or hearing impairments, and certain rare neurological diseases have autistic-like characteristics, but do not have autism. In older literature, autism may be called infantile autism or Kanner's syndrome. *See Pervasive Developmental Disorder.*

Autism Society of America (ASA) – National nonprofit organization that promotes lifelong access and opportunities for persons within the autism spectrum.

Autism Spectrum Disorder – A term encompassing the condition(s) known as pervasive developmental disorder(s). *See Pervasive Developmental Disorder.*

Behavior Intervention Plan – A written document that becomes part of the IEP and which identifies problem behaviors; sets goals for decreasing unwanted behaviors and increasing desired behaviors; and outlines interventions to use when specific behaviors occur. Sometimes called a behavior management plan.

Behavioral Assessment – Gathering (through direct observation and by parent report) and analyzing information about a child's behaviors. The information may be used to help the child change unwanted behaviors. Variables that are noted include when a behavior occurs as well as its frequency and duration. *See Functional Assessment of Behavior.*

CARS – Childhood Autism Rating Scale, a screening tool for autism.

Central Nervous System (CNS) – The structure that consists of the brain, the spinal cord and related systems that controls all aspects of learning, thinking and movement.

CHAT – Checklist for Autism in Toddlers, a screening tool for autism in young children.

CNS – *See Central Nervous System.*

Cognitive – Referring to the developmental area that involves thinking skills, including the ability to receive, process, analyze and understand information. Matching red circles and pushing the button on a mechanical toy to activate it are examples of cognitive skills.

Communication – The developmental area that involves skills which enable people to understand (receptive language) and share (expressive language) thoughts and feelings. Waving goodbye, using spontaneous single-word utterances and repeating five-word sentences are examples of communication skills.

Communication Aid – A nonverbal form of communication such as gesture, sign language, communication boards and electronic devices (for example, computers and voice synthesizers).

Communication Board/Book – A board or book with pictures or symbols that a child or adult can point to for expression of his or her needs.

Communication Disorder – Difficulty with understanding and/or expressing messages. Communication disorders include problems with articulation, voice disorders, stuttering, language disorders and some learning disabilities.

Department of Disabilities and Special Needs (DDSN) – This South Carolina agency provides services to people with autism; brain injuries; spinal cord injuries and similar disabilities; and mental retardation and related disabilities.

DDSN – The Department of Disabilities and Special Needs. *See above.*

Developmental Delay – The term used to describe the condition of an infant or young child who is not achieving new skills in the typical time frame and/or is exhibiting behaviors that are not appropriate for his or her age. Some children who are developmentally delayed eventually have a specific diagnosis of a particular developmental disability. Other children with delays catch up with their typically developing peers.

Developmental Disability (DD) – Any physical or mental condition (such as mental retardation, cerebral palsy, epilepsy, autism or a neurological disorder) that has the following characteristics: (1) begins before the age of 22 years, (2) causes the child to acquire skills at a slower rate than peers, (3) is expected to continue indefinitely and (4) impairs the child's ability to function normally in society.

(This description is based on the federal definition of developmental disability, which is used to determine who receives particular services through federal funds.)

Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) – The fourth edition of the reference manual published by the American Psychiatric Association, for which the text was revised in 2000. The DSM-IV-TR appears to be the most widely used manual of diagnostic criteria for autism spectrum disorders in the United States. Under the heading of Pervasive Developmental Disorders, the manual lists and describes Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism).

Diphtheria, Pertussis and Tetanus Vaccine (DPT) – An immunization against diphtheria, pertussis and tetanus that is usually given to infants and young children. Research suggests that consideration should be given as to whether or not the pertussis vaccine should be administered to some children, specifically

infants with a non-stable neurological disorder, such as seizures, or infants who have had a serious reaction to a prior DPT shot.

Discrete Trial – A method for teaching desired behaviors, skills or tasks. The skill being taught is “broken” down or sequenced into small, “discrete steps” that are taught in a highly structured and hierarchical manner. The therapist or caregiver systematically rewards or reinforces desired responses and ignores, redirects or discourages inappropriate responses. Data on all learning is recorded regularly and the therapist adjusts the teaching program as needed

Early Intervention – Individualized services for infants and toddlers who are at risk for or are showing signs of developmental delay.

Echolalia – The repetition of speech that is produced by others (a relatively common symptom of autism). Echoed words or phrases can include the same words and inflections as were originally heard or they may be somewhat modified. *Immediate echolalia* refers to words immediately repeated or repeated a brief time after they were heard. *Delayed echolalia* refers to the repetition of speech much later – even after days or years.

Epilepsy – Sometimes called a *seizure disorder*. Epilepsy is a condition characterized by recurrent seizures that are caused by abnormal electrical activity in the brain. Seizures can occur for many reasons, including damage to the brain due to infection, injury, birth trauma, tumor, stroke, drug intoxication and chemical imbalance. Epilepsy is usually treated with antiepileptic drugs. It is estimated that about one third of individuals with autism have seizures at some time during their lifetime. *Also see Seizure*.

Expressive Language – The ability to communicate thoughts and feelings by gesture, sign language, verbalization, or written word. *Compare to Receptive Language*.

Extended School Year – Special education and related services provided beyond the normal school year, in accordance with the child’s IEP and at no cost to the parents.

Extinction – Eliminating or decreasing a behavior by removing reinforcement from it.

Functional Analysis of Behavior – The process of systematically determining the function of behaviors, usually inappropriate, that are displayed by people. Behaviors are defined, measured and analyzed in terms of what happened

before and after their occurrence. Over time the events before and after the behavior occurs are systematically changed in order to determine the function of the behavior for the person displaying it.

Sometimes an inappropriate behavior can have a communicative function. A temper tantrum can sometimes be communicating “I am upset”, or “I am bored”. Sometimes a functional analysis of behavior is conducted for research purposes, but it can also be performed in order to develop behavior interventions and supports that address the display of challenging or inappropriate behavior. *See Functional Assessment of Behavior.*

Functional Assessment of Behavior – It is similar to the functional analysis of behavior, but it differs in that those events before and after the behavior are not systematically changed in order to prove the function of the behavior. Based on the information gathered a judgment is made about the possible communicative function of the behavior(s). Functional Assessments are usually performed in order to develop behavior interventions and supports that address challenging or inappropriate behaviors. *See Behavioral Assessment and Functional Analysis of Behavior.*

Generalization – The ability to take a skill learned in one setting, such as the classroom, and use it in another setting like the home or community.

Hand-Over-Hand Guidance – Physically guiding an individual through the movements involved in a fine motor task. Helping someone to grasp a spoon and bring it to his or her mouth is an example of hand-over-hand guidance.

Head Banging – A form of self-stimulation in which the child repetitively bangs head on the floor or another surface. *Refer to Self-Stimulation and Self-Injurious Behavior.*

Hyper- – A prefix meaning above, elevated or excessive. *Compare to Hypo-*.

Hyperactivity – Abnormally increased motor activity, resulting in difficulty with concentrating on one task or sitting still. Due to their overactivity and impulsivity, children who are hyperactive often have difficulty with learning, even if they score in the normal range on IQ tests. Hyperactivity can occur with attention deficit disorder, mental retardation, seizure disorder, sensory deficit disorders (such as hearing impairment) or other central nervous system damage. Also known as hyperkinetic.

Hypo- – Prefix for under, beneath, down or less than normal. Opposite of Hyper-.

IEP – The abbreviation for Individualized Education Program. *See Individualized Education Plan.*

IFSP – The abbreviation for Individualized Family Service Plan for children under three years of age. *See Individualized Family Service Plan.*

Inclusion – The general concept of including people with disabilities in all aspects of life, such as (but not limited to) education, community living, employment and recreation.

Individualized Education Plan (IEP) – A written statement of a child’s current level of development (abilities and impairments) and an individualized plan of instruction, including the goals, the specific services to be received, the people who will carry out the services, the standards and time lines for evaluating progress, and the amount and degree to which the child will participate with non-handicapped peers at school. The IEP is developed by the child’s parents and the professionals who evaluated the child. It is required by the Individuals with Disabilities Education Act (IDEA) for all children in special education, age’s three years and up.

Individualized Family Service Plan (IFSP) – A written plan describing the infant’s current level of development; the family’s strengths and needs related to enhancement of the infant’s or toddler’s development; goals for the infant and the other family members (as applicable), including the criteria, procedures and time lines used to evaluate progress (the IFSP should be evaluated and adjusted at least once a year and reviewed at least every six months); and the specific early intervention services needed to meet the goals (including the frequency and intensity and method of delivering services, the projected date of initiating services and the anticipated duration of services). The IFSP is developed and implemented by the child’s parents and a multidisciplinary early intervention team (for example, the case manager, infant educator, physical therapist, occupational therapist, or speech and language therapist). The name of the person responsible for implementation of the IFSP, the case manager, should be listed on the IFSP. If it is likely at age three that the child will require special education services, a transition plan should also be stated in the IFSP. The Individualized Family Service Plan is required by the Individuals with Disabilities Education Act (IDEA) for all infants receiving early intervention services. *Refer to Early Intervention.*

Individuals with Disabilities Education Act (IDEA) – A federal law passed in 1997 that reauthorizes and amends the Education for All Handicapped Children Act (Public Law 94-142). Part C of the law focuses on services to infants and toddlers who are at-risk or have developmental disabilities.

Least Restrictive Environment (LRE) – The educational setting that permits a child with disabilities to derive the most educational benefit while participating in a regular educational environment to the maximum extent appropriate. LRE is a requirement under the IDEA.

Local Education Agency (LEA) – The agency responsible for providing special educational services on the local (school district, city or county) level.

Mainstreaming – Placing a child with disabilities in the educational setting that is as close to normal as possible. Mainstreaming may allow the child with disabilities to be educated in a regular classroom, even though supplemental resource services may be needed and provided.

Medically Fragile – Referring to an infant or child whose health status either is unstable or renders him at risk for developmental delay, often due to poor health.

Mental Retardation – According to the American Association on Mental Retardation (1992), “Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work.” In other words, someone with mental retardation performs significantly below his age level in both intellectual functioning (intelligence) and adaptive behavior. Mental retardation is the most common developmental disorder, affecting about two to three percent of the total population.

MMR – The abbreviation for Measles, Mumps and Rubella Vaccine.

Motor Skill – The learned ability to perform movements, such as holding the body in an upright position to sit, using the hands to manipulate small items, scooping food onto a spoon and bringing the spoon to the mouth, and moving the lips and tongue to articulate different sounds.

Nonverbal Communication – Any form of or attempt at unspoken or “physical” communication. Examples are temper tantrums, gestures, pointing and leading another person to a desired object.

Occupational Therapy (OT) – Therapeutic treatment aimed at helping the injured, ill or disabled individual to develop and improve self-help skills and adaptive behavior and play. The occupational therapist also addresses the young child’s motor, sensory and postural development with the overall goals of preventing or minimizing the impact of impairment and developmental delay. The therapist also promotes the acquisition of new skills to increase the child or adult’s ability to function independently.

Parent-Professional Partnership – The teaming of parents and teachers, doctors, nurses, therapists and other professionals to work together to facilitate the development of children and adults with special needs.

PDD (Pervasive Developmental Disorder) – See *Pervasive Developmental Disorder*.

Perseveration – Redundant repetition of word(s) or action(s) without stopping or moving on.

Pervasive Developmental Disorder (PDD) – A diagnostic *category* in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR) that includes Autistic Disorder. The DSM uses the term Pervasive Developmental Disorder to refer to a “severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interests, and activities.” Sometimes doctors use the abbreviation PDD alone when diagnosing a child who has some, but not all, of the symptoms of autism.

Physical Therapy (PT) – Therapeutic treatment designed to prevent or alleviate movement dysfunction through a program tailored to the individual child. The goal of the program may be to develop muscle strength, range of motion, coordination or endurance; to alleviate pain; or to attain new motor skills. Therapeutic exercise may include passive exercise (in which the therapist moves and stretches the child’s muscles) or the child may actively participate in learning new ways to acquire and control positions and movement.

Prognosis – An estimate of the course and outcome of a disease or other condition, including the chances of recovery.

Prompt – Input that encourages an individual to perform a movement or activity. A prompt may be verbal, gestural or physical. An example of a prompt is tapping beneath one’s chin as a visual reminder to the child to close her mouth to prevent drooling. Also known as a cue.

Qualitative Developmental Assessment – An evaluation of the quality, rather than the quantity, of a child’s cognitive skills.

Receptive Language – The ability to understand what is being expressed, including verbal and nonverbal communication, such as sign language. *Compare to Expressive Language.*

Regression – Reverting to a more immature form of behavior or decreased skill level. For example, a child who resumes sucking her thumb after a substantial period (months or years) of no thumb-sucking. Regression is usually felt to be an unconscious protective mechanism.

Reinforcement – A behavior modification technique used to increase the likelihood of a desired response or behavior. Positive reinforcement is accomplished by immediately strengthening or rewarding a desirable behavior. The reward can be a social reinforcer, such as praise or a hug, or it can be material, such as a sticker or cookie. One form of negative reinforcement is to withdraw a privilege.

Resource Specialist – A teacher who provides special education instruction to children who are taught by regular classroom teachers for the majority of the school day. Sometimes called resource teachers.

Screening Test or Tool – An evaluation tool designed to identify children who are at-risk for having or developing a developmental disability. This is different from a diagnostic tool that is used to determine if a person has, or does not have, autism. *See ADI-R (diagnostic), ADOS-G (diagnostic), CARS (screening) and CHAT (screening).*

Seizure – Involuntary physical movement or changes in consciousness or behavior brought on by abnormal bursts of electrical activity in the brain. *See Epilepsy.*

Seizure Disorder – *Refer to Epilepsy.*

Self-Injurious Behavior (SIB) – Abnormal behaviors that are harmful to oneself, such as head-banging or scratching or biting oneself. *See Self-Stimulation.*

Self-Stimulation – Defined as abnormal behaviors that interfere with the individual's ability to pay attention or participate in meaningful activity, such as head banging, watching the fingers wiggle or rocking side to side. It is often referred to as "self-stimming" or "stimming." Unpurposeful play with a toy can be self-stimulating, such as repetitively spinning the wheels of a toy truck instead of exploring the different ways it can be used. In children, self-stimulation is most common when there is a diagnosis of mental retardation, autism or a psychosis.

Sensory Impairment – A problem with receiving information through one or more of the senses (sight, hearing, touch, etc.). For example, deafness is a sensory impairment.

Sensory Integration – The ability of the central nervous system to receive, processes, and learn from sensations in order to develop skills. The sensations include touch, movement, sight, sound, smell and the pull of gravity.

Sensory Stimulation – Any arousal of one or more of the senses. For example, a play activity that includes touching strips of shiny cellophane, listening to them crinkle, and watching while a bright light is shining on them against a contrasting background might be fun and stimulating for a child with visual impairment.

SIB – The abbreviation for self-injurious behavior. *See Self-Injurious Behavior.*

Spectrum Disorder – A disorder, such as autism, that appears with a wide range of characteristics and functioning. At one end of the spectrum of autism individuals tend to have many challenging behaviors. At the other end individuals generally have greater cognitive abilities and can communicate relatively well with spoken language.

Speech Therapy – Therapy to improve the individual's speech and language skills, as well as oral motor abilities.

Task Analysis – Process of breaking a skill down into smaller steps.

3. Suggested Reading Material

** Donated to each County Public Library*

*** Donated to each County Public Library branch*

General Interest

1001 Great Ideas for Teaching and Raising Children with Autism Spectrum Disorders*, E. Notbohm & V. Zysk

A Parent's Guide to Autism, Charles Hart

A Parent's Introduction to Behavior Modification, Jim Wilson

A Treasure Chest of Behavioral Strategies for Individuals with Autism *, Beth Fouse & Maria Wheeler

Asperger Syndrome and Difficult Moments, Brenda Smith Myles & Jack Southwick

Autism and Asperger Syndrome, Uta Frith

Autism-Asperger's & Sexuality, Jerry & Mary Newport

Autism Spectrum Disorders *, Mitzi Waltz

Autism Spectrum Disorders from A to Z *, Barbara Doyle & Emily Doyle Iland

Autism Treatment Guide, Elizabeth Gerlach

Behavioral Intervention for Young Children with Autism, Catherine Maurice

Biological Treatments for Autism and PDD, William Shaw

Children with Autism: A Parent's Guide **, Michael D. Powers

Circle of Friends, Robert Perske

Communication-Based Intervention for Problem Behavior: A User's Guide for Producing Positive Change, Edward G. Carr & others

Creating a "Win-Win IEP" for Children with Autism, Beth Fouse

Exiting Nirvana: A Daughter's Life with Autism, Clara Claiborne Park

Keys To Parenting the Child with Autism, M.T. Brill

Laughing and Loving with Autism, R. Wayne Gilpin

Laying Community Foundations for Your Child with a Disability *, Linda J. Stengle

Let Me Hear Your Voice: A Family's Triumph Over Autism, Catherine Maurice

Life Beyond the Classroom, Paul Wehman

Living with Autism: The Parents' Stories *, Kathleen Dillon

Parent Survival Manual, Eric Schopler

Positive Behavioral Support: Including People with Difficult Behavior in the Community, Lynn Kern Koegel & others

Preschool Issues in Autism, Eric Schopler

Sex Education for Parents of Children with Autism, Mark Steege & Shannon Peck

Siblings of Children with Autism: A Guide for Families, Sandra Harris

Social Stories: Teaching Social Skills, Carol Gray

Special Diets for Special Kids, Lisa Lewis

Taking Autism to School *, Andreanna Edwards

Teach Me Language: A Language Manual for Children with Autism, Asperger's Syndrome and Related Developmental Disorders, S. Freeman & S. Davis

Teaching Children with Autism, Robert L. & Lynn Kern Koegel

Teaching Children with Autism: Strategies to Enhance Communication and Socialization, Kathleen Ann Quill

Ten Things Every Child with Autism Wishes You Knew *, Ellen Notbohm

The Complete IEP Guide *, Lawrence M. Siegel

The Law and Special Education - 2nd Edition, Mitchell L. Yell

Thinking in Pictures, Temple Grandin

Toilet Training for Individuals with Autism & Related Disorders *, Maria Wheeler

Visual Strategies for Improving Communication: Practical Supports for School and Home, Linda A. Hodgdon

Wrightslaw: Special Education Law, Peter W.D. Wright & Pamela Darr Wright

You're Going to Love this Kid!, Paula Kluth

Books for Children

Andy and His Yellow Frisbee *, Mary Thompson

The Babysitters Club: Kristy and the Secret of Susan, Ann Martin

Captain Tommy, Abby Ward Messner

The Curious Incident of the Dog in the Night-Time, Mark Haddon

Ian's Walk, Laurie Lears & Karen Ritz

Joey and Sam, Illana Katz and Edward Ritvo

Oliver Onion: The Onion Who Learns to Accept and Be Himself, Diane Murrell

Tacos, Anyone? *, Marvie Ellis

The Legendary Blobshocker, Ryan Wilson (author has autism)

Russell is Extra Special: A Book about Autism for Children, Charles Amenta, III

Trevor, Trevor, Diane Twachtman-Cullen

**** Donated to each County Public Library***

***** Donated to each County Public Library branch***

Therapies and Treatments

The South Carolina Department of Disabilities and Special Needs and the South Carolina Autism Society do not endorse nor promote any particular treatment or therapy. Some of the therapies and treatments listed are not viewed as credible approaches by some medical and professional associations.

Anti-Yeast Therapy

Complete Candida Yeast Guidebook: Everything You need to Know about Prevention, Treatment, and Diet. Jeanne Marie Martin, With Zoltan P. Rona/Paperback/Prima Communications, Inc.

Candida Albicans: Could Yeast Be Your Problem? Leon Chaitow/ Paperback/ Inner Traditions International, Limited/ September 1998.

Recommended Web Sites:

<http://www.yeastconnection.com/informat.htm>

Applied Behavior Analysis

Behavioral Intervention for Young Children With Autism: A Manual for Parents and Professionals, By Catherine Maurice (Editor), et. al., Paperback

A Work In Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism. Ron Leaf & John McEachin, Editors. DRL Books.

Also refer to: **Discrete Trial Therapy** and **Lovaas**

Recommended Web Sites:

<http://www.rci.rutgers.edu/~rapsite/abalinks.html>

<http://www.wmich.edu/aba>

Aromatherapy

Flower Power: Flower Remedies for Healing Body and Soul Through Herbalism, Homeopathy, Aromatherapy, and Flower Essences. Anne McIntyre, Foreword by David Hoffman/paperback/Henry Holt & company, incorporated/ September 1996.

Aromatherapy: A Lifetime Guide To Healing with Essential Oils. Valerie Cooksley/Paperback/ Prentice Hall

Recommended Web Sites:

<http://home.freeuk.net/aromatherapist>

<http://www.gragrant.demon.co.uk/>

Auditory Integration

Assessment and Management of Central Auditory Processing Disorders in the Educational Setting: From Science to Practice. Teri James Bellis, John R. Burke/Paperback/Singular Publishing Group, Inc.

The Sound of a Miracle, by Annabel Stehli. Distributed by the Georgiana Foundation.

Recommended Web Sites:

<http://www.autism.com/ari> <http://www.vision3d.com/adhd/>

Craniosacral Therapy

Craniosacral Therapy, Vol. 1 John E. Upledger, Jon Vredevoogd/ hardcover/ Eastland Press/February 1993

An Introduction to Craniosacral Therapy: Anatomy, Function, and Treatment Don Cohen, Amie Forest (Illustrator), Jules Rodriguez (Illustrator), Foreword by John E. Upledger/ Paperback/ North Atlantic Books.

Recommended Web Sites:

<http://10ac.com/network/CranioSacral-text.htm>

<http://craniosacral.com/>

Dance Therapy

Stepping to the Dance: the Training of a Family Therapist, Carolyn Cressy Wells/ paperback/ international Thomson Publishing/ July 1997

Dance as a Healing Art: Returning to Health through Movement and Imagery, Anna Halprin/ Paperback/ LifeRhythm/ March 2000

Recommended Web Sites:

<http://www.healthfinder.gov/text/orgs/hr1806.htm>

<http://userpages.itis.com/hancock>

Dietary Intervention

The Yeast Connection Handbook: How Yeasts Can Make You Feel Sick All Over and the Steps You Need to Take to Regain Your Health, William G. Crook/ Paperback/ Professional books.

The Yeast connection Cookbook: A Guide to Good Nutrition and Better Health, William G Crook, Marjorie Hurt Jones/paperback.

Recommended Web Sites:

<http://www.autism.com/ari/>

<http://members.aol.com/autismndi/PAGES/index.htm>

Discrete Trial Training

Let me hear Your voice: A Family's triumph Over Autism, by Catherine Maurice, Random House, Inc.

A Work In Progress: Behavior Management Strategies and a Curriculum for Intensive Behavioral Treatment of Autism. Ron Leaf & John McEachin, Editors. DRL Books.

Also refer to: Applied Behavior Analysis and Lovaas Therapy

Recommended Web Sites:

<http://www.autism-society.org/packages/discrete-trial.html>

<http://www.wmich.edu/aba/Autismwebfile.htm>

Dolphin Therapy

Swimming with Dolphins: A Healing Experience. Lisa Tenzin-Dolma, Foreword by Robert Barnes/ Paperback/ Trans-Atlantic Publications, Inc.

Dolphins and Their Power to Heal, Amanda Cochrane, Karena Callen/ Paperback/ Inner Traditions International, Limited/ September 1992

Recommended Web Sites:

<http://www.eisa.net.au/~dolphins/>

Doman/Delacato Method

No Time for Jello: One Family's Experience with the Doman-Delacato Patterning Program, Berneen Bratt/Paperback/ Brookline Books Inc./ August 1991

The Neurologically-Impaired Child: Doman-Delacato Techniques Reappraised, Robert A. Cummins/ Library Binding/ Routledge, Chapman & Hall, incorporated/ January 1988.

Recommended Web Sites:

<http://www.aap.org/policy/155.html>

<http://www.autism-pdd.net/treaforme.html>

Facilitated Communication

A Passion to Believe: Autism and the Facilitated Communication Phenomenon, Diane Twachtman-Cullen, Diane C. Twachtman/ hardcover/Westview Press

Communication Unbound: How Facilitated Communication Is Challenging Traditional Views of Autism and Ability-Disability., Douglas P. Bilken, Peter Knoblock (Editor)/Paperback/Teachers College Press, Teachers College, Columbia University. September 1995.

Recommended Web Sites:

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

Inclusion

Inclusion: A Guide for Educators. Susan Bray Stainback/ Paperback/ Paul H. Brookes/ January 1996.

The Exceptional Child: Inclusion in Early Childhood Education, K. Eileen Allen, Ilene S. Schwartz/ Paperback/ Delmar Publishers/ January 1996

Recommended Web Sites:

http://www.suite101.com/links.cfm/disability_advocacy

http://www.dssc.org/nta/html/index_2.htm

Immune System Therapy

Immune Globulin: Proceedings of the Immune Globulin Workshop, Bethesda, MD., October 1982., S. //Karger#AG (Editor)/ Paperback/ S. Karger AG/ October 1985

Singh, V. K. "Plasma increase of interleukin-12 and interferon-gamma: Pathological significance in autism." **Journal of Neuroimmunology** vol. 66, 1996, PP 143-145.

Recommended Web Sites:

<http://library.tcu.edu/www/staff/lruede/latitudes>

<http://www.gti.net/truegrit>

Lovaas Therapy

Teaching Developmental Disabled Children: The ME book. Dr. O. Ivar Lovaas, pro-Ed 1981.

Also refer to: **Applied Behavior Analysis** and **Discrete Trial Therapy**

Recommended Web Sites:

<http://www.lovaas.com/>

<http://pages.prodigy.net/damianporcari/recovery.htm>

Medication

Psychiatric Drugs: Hazards to the Brain, Peter Roger Breggin/ Hardcover/ Springer Publishing Company, Inc./January 1983

Practical Drug Enforcement: Procedures and Administration, Michael D. Lyman/ hardcover/ CRC Press, LLC/ January 1989

Recommended Web Sites:

<http://www.autism-society.org/packages/medication.html>

<http://osiris.sunderland.ac.uk/autism/hci/parent/drug.htm>

Melatonin Therapy

Biological Rhythms, Mood Disorders, Light Therapy and the Pineal Gland, Mohammad Shafii (Editor), Sharon Lee Shafii (Editor)/ Hardcover/ American Psychiatric Press, Incorporated/ April 2000

Melatonin in Psychiatric and Neoplastic Disorders, Vol. 55, Sharon Lee Shafii, Mohammad Shafii (Editor)/ Hardcover/American Psychiatric Press, Incorporated/ January 1998

Recommended Web Sites:

<http://www.cidtech-research.com/Melatonin.html>

<http://www.autism.org/melatonin.html>

Music Therapy

Music therapy for the Autistic Child, Juliette Alvin, Auriel Warwick/ Paperback/ Oxford University Press, Incorporated/ April 1992

Music Lessons for Children with Special Needs, T. M. Perry/ Paperback/ Taylor & Francis, Inc./ July 1995

Recommended Web Sites:

<http://www.autism.org/music.html>

Neurofeedback

Introduction to Quantitative EEG and Neurofeedback, James R. Evans (Editor), Andrew Abarbanel (Editor)/ Hardcover/Academic Press, Incorporated/ June 1999

Mindfitness Training: Neurofeedback and the Process, Consciousness, Self-Renewal, and the Technology of Self-Knowledge, Adam Crane/ Paperback/ iUniverse.com, Inc./ June 2000

Recommended Web Sites:

<http://www.shsu.edu/~counsel/neurofeedback.htm>

<http://www.camalot.com/~hconnect/what.html>

Picture Exchange Communication System (PECS)

PECS – the Picture Exchange Communication System, Andrew S. Bondy, Lori Frost/ Hardcover/ Pyramid Educational Consultants, Incorporated/January 1996

Communication for the speechless (3rd. Ed.). Boston: Allyn & Bacon.

Recommended Web Sites:

<http://www.pecs.com/asaPEC3panel.html>

<http://www.pecs-uk.com/>

Secretin Therapy

Unlocking the Potential of Secretin, by Victoria Beck. What parents and physicians need to know about using Secretin in Autism, PDD, and related disorders.

Secretin Treatments for Autism **New England Journal of Medicine**, Dr. Adrian Sandler and Fred Volkmar. April 20, 2000. Vol. 346, No. 16

Recommended Web Sites:

<http://www.isn.net/~jypsy/viclett1.htm>

<http://www.autism.com/ari/editorials/march99.html>

Sensory Integration Therapy

Sensory Integration and the Child, Jean Ayres, Jeff Robbins/ Paperback/ Western Psychological Ser./January 1991

Sensory Integration: Theory and Practice, Anne G. Fisher (Editor), Anita C. Bundy (Editor), Elizabeth A> Murray (Editor), Foreword by Florence Clark/ hardcover/

Recommended Web Sites:

[Info@sensoryint.com email](mailto:Info@sensoryint.com)

<http://www.sinetwork.org/resources.htm>

Social Stories

The New Social Story Book, Carol Gray/Paperback/ Future Horizons, Incorporated/ June 1994

The Original Social Story Book, Erica Broek (Editor), Leslie Moore (Editor), Joanna Gray (Editor), Christopher Fleck (Editor), Carol Gray (Editor), Sarah Lynn Cain (Editor), Maureen Dutkiewicz (Editor), Barret Gray (Editor), Sue Jonker (Ed/Paperback/Future Horizons, Incorporated/ May 1993.

Recommended Web Sites:

<http://cbr.nc.us.mensa.org/homepages/mmdenincourt/ss.htm>

<http://www.futurehorizons-autism.com/buyoriginal.html>

Squeeze Machine

Emergence: Labeled Autistic, by Temple Grandin Arena Press, 1986
0446671827

Imamura KN, Wiess T, Parham D: **The effects of hug machine usage on behavioral organization of children with autism and autistic-like characteristics**. Sensory Integra Quarterly 27: 1-5, 1990.

Recommended Web Sites:

<http://www.grandin.com/inc/intro-squeeze.html>

<http://www.choice.net/marybast/squeezemachine.htm>

Tomatis Method

The Conscious Ear, by Alfred Tomatis, Station Hill Press.

The Ear and Language, By Alfred A. Tomatis

Recommended Web Sites:

<http://www.tomatis.com/autism.html>

<http://www.mozartcenter.com/overview.html>

Vision Therapy

The Power behind Your Eyes: Improving Your Eyesight with Integrated Vision Therapy, Robert Michael Kaplan/ Paperback/ Inner Traditions International, Limited/ June 1995

Optometric Management of Reading Dysfunction, John R. Griffin, John R. Griffin, Garth N. Christenson, Michael D. Wesson, Graham B. Erickson/ Paperback/Butterworth-Heinemann/November 1996

Recommended Web Sites:

http://www.eyenet.org/public/faqs/learn_dis/learn_dis_work.html

<http://www.visiontherapy.org/index.html>

Vitamin Therapy

Vitamin B6 (and Magnesium) in the treatment of autism, By Bernard Rimland, Ph.D. (Article available through the ARI)

Vitamin B6 in Autism: the safety issue, By Bernard Rimland, Ph.D. (article available through ARI)

Recommended Web Sites:

<http://www.autism.org/vitb6.html>

<http://www.autism.com/ari/>

4. Primary Resources

Autism Division of the South Carolina Department of Disabilities and Special Needs (DDSN)

A part of the South Carolina Department of Disabilities and Special Needs (DDSN), the Autism Division provides consultation, training and evaluation services for families of individuals with autism and the professionals who work with them. The Autism Division has an office in the DDSN agency building in Columbia.

SC Department of Disabilities and Special Need

Autism Division

3440 Hardin Street Ext.
P.O. Box 4706
Columbia, SC 29240
(803) 898-9609
(888) 376-4636 (toll free)

<http://www.state.sc.us/ddsn>

The Autism Division also has four regional offices located in different parts of the state to provide services locally. The addresses of those offices and the respective counties they serve are on the following page.

Coastal Autism Division

Fairfield Office Park
1064 Gardner Road, Suite 302
Charleston, SC 29407
(843) 852-4120
(843) 852-4175 (fax)

Counties Served

Allendale	Colleton
Bamberg	Dorchester
Barnwell	Hampton
Beaufort	Jasper
Berkeley	Orangeburg
Charleston	

Midlands Autism Division

8301 Farrow Road
Columbia, SC 29203-3294
(803) 935-5090
(803) 594-6172 (fax)

Counties Served

Aiken	Lancaster
Calhoun	Lexington
Chester	Newberry
Fairfield	Richland
Kershaw	York

Pee Dee Autism Division

P.O. Box 3209
Florence, SC 29502
(843) 664-2720
(843) 664-2735

Counties Served

Chesterfield	Horry
Clarendon	Lee
Darlington	Marion
Dillon	Marlboro
Florence	Sumter
Georgetown	Williamsburg

Piedmont Autism Division

269 S. Church Street, Ste 309
Spartanburg, SC 29306
(864) 594-4907
(864) 594-4923

Counties Served

Abbeville	McCormick
Anderson	Oconee
Cherokee	Pickens
Edgefield	Saluda
Greenville	Spartanburg
Greenwood	Union
Laurens	

The Autism Division also has three **Carolina Autism Resource and Evaluation (CARE) centers** for diagnosis and intervention.

Carolina Autism Resource and Evaluation (CARE) Centers

Midlands CARE Center

USC School of Medicine
Center for Disability Resources
Columbia, SC 29208
(803) 935-5390
(803) 935-5410 (fax)

Coastal CARE Center

Fairfield Office Park
1064 Gardner Road, Ste 301
Charleston, SC 29407
(843) 852-4172
(843) 852-4175

Piedmont CARE Center

Greenville Hospital System
Center for Developmental Services
29 North Academy Street
Greenville, SC 29601

South Carolina Autism Society

806 12th Street
West Columbia, SC 29169
(803) 750 6988
(800) 438-4790 (toll free)
(803) 750 8121 (fax)
e-mail: scas@scautism.org

website:

www.scautism.org

The South Carolina Autism Society (SCAS) is a chapter of the Autism Society of America. SCAS is a statewide organization whose mission is to enable all individuals with autism in South Carolina to reach their maximum potential. SCAS works to achieve this by providing information and referrals, regional support groups, educa-

tional opportunities and individual and system wide advocacy as well as service coordination to select counties. SCAS publishes a quarterly newsletter, *Update*.

It offers various educational/informational opportunities, including an annual conference. The society is the only statewide advocacy organization on issues involving autism in South Carolina.

SCAS programs include Autism and Informed Response training for emergency responders; the Parent-School Partnership to support families and schools in determining the most appropriate school placement for students with autism; and the organization's annual conference for families and professionals as well as service coordination to limited counties.

Other Resources

Autism Society of America

7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
(800) 3-AUTISM
(301) 657-0869 (fax)

Provides information and referrals to individuals, professionals, and people with autism and their families. Advocates for people with autism on the national level.

website:

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

Office of Programs for Exceptional Children, South Carolina State Department of Education

1429 Senate Street
Columbia, SC 29201
(803) 734-8806
(800) 763-KIDS

The State Department of Education, through school districts in each county, is responsible for ensuring that all children, ages three through 21 years, have available to them a free, appropriate public education that emphasizes special education and related services designed to meet the unique needs of the child. The Office of Programs for Exceptional Children ensures that children with disabilities have public education, that the rights of the children and their parents are protected, and that school districts receive assistance in providing for the education of all children.

Parents Reaching Out to Parents (PRO-Parents)

652 Bush River Road
Suite 218
Columbia, SC 29210
(803) 772-5688
(800) 759-4776 (toll free)
(803) 772-5341 (fax)

A nonprofit organization for and founded by parents of children with special needs. Provides information, trains parents, holds workshops and provides referrals to support groups and networks.

The Arc

1823 Gadsden Street
Columbia, SC 29201
(803) 748-5020
(803) 779-0017 (fax)
e-mail: TheArcSC@aol.com

Advocacy organization that provides information, training and support to people with mental retardation and their families.

South Carolina Protection and Advocacy Inc. (P&A)

3710 Landmark Drive, Suite 208
Columbia, SC 29204

(803) 782-0675 (Columbia)	(800) 800-6997 (Columbia toll free)
(843) 763-8571 (Charleston)	(800) 743-2553 (Charleston toll free)
(843) 662-0752 (Florence)	(800) 868-0752 (Florence toll free)
(864) 235-0273 (Greenville)	(800) 782-5212 (Greenville toll free)
(803) 790-1946 (fax)	(800) 922-5225 (V/TTY)

A private, nonprofit organization that provides a variety of protection and advocacy services for people with disabilities. Offers printed materials about advocacy for and legal rights of people with disabilities. Regional offices in Charleston, Columbia, Florence and Greenville.

Disability Action Center Inc.

1115 Belleview Street

Columbia, SC 29201

(803) 779-5121 (Columbia)

(803) 779-5114 (fax)

Provides counseling, independent-living skills training, peer support groups, referral services, community education, and individual and systems advocacy to people with disabilities. Offices in Columbia and Greenville.

Family Connection of South Carolina Inc.

2712 Middleburg Drive, Suite 103B

Columbia, SC 29204

(803) 252-0914 (Columbia)

(864) 455-6213 (Greenville)

(800) 578-8750 (toll free)

(803) 799-8017 (fax)

Family Connection is a nonprofit, statewide support network for families of children with developmental delay, disability or chronic illness. It fosters family to family support and communication between families and professionals through statewide conferences and support groups. Family Connection provides the following: one-to-one matches to parents by disability or chronic illness for emotional and informational support; specialized training to parents as support parents, family partners to families with children who qualify for early intervention; and publishes a quarterly newsletter.

5. Possibilities and Prognosis

Great strides have been made in our knowledge and understanding of autism since 1943, when the disorder was first described. Autism was first seen as an emotional and psychological disorder. Today most professionals believe it is a biologically based disorder of the brain.

Families and professionals are finding better ways to understand autism and help those who have the disorder to cope with its many symptoms. Some symptoms may lessen as the child ages; others may disappear altogether. With appropriate intervention, many autistic behaviors can be changed, perhaps to the point that to the untrained, the individual may appear to no longer have autism. However, most children and adults with autism will continue to exhibit some degree of symptoms throughout their lives.

Some children with autism maintain an age-appropriate educational level and attend general education classes, while others need specialized educational settings and supports.

It is difficult to predict the future when a child is young, but some individuals with autism learn to live and work independently in the community. Others depend on the support of family and professionals. Adults with autism can benefit from job skills training and social and recreational programs. They may live in a variety of residential settings. Options can include living independently at home, in apartments, or with other family members, as well as supported living arrangements in group homes, supervised apartment settings, and structured residential care.

6. Treatment Options

No single treatment approach can take away all the traits of autism for everyone, but many behaviors can be positively changed with appropriate intervention. Sometimes the resulting changes are so significant the person appears to no longer have autism. However, the majority of children and adults will continue to show some characteristics of the disorder to some degree throughout their lives.

While some students with autism attend regular school classes, most need training in vocational skills and community living skills at the earliest possible age. Learning to cross a street safely, shop and make change, or ask for assistance are critical skills that may be difficult even for individuals with average intelligence. Skills should be taught that would enhance the person's independence, give more opportunity for personal choice and allow more freedom in the community.

To be effective, any approach should be flexible in nature, rely on positive strategies, be re-evaluated on a regular basis, and provide a smooth transition from home to school to community environments. A good program will also incorporate training and support systems for caregivers as well. Rarely can a family, classroom teacher or other caregiver provide effective habilitation for a person with autism unless offered consultation or in-service training by a knowledgeable specialist.

A generation ago, most people with autism were eventually placed in institutions. Today, as a result of appropriate and individualized services and programs, even the more severely disabled can be taught skills that will allow them to develop to their fullest potential.

Effective Treatment Approaches

Several treatment approaches have consistently been demonstrated to benefit people with autism. These approaches are described below.

The South Carolina Department of Disabilities and Special Needs and the South Carolina Autism Society do not endorse nor promote any particular treatment or therapy.

For additional information about Treatment and Therapies for autism go the South Carolina Services Information System (SCSIS) website: www.scsis.org.

1. Behavior Technology (Applied Behavior Analysis)

Principles and techniques from the field of applied behavior analysis (ABA) are very effective in the treatment of people with autism. Behavior principles help family members and professionals to be clearer in how they teach and give directions to children and adults with autism. Behavior principles are also useful in helping people to respond productively to the unusual behaviors of some autistic individuals. Strategies based on ABA are particularly useful in evaluating inappropriate (and even bizarre) behaviors to understand what the person is communicating through the behaviors.

Refer to **Section 2. Glossary of Terms** to read the definition of Applied Behavior Analysis.

2. Discrete Trial Training

One form of ABA is discrete trial training. Discrete trial training is an intensive, one-on-one teaching session in which small parts of behaviors or skills are taught in short, repeated “trials.” As the skills are learned, new skills are added in a carefully planned sequence. There is evidence that Discrete Trial Training can be effective for some children with autism from birth through six years. The success of discrete trials depends upon the following: (1) individual child; (2) number of hours of therapy; and (3) the curriculum or content of the training sessions. Lovaas therapy is a widely known type of discrete trial training. Professor O. Ivar Lovaas of the University of California at Los Angeles published a landmark study of discrete trial training. He has developed a curriculum for preschool children using discrete trials. Not all discrete trial training is the same, nor is all of it the same as the Lovaas method.

Setting up a discrete trial training program that utilizes applied behavior analysis requires a professional trained in ABA.

3. Communication Training

Because one of the main areas affected by autism is the ability to communicate, treatment programs should include methods to increase communication skills. Depending on the individual's needs, speech therapy may focus on acquiring language skills or teaching sign language. Electronic devices or picture boards may be used to help the person communicate more effectively. Teaching programs based on behavioral principles can be written specifically for the person's individual communication needs. Communication therapy can include a combination of methods. To determine your child's communication needs, it is recommended that you have your child evaluated by a speech/language pathologist who is knowledgeable about autism.

4. Social Skills Training

Another major area associated with autism is a lack of social ability or the understanding of social cues. Individuals with autism may spend time alone instead of with others, show little apparent interest in making friends and be less responsive than others to social cues such as eye contact or facial expressions. Social skills programming may include techniques such as helping the individual to (1) learn to recognize facial expressions and other indicators of emotions (as expressed by others); (2) communicate in social situations; or (3) wait calmly in line at the grocery store. Social skills programs need to be based on behavior principles. As with other autism treatments, social skills programming will vary depending upon individual needs.

Other Helpful Approaches

Visual Supports

Visual supports are symbols or pictures that help to signal to the person with autism what to do (the appropriate behavior) or what not to do (the inappropriate behavior). They have been demonstrated to be helpful to many people who have autism. One of the most commonly used and effective types of visual supports is the visual schedule.

Social Stories

Social stories help people with autism to deal with specific situations that are difficult for them to handle. In simple terms, the written (and sometimes illustrated) story outlines the situation. The person may tend to have inappropriate behaviors in the situation or lack the skills needed to appropriately deal with the situation. The story goes on to describe what

the person should do. When written correctly and presented correctly, social stories have been shown to be very helpful to some people with autism.

Circle of Friends

A circle of friends is a group of peers who support the person with autism. The method was first used in school settings, where children were invited (but not pressured) to be in the “circle” for the student with autism. An adult facilitator explains autism to the group, at the children’s level of comprehension, providing information specific to the particular child. The facilitator encourages and guides the children as they express their concerns about the child and come up with solutions to difficulties he or she is having. When done for adults, the method may be called a Circle of Supports and usually addresses broader life issues.

Other Treatment Options

What follows is an overview of other treatment options available to individuals with autism. This is not an exhaustive list, and it is intended to provide a general overview of available options as opposed to specific treatment recommendations. Some of the therapies and treatments listed in this next section are not viewed as credible approaches by some medical and professional associations.

Auditory Integration Training

The technique of auditory integration training may help some individuals who are oversensitive (hypersensitive) to sounds. The individual listens to a variety of sound frequencies, coordinated to his or her level of impairment. Auditory training is performed by an audiologist trained in this method.

Diet/Vitamins

Some individuals with autism exhibit low tolerance for and/or allergies to a variety of substances, such as yeast and gluten. Although no rigorous scientific studies support the idea that dietary modifications reduce or eliminate symptoms of autism, some professionals and parents have reported positive changes in behavior following the modifications. Vitamin supplements have been reported by some parents to affect particular behaviors, such as increasing attention spans.

Facilitated Communication

Facilitated communication is a technique by which a trained professional, the "facilitator," supports the hand, arm or shoulder of the individual who has communication impairments. This method helps the individual to point to or press the keys of a communication device to spell out words.

Medications

There is no single medication to treat autism, but a wide variety of them have been prescribed to alleviate symptoms such as aggression, seizures, inattention, hyperactivity, anxiety or obsessive/compulsive behaviors. For information on the use of medications, consult a physician who has experience in treating the symptoms of autism.

Music

When used in a structured setting, music can be incorporated into the teaching of cognitive, motor and daily living skills. Effective for some individuals with autism, music therapy may be provided in a private setting or included in a child's school program.

Sensory Integration

Difficulty integrating sensory messages may not be an obvious problem for people with autism, but it appears to occur quite often. Some people have unusual sensory reactions, such as being overly sensitive to touch or less than normally responsive to pain. Sight, hearing, touch, smell and taste may be affected to a lesser or greater degree. Noises may sound too loud or too soft; colors may appear to be too bright or possibly even painful to see. Different treatments exist, depending upon the area that is affected.

One approach is sensory integration therapy, which is usually provided by an occupational therapist trained in the method.

Vision

Some individuals with autism experience vision difficulties, such as poor eye contact, difficulty with visual attending, visual fixation and hyper- or hypo-sensitivity to light and/or color. Developmental or behavioral optometrists may be able to treat them. They believe that some of the unusual behaviors associated with autism may be related to visual-perceptual problems. Treatments include specialized colored or prism lenses and vision exercises.

Other Treatments

The treatments mentioned above are not a comprehensive list of all options available to individuals with autism. There are a variety of others, including therapy using animals, treatments to reduce yeast in the body and cranial-sacral therapy.

Evaluating Treatments

To help parents or other caregivers as they consider possible treatments, Dr. B. J. Freeman developed the following list of guidelines.

Principles for Evaluating Treatment of Autism

1. Approach any new treatment with hopeful skepticism. Remember that the goal of any treatment should be to help the person with autism become a fully functioning member of society.
2. Beware of any program or technique that is touted as effective or desirable for every person with autism.
3. Beware of any program that thwarts individualization and potentially results in harmful program decisions.
4. Be aware that any treatment represents one of several options for a person with autism.
5. Be aware that treatment should always depend on individual assessment information that points to it as an appropriate choice for a particular child.
6. Be aware that no new treatment should be implemented until its proponents can specify assessment procedures necessary to determine whether it will be appropriate for an individual with autism.
7. Be aware that debate over use of various techniques are often reduced to superficial arguments over who is right, moral and ethical and who is a true advocate for the children. This can lead to results that are directly opposite to those intended.
8. Be aware that new treatments often have not been validated scientifically.

Questions to Ask Regarding Specific Treatments

1. Will the treatment result in harm to the child?
2. How will failure of the treatment affect my child and family?
3. Has the treatment been validated scientifically?
4. Do specified assessment procedures exist?
5. How will the treatment be integrated into the child's current program?

Try to avoid becoming so infatuated with a given treatment that functional curriculum, vocational life and social skills are ignored.

7. Transition

Transition refers to any significant change in a person's life. Some examples of common transitions include entering school for the first time, going to High School, starting a new job, and moving into a new home. People with autism experience many of the typical transitions of course, but they will also experience several unique and important transitions.

While significant transitions are difficult for most people, any change at all might be difficult for a person with autism. Some people with autism have a need to keep routines or follow set patterns of activities. Transitions that involve new places, new people and new expectations are hard for individuals with autism. The stress that results from these transitions can affect the whole family. However, there are certain strategies that have been shown to be effective in helping the family, as well as the child, be successful in passing through a transition.

Helpful Strategies for Transition

Write a Plan

Development and implementation of a simple written plan will facilitate successful transition experiences. Such a plan should include activities necessary to prepare your child for the transition. The plan should also identify someone to be responsible for each activity and a date for each one's completion. Following are some strategies that should be addressed in the plan.

1. Communicate With Your Child

Tell your child what is going to happen. Even if you think your child does not appear to be listening or to understand, it is still important to tell him in simple

terms about the upcoming transition. It is hard to know how much spoken language people with autism understand and it is not uncommon for them to understand more than we realize. Pictures and symbols are sometimes used to communicate with a person with autism. A therapist or a professional trained to work with people who have autism can assist the family in using pictures to communicate.

2. Visit the New Location(s)

Take your child to visit the new place or places before the “official” time to begin. More than one visit might be helpful. Before and during the visit describe in simple terms what is going to happen, the people who will be involved and the place where he will be attending the new activity. Plan on doing something your child likes to do after the visit, letting him know about it in advance. The use of pictures or symbols may be helpful.

3. Meet Key People

During the visit introduce your child to the key people who will be involved with him, such as the teacher, teacher’s aide, or the bus driver, just to mention a few. Even if your child shows no interest in the people or surroundings this is still an important activity. Remember that people with autism sometimes understand more than we realize. Keep the introductions brief, simple, and as cheerful as possible.

4. Use Visual Supports

“Visual supports” refer to a set of tools that have proven to be effective in helping people with autism in a variety of settings and situations. Visual

supports help guide a person to do appropriate behaviors, or control inappropriate behaviors, in specific places or situations. Examples of visual supports include pictures, diagrams, symbols, and color-coding. Regional Consultants with the SCDDSN Autism Division (refer to section 8, Services of SCDDSN Autism Division) can assist families and professionals in developing appropriate visual supports.

Know Your Rights as a Parent

There are key laws in place for families with a child who has a disability. These laws include the Individuals with Disabilities Education Act (IDEA); Section 504 of the Rehabilitation Act of 1973; the Family Educational Rights and Privacy Act (FERPA), and the Americans with Disabilities Act (ADA). Various agencies, organizations and advocacy groups can provide guidance and information about these laws. For example, families may contact their local school district, state agencies, Protection and Advocacy for People with Disabilities (P&A) and PRO-Parents.

If a child with autism is receiving services then a plan needs to be in place to guide professional treatment. For the preschool child the plan is called the Individual Family Service Plan (IFSP); for the school age child it is called the Individual Educational Program (IEP). Professionals who provide services should hold a meeting to write the plan and parents should be included in these meetings. Transition plans should be incorporated as appropriate into IFSPs and IEPs.

Protection and Advocacy for People with Disabilities and PRO-Parents can assist families in understanding their rights and in preparing for these

meetings. Representatives from either organization can attend these meeting with parents to help them understand all the issues and assist in writing the most appropriate plan for their child. *Refer to **Section 4, Primary Resources**, for contact information.*

8. Services provided by the Autism Division

One of the agencies in South Carolina responsible for providing services for people with autism is the Autism Division of the Department of Disabilities and Special Needs (SCDDSN). The Autism Division provides evaluation services, consultation, and training for families, professionals, and volunteers. The Regional Consultant is the primary service delivery professional for the Autism Division. Regional Consultants can provide assistance to families, classroom teachers, early interventionists, staff of the local Disability and Special Needs Boards and other professionals in several ways. They can assist in developing the Individualized Educational Program (IEP) for school services and an Individual Plan of Support (IPOS) for DDSN services. Consultants can also provide technical support in the design of specific teaching plans and training to help families or professionals implement those plans.

Each Regional Consultant serves a group of counties. To determine your Autism Division Regional Consultant refer to **Primary Resources, Section 4** of this packet, and contact the Autism Division office that is responsible for the county in which you reside.

Training is provided by the Autism Division

Please contact your local board for a listing of what trainings are available in your area. This list can also be seen at:

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



South Carolina Autism Society

Together We Can Solve the Puzzle

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