



An Autism Primer

Compiled by The Family Alliance to Stop Abuse and Neglect

An Autism Primer

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What is autism?

Autism is a developmental disability that typically affects how a person processes, integrates, and organizes information. The condition significantly impacts communication abilities, social interaction, functional skills, and educational performance. Essential features (generally appearing during the first three years of life) may include—

- Inconsistencies or discrepancies in the development of physical, language, social, or cognitive skills
- Unusual responses to sensory information
- Impaired verbal/nonverbal language or social communication
- Impaired ability to relate to people or the environment²

The Autism Spectrum

The term Autism Spectrum is used because people with autism display such a wide variety and severity of symptoms. Some are so seriously impaired that they cannot interact with the outside world – Kanner’s syndrome. Others look so “normal” that some people don’t recognize that the person has a developmental disability – Asperger’s Syndrome. Some people with autism have savant capabilities – like “Rainman” of the movies. People with autism have the same range of cognitive abilities (intelligence) as the general population. Some are geniuses, some are average, and some are significantly below the norm.

“People with autism are people first, disabled second. They should be entitled to the same rights under the law as every other person.”

Victoria Horrocks

Core Issues

Communication

The communication problems of autism vary, depending upon the intellectual and social development of the individual. Some people with autism may be unable to speak, whereas others may have rich vocabularies and be able to talk about topics of interest in great depth. Despite this variation, the majority of individuals with autism have little or no problem with pronunciation. Most have difficulty effectively using language. Many also have problems with word and sentence meaning, intonation, and rhythm.

Those who can speak sometimes say things that lack content or information. For example, an autistic individual may repeatedly count from one to five. Others use echolalia, a repetition of something they previously heard. One form, immediate echolalia, may occur when the individual repeats the question, “Do you want something to drink?” instead of replying with a “yes” or “no.” In another form called delayed echolalia, an individual may say, “Do you want something to drink?” whenever he or she is asking for a drink.

Others may use stock phrases such as, “My name is Tom,” to start a conversation, even when speaking with friends or family. Still others

may repeat learned scripts, such as from television commercials. Some individuals with higher intelligence may be able to speak in depth about topics that interest them, such as dinosaurs or railroads, but be unable to engage in an interactive conversation on those topics.

Many individuals with autism do not make eye contact and have a poor attention span. They may be unable to use gestures either as a primary means of communication, as in sign language, or to assist verbal communication, such as pointing to an object they want. Some individuals with autism speak in a high-pitched voice or use robot-like speech. They are sometimes unresponsive to the speech of others and may not respond to their own names. As a result, some are mistakenly thought to have a hearing problem. The correct use of pronouns is also a problem for some people with autism. For example, if asked, “Are you wearing a red shirt today?” the individual may respond with, “You are wearing a red shirt today,” instead of “Yes, I am wearing a red shirt today.”

For many, speech and language develop, to some degree, but not to a normal ability level. This development can be uneven. For example, they may quickly develop an extensive vocabulary in their specific areas of interest. Many have good memories for information just heard or seen. Some may be able to read words well before the age of five but may not understand the meaning of what they have read. Others have musical talents or advanced ability to count and perform mathematical calculations. Approximately 10 percent show “savant” skills or detailed abilities in specific areas such as calendar calculation, musical ability, or math.³

Sensory Processing

Children and adults with autism, as well as those with other developmental disabilities, may have a dysfunctional sensory system. Sometimes one or more senses are either over-reactive or under-reactive to stimulation. Such sensory problems may be the underlying reason for behaviors like rocking, spinning, and hand-flapping. Although the receptors for the senses are located in the peripheral nervous system (which includes everything but the brain and spinal cord), it is believed that the problem stems from neurological dysfunction in the central nervous system—the brain. Sensory integration techniques, such as pressure-touch, can facilitate attention and awareness and reduce overall arousal. Temple Grandin, in her descriptive book, Emergence: Labeled Autistic, relates the distress and relief of her sensory experiences.

Sensory integration is an innate neurobiological process and refers to the integration and interpretation of sensory stimulation from the environment by the brain. In contrast, sensory integrative dysfunction is a disorder in which sensory input is not integrated or organized appropriately in the brain and may produce varying degrees of problems in development, information processing, and behavior. A general theory of sensory integration and treatment has been developed by Dr. A. Jean Ayres from studies in the neurosciences and those pertaining to physical development

“Hey, that autistic kid is my son. He is a great kid! He has a great sense of humor. He loves to listen to CD’s in his room at night. He’ll tell me to leave his room and go to the kitchen and then he proceeds to close his bedroom door and raise the volume! He draws very well and one of his pictures won the grand prize in an art contest and was designated as ‘Poster of the Year’! Oh yes, his jumping up and down does seem a bit unusual. Well, he has a disability called autism and he jumps when he’s happy or excited. That’s how I view my son. He’s a kid! He’s a person, too!”

*Debra Fernandez, Director,
Parent Training & Information
Center, SPAN*

and neuromuscular function.

Sensory integration focuses primarily on three basic senses—tactile, vestibular, and proprioceptive. Their interconnections start forming before birth and continue to develop as the person matures and interacts with his/her environment. The three senses are not only interconnected, but are also connected with other systems in the brain. Although these three sensory systems are less familiar than vision and hearing, they are critical to our basic survival. The inter-relationship among these three senses is complex. Basically, they allow us to experience, interpret, and respond to different stimuli in our environment.

The tactile system includes nerves under the skin's surface that send information to the brain. This information includes light touch, pain, temperature, and pressure. These play an important role in perceiving the environment as well as protective reactions for survival.

Dysfunction in the tactile system can be seen in withdrawing when being touched, refusing to eat foods with a certain texture and/or refusing to wear certain types of clothing, complaining about having one's hair or face washed, avoiding getting one's hands dirty (i.e., glue, sand, mud, finger-paint), and using one's finger tips rather than whole hands to manipulate objects. A dysfunctional tactile system may lead to a misperception of touch and/or pain (hyper-sensitive or hypo-sensitive) and may lead to self-imposed isolation, general irritability, distractibility, and hyperactivity.



Tactile defensiveness is a condition in which an individual is extremely sensitive to light touch. Theoretically, when the tactile system is immature and working improperly, abnormal neural signals are sent to the cortex of the brain, which can interfere with other brain processes. This, in turn, causes the brain to be overly stimulated and may lead to excessive brain activity, which can neither be turned off nor organized. This type of over-stimulation in the brain can make it difficult for an individual to organize his or her behavior and concentrate and may lead to a negative emotional response to touch sensations.

The vestibular system refers to structures within the inner ear (the semi-circular canals) that detect movement and changes in the position of the head. For example, the vestibular system tells you when your head is upright or tilted (even with your eyes closed). Dysfunction within this system may manifest itself in two different ways. Some children may be hypersensitive to vestibular stimulation and have fearful reactions to ordinary movement activities (e.g., swings, slides, ramps, inclines). They may also have trouble learning to climb or descend stairs or hills; and they may be apprehensive walking or crawling on uneven or unstable surfaces. As a result, they seem fearful in space. In general, these children appear clumsy. On the other extreme, the child may actively seek very intense sensory experiences such as excessive body whirling, jumping, and/or spinning. This type of child demonstrates signs of a hypo-reactive vestibular system; that is, they are trying continuously to stimulate their vestibular systems.

The proprioceptive system refers to components of muscles, joints, and tendons that provide a person with a subconscious awareness of body position. When proprioception is functioning efficiently, an individual's body position is automatically adjusted in different situations; for example, the proprioceptive system is responsible for providing the body with the necessary signals to allow us to sit properly in a chair and to step off a curb smoothly. It also allows us to manipulate objects using fine motor movements, such as writing with a pencil, using a spoon to drink soup, and buttoning a shirt. Some common signs of proprioceptive dysfunction are clumsiness, a tendency to fall, a lack of awareness of body position in space, odd body posturing, minimal crawling when young, difficulty manipulating small objects (buttons, snaps), eating in a sloppy manner, and resistance to new motor movement activities.

Another dimension of proprioception is praxis or motor planning. This is the ability to plan and execute different motor tasks. In order for this system to work properly, it must rely on obtaining accurate information from the sensory systems and then organizing and interpreting this information efficiently and effectively. (See "Motor Planning & Sequencing Issues," below.)

In general, dysfunction within these three systems manifests itself in many ways. A child may be over-responsive or under-responsive to sensory input; activity level may be either unusually high or unusually low; a child may be in constant motion or fatigue easily. In addition, some children may fluctuate between these extremes. Gross and/or fine motor coordination problems are also common when these three systems are dysfunctional and may result in speech/language delays and in academic under-achievement. Behaviorally, the child may become impulsive, easily distractible, and show a general lack of planning. Some children may also have difficulty adjusting to new situations and may react with frustration, aggression, or withdrawal.

Evaluation and treatment of basic sensory integrative processes is performed by occupational therapists and/or physical therapists. The therapist's general goals are—

- To provide the child with sensory information which helps organize the central nervous system
- To assist the child in inhibiting and/or modulating sensory information,
- To assist the child in processing a more organized response to sensory stimuli⁴

Motor Planning & Sequencing Issues (Dyspraxia)

Praxis is the ability to plan and sequence unfamiliar actions. It evolves from the interaction between the child and the environment and reflects the quality of sensory integration.



Praxis consists of three different components—

- Ideation
- Motor planning
- Execution

Ideation is the ability to formulate a goal for action. It is the cognitive step of recognizing the multiple ways that toys, objects, or one's body can be used in play and learning situations. For example, the child appreciates that there are a number of ways to play with a toy truck. Motor planning involves figuring out how to get one's body to carry out the goal for action. This step of planning and sequencing of motor tasks is based on the child's body scheme; that is, an internal sensory awareness of body parts, how they fit together, and how they move through space. Motor planning is active problem solving and reflects an inner, sensory awareness of one's physical self. Execution is the actual performance of the planned action. It involves gross and fine motor coordination to accomplish the task. Children with dyspraxia may have difficulty with any one or a combination of these three components. A lack of ideation is noted if the child is unable to formulate new goals specific to situational demands. The child does not have an idea of what to do or is rigid or inflexible in goal formulation. With a deficit in motor planning, the child knows the purpose of the object or task but cannot organize motor patterns to interact effectively with the environment or solve the problem. Children may tend to be inactive or play in a limited, perseverative pattern (e.g., lining up toys). Children with autistic spectrum disorders tend to have a primary deficit in ideation and a secondary one in motor planning. Impairment in execution is relatively less common in children with autism.

"We should be careful not to assume that having language equates with having speech capability, or that the better or more one can speak the more language and/or intelligence one has. We need to understand that individuals with severe motor planning difficulties and severe apraxia may have great difficulty speaking (or be unable to speak at all) yet when introduced to appropriate assistive and augmentative communication methods and devices can make excellent use of their language capacities. (I know a number of young people with autism who are unable to speak a word, but are now doing very well in college.) As the Center for Human Policy says on their t-shirts, 'Just because I can't speak doesn't mean I have nothing to say!'"

Pat Amos

Children with dyspraxia are typically clumsy with a poor body scheme. They do not know where their body is in space and have difficulty judging their relationship to objects and people. As a result, they are accident-prone and tend to stumble, bump into furniture or others, and break toys. They are generally poor in athletics. Since these children have difficulty in sequencing daily activities, they tend to be disorganized and disheveled looking. Due to their inflexibility in activity, they may perseverate and tend to prefer the familiar. Self-esteem is often poor as a result of frustration and repeated failure. They may be judged at times as manipulative and controlling. These behaviors reflect the child's use of language to compensate for the dyspraxia (e.g., distracting and redirecting attention away from the motor disorder). Problems in sequencing can include language, in which case organizational and educational deficits are generally present.

Dyspraxia Indicators—

- Inflexibility—perseverates on one aspect of the task and has difficulty in making transitions
- Lack of sensorimotor exploration
- Limited complexity of play
- Restricted problem solving of new tasks

- Low frustration tolerance
- Presence of “crash” solutions to terminate demanding activities (e.g., knocking down or throwing)
- Lack of organization in performance of activities
- Clothes in disarray and/or unfastened
- Poor quality of fine motor skills
- Poor temporal awareness and sequencing of daily living tasks
- Avoidance of group activities and peer play
- Preference for adult one-to-one interaction⁵

How can I tell if my child has autism?

If you sense that your child just isn't like other children and may have a developmental disorder, take action immediately. Don't let friends, family, or medical professionals influence you in to believing that your child might "grow out of it." Maybe your concerns are unfounded; but, if not, your child deserves to have the advantages of a good diagnosis and treatment program that starts as soon as possible.

Warning Signs

According to the National Institute of Child Health and Human Development's Autism Facts, you should be concerned if your child—

- Does not babble or coo by 12 months of age
- Does not gesture (point, wave, grasp, etc.) by 12 months of age
- Does not say single words by 16 months of age
- Does not say two-word phrases on his or her own (rather than just repeating what someone says) by 24 months of age
- Has any loss of any language or social skill at any age



Other signs of autism—

- Does not respond to his/her name
- Cannot explain what he/she wants
- Language skills or speech are delayed
- Doesn't follow directions
- At times, seems to be deaf
- Seems to hear sometimes, but not others
- Doesn't point or wave bye-bye
- Previously said a few words or babbled, but now he/she doesn't.
- Throws intense or violent tantrums
- Has odd movement patterns
- Hyperactive, uncooperative, or oppositional
- Doesn't know how to play with toys
- Doesn't smile when smiled at
- Poor eye contact
- Gets "stuck" on things over and over and can't move on to other things
- Seems to prefer to play alone
- Gets things for him/herself only
- Is very independent for his/her age
- Does things "early" compared to other children
- Seems to be in his/her "own world"

- Seems to tune people out
- Not interested in other children
- Walks on his/her toes
- Shows unusual attachments to toys, objects, or schedules (i.e., always holding a string or having to put socks on before pants)
- Spends a lot of time lining things up or putting things in a certain order⁶

Behavior

Certain traits and behaviors are sometimes seen in people with autism—

- Aggressive or self-injurious behavior
- Noticeable extreme underactivity or overactivity
- Uneven gross and/or fine motor skills (well developed in some areas, poorly developed in others)
- Difficulty expressing needs and wants, verbally and/or nonverbally
- Repeating words or phrases back rather than responding appropriately to conversation (known as echolalia)
- Showing pleasure (laughing) or distress (crying) for reasons not apparent to others
- Insisting on sameness, resisting change
- Remaining aloof, preferring to be alone
- Not responding to verbal cues (acting as if deaf)
- Difficulty interacting with other people
- Throwing tantrums
- Avoiding eye contact
- Not wanting to cuddle or have physical contact
- Not responding to normal teaching methods
- Playing in odd or unusual ways
- Having inappropriate attachments to objects
- Spinning objects
- Expressing oversensitivity or undersensitivity to pain or heat/cold
- Having no apparent fear of dangerous situations

What To Do

Contact professionals who will identify core issues, provide a diagnosis, and recommend a treatment program. Consult—

- A Developmental Pediatrician – Evaluates the child and provides a diagnosis. Treats health problems of children with developmental delays or handicaps.
- An Occupational Therapist – Evaluates the child’s physical and sensory issues and provides therapy for sensory integration, coordination of movement, and fine motor skills.
- A Speech/language Pathologist – Helps improve communication skills, including speech/language, social skills, and many other issues relating to interacting with other people.
- An Audiologist – Identifies hearing/auditory processing issues and recommends options.

These professionals can also help—

- A Child Psychiatrist – A medical doctor who may be involved in the initial diagnosis; can prescribe medication and provide help in behavior, emotional adjustment, and social relationships.
- A Clinical Psychologist – Specializes in understanding the nature and impact of developmental disabilities including Autism Spectrum Disorders. May perform psychological and assessment tests and may help with behavior and social skills.
- A Physical Therapist – Helps to improve the use of bones, muscles, joints, and nerves to develop muscle strength, coordination and motor skills.
- A Social Worker – May provide counseling services or act as case manager helping to arrange services.



After a diagnosis, you should find—

- An Advocate – Will help you understand the IEP (Individual Education Plan) process, explain your child’s rights in the complicated educational system, and help you get the services your child is entitled to receive.
- Family and friends to support you in the task ahead of you. You’ll need help with childcare, frustration, fatigue, finances, transportation, advocacy, and many other issues that can stand in the way of your child’s successful development and can threaten your own sanity.

What treatments are available?

Speech/Language Therapy and Occupational/Sensory Integration Therapy are the “core treatments” that will address your child’s “core issues.” You might decide to try other therapies based on information from your medical professionals, publications you may read, friends and family, other parents of children with autism, the Internet, or even TV shows. If you decide to try a new therapy, follow the advice in the “Evaluating Treatment Options for Autism” section of this booklet.

Speech/Language Therapy

Speech and language pathologists work to assess, diagnose, and develop a program of care to maximize the communication potential of the people under their care. When working with people who have an Autism Spectrum Disorder, a speech and language pathologist will adapt the therapy given according to the presenting problem. It is likely that the therapist will work on one of the following when giving therapy to a person with an Autism Spectrum Disorder—

- Listening and Attention Skills
- Play Skills
- Social Skills
- Social understanding
- Understanding of language
- Expressive Language

This list may seem far removed from actually “teaching a child to speak;” however, children develop and learn to use speech appropriately through skills such as play and listening/paying attention to other peoples’ use of communication.

It is also important to remember that a child who does not communicate *at all* is unlikely to speak. Therefore, any therapy offered by a speech/language therapist is initially likely to focus on getting the child to communicate using something other than spoken words, such as a signing system, symbol system, or picture system, rather than focusing on speech alone.⁷

Sensory Integration Therapy

The senses work together. Each sense works with the others to form a composite picture of who we are physically, where we are, and what is going on around us. Sensory integration is the critical function of the brain that is responsible for producing this composite picture. It is the organization of sensory information for ongoing use.

Sensory experiences include touch, movement, body awareness, sight, sound, and the pull of gravity. The process of the brain organizing and interpreting this information is called sensory integration. Sensory



integration provides a crucial foundation for later, more complex learning and behavior.

For most children, sensory integration develops in the course of ordinary childhood activities. Motor planning ability is a natural outcome of the process, as is the ability to adapt to incoming sensations. But for some children, sensory integration does not develop as efficiently as it should. When the process is disordered, a number of problems in learning, development, or behavior may become evident.

Some children, although bright, have difficulty using a pencil, playing with toys, or doing self-care tasks, like dressing. Some children are so fearful of movement that ordinary swings, slides, or jungle gyms generate fear and insecurity. Some children's problems lie at the opposite extreme—they are uninhibited and overly active, often falling and running headlong into dangerous situations. In each of these cases, a sensory integrative problem may be an underlying factor. Its far-reaching effects can interfere with academic learning, social skills, even self-esteem.

Research clearly identifies sensory integrative problems in children with developmental or learning difficulties. Independent studies show that a sensory integrative dysfunction can be found in up to 70% of children who are considered learning disabled by schools.

Severe difficulty with sensory processing is a hallmark of autism. Children with autism seek out unusual quantities of certain types of sensations and are extremely oversensitive to other types. Improving sensory processing leads these children to more productive contacts with people and environments.

In Sensory Integration Therapy, the child is guided through activities that challenge his or her ability to respond appropriately to sensory input by making a successful, organized response. Training of specific skills (shoe tying, dressing, using the toilet) is not usually the focus of this kind of therapy. One important aspect of therapy that uses a sensory integrative approach is that the motivation of the child plays a crucial role in the selection of the activities. Most children tend to seek out activities that provide sensory experiences most beneficial to them at that point in development. It is this active involvement and exploration that enables the child to become a more mature, efficient organizer of sensory information.⁸

Auditory Integration Training (AIT)

Auditory Integration Training is intended to decrease hypersensitivity to certain frequencies and attempts to reduce problems with auditory processing which some people with autism experience. AIT is administered with a device that filters some sound frequencies from recorded music, which the trainee listens to via headphones. The training involves listening to individually prepared music with earphones for a total of ten hours (1/2 an hour, twice a day for 10 days). The design of

each child's training is based on the results of an audiogram.

Dr. Guy Berard is the developer of the Berard Method of AIT, and Bill Clark is the developer of the BGC method of AIT. The music is, in all cases, modulated throughout the 10 hours of listening. The Berard method of AIT has relieved thousands of sufferers from dyslexia, hyperactivity and other conditions, including suicidal depression.

The Tomatis Method is a kind of AIT developed by Alfred Tomatis. Over several weeks, the person listens to classical music with the low frequencies filtered out. Over time, voices (also filtered) are introduced, then the missing frequencies. Treatment requires weeks, (three weeks on – off for approximately three months – back again for three weeks) typically two hours of listening a day.⁹

Floortime

Floortime is the centerpiece of the “Developmental, Individual-Difference, Relationship-Based” (DIR) Model. The DIR/Floortime approach involves meeting children at their current developmental level and building upon their particular set of strengths to help them develop. The approach suggests following the children's lead: tuning in to their interests and desires in interactions and play to harness the power of their motivation and help them climb the developmental ladder. It also involves tailoring these interactions to the child's individual differences in sensory reactivity, processing, and motor planning.

An important part of this program is engaging in developmentally appropriate interactions at every opportunity. Floortime literally involves getting down on the floor to play with the child.

By following children's interests, joining what they are doing, and wooing them with warm but persistent attempts to engage their attention, the parent or therapist can lead them to climb the developmental ladder. Through playful, engaging interactions, parents or therapists can help them want to learn to pay attention, want to engage in some sort of dialogue, and want to initiate communication, even before they speak in any meaningful conversation.

By entering into the children's worlds, parents and therapists can help the children learn to relate in a meaningful, spontaneous, flexible, and warm way. This does not happen overnight; adopting this approach involves the parents' commitment to spending a considerable period of time on the floor, playing with their children and becoming a part of their worlds, even if their activities are limited. It involves responding to their every utterances or gestures in an effort to spark responses—the beginning of two-way communication.

DIR/Floortime is very different from earlier interventions that did not address underlying problems or the full range of skills that children need to acquire. Key to the DIR/Floortime methodology is an approach that focuses on the individual children's unique characteristics, including how

they process information, their developmental level, and their dynamic interactions with caregivers. The DIR/Floortime methodology has demonstrated its capability to enhance the quality of life of almost every child. While all children have different potential, every child can become more engaged and connected and can advance up the developmental ladder.

The DIR/Floortime model affirms that—

- Relationships and affect are at the core of learning.
- Every child is different and must be treated and nurtured differently.
- Every child can advance and grow.
- Parents and guardians must play an active and vital role in their child's process of development and discovery.
- Parents and families, childcare providers, clinicians, and educators must all be involved in a multi-faceted treatment approach.



Studies have demonstrated that the DIR/Floortime methodology has the capacity to have a dramatic impact in the lives of children with severe communication and developmental disorders. In one recent chart review of 200 children with some of the most complex and challenging developmental disorders, over 50% of children originally diagnosed with autistic spectrum disorders who were treated intensively with DIR/Floortime approaches for four to six years have become warm, engaging and loving. These children have become active learners with highly developed verbal skills, creative imaginations, logical and abstract thinking, and pleasurable peer relationships. Many of them attend regular education schools and, often, their teachers are unaware of the child's original diagnosis. Other children, because of greater neurological challenges, make slow and steady progress. Nevertheless, even these children can become warm, loving, more connected, and make more progress in their language, cognitive and social skills than previously thought possible.¹⁰

SCERTS

The SCERTS model is a comprehensive, multidisciplinary framework designed to enhance the communication and socio-emotional abilities of young children with Autism Spectrum Disorders (ASD). Collaborators on the SCERTS model include: Barry Prizant, Ph.D., Amy Wetherby, Ph.D., Emily Rubin, MS, CCC-SLP, Pat Rydell, Ph.D., and Amy Laurent, OTR/L. The model is not exclusionary of other treatment approaches and methodologies. Rather, the model provides a framework for those who are seeking guidelines for implementing a comprehensive therapeutic and educational plan that is based on the core developmental challenges faced by children with Autism Spectrum Disorders (ASD) as well as the recommended tenets of practice, as indicated by the National Academy of Sciences.

The acronym “SCERTS” refers to Social Communication (SC), Emotional

Regulation (ER) and Transactional Support (TS), which we believe are the primary developmental dimensions to be prioritized in a program designed to support the development of children with ASD and their families. In the SCERTS model, it is recognized that the most meaningful learning experiences in childhood occur in everyday activities. Therefore, efforts to support a child's development should occur with a variety of partners (e.g., parents, brothers and sisters and other children) in everyday routines in a variety of social situations. The SCERTS framework has been designed to target priority goals in social communication (SC) and emotional regulation (ER) by implementing transactional supports (TS) throughout a child's daily activities and across social partners.¹¹

TEACCH

Division TEACCH was started in 1966 as part of the Department of Psychiatry of the School of Medicine at the University of North Carolina.

The primary aim of the TEACCH program is to help prepare people with autism to live or work more effectively at home, at school, and in the community. Special emphasis is placed on helping people with autism and their families live together more effectively by reducing or removing "autistic behaviors."

Educational strategies are established individually on the basis of a detailed assessment of the learning abilities of the person with an autistic spectrum condition, trying to identify potential for acquisitions rather than deficits. The assessments are called Pep's (Psycho Educational Profiles) and try to identify areas where the person "passes," areas where the skill isn't there yet, and areas where the skill is emerging. These areas are then developed into an education program for the person. The assessment is multi-dimensional, since skills vary greatly.

The strategies put forward by TEACCH do not focus on the behavior directly, rather on underlying conditions that will foster learning experiences. They also make use of recent cognitive psychology research results about some differences in particular areas of the brain processing in autistic people versus "typical" people.

When behavior problems occur, they are not treated directly. The approach calls for efforts to understand the underlying reasons for the behavior problem, such as anxiety, physical pain, difficulty with task, unpredictable changes, boredom, etc.

By giving the person a way to better understand his or her environment, the environment becomes more predictable and less intimidating. This may require a simpler environment in the early phases of development and progressively reintroducing complexity as the child progresses.

When a person with autism can communicate, he or she can better understand what is being told/asked and can express needs and feelings by means other than behavior problems. Direct Behavioral Modification is rarely used, but isn't completely ruled out. It is reserved for those

"I am becoming increasingly concerned that intellectually gifted children are being denied opportunities because they are being labeled either Asperger's or high functioning autism. Within the last year I have talked to several parents, and I was disturbed by what they said. One mother called me and was very upset that her six-year-old son had Asperger's. She then went on to tell me that his IQ was 150. I replied that before people knew about Asperger's Syndrome, their child would have received a very positive label of intellectually gifted."

Temple Grandin, Ph.D.

behaviors that endanger the person and for which the above strategy didn't work.¹²

Picture Exchange Communication Systems – PECS

The Picture Exchange Communication System (PECS) was developed in 1987 by Lori Frost, MS, CCC/SLP and Dr. Andrew Bondy.

PECS is primarily used with individuals who are nonverbal or use speech with limited effectiveness. PECS helps them in acquiring functional communication skills. The system has received international recognition. It does not require complex or expensive materials and can be easily implemented by educators and family members. The system emphasizes learning to approach a communicative partner. A variety of prompting, shaping, and fading techniques are incorporated to gradually improve and modify the person's use of the system.

PECS begins with teaching the person to exchange a picture of a desired item or activity with another person, a communication partner, who immediately honors the request. Verbal prompts are not used, thus building immediate initiation and avoiding prompt dependency. Once this step is mastered, the individual advances to the next phase of the system, which teaches discrimination of symbols, and then puts them together in simple sentences such as "I want _____."

The final of the six phases teaches the person to respond to a question. The system can be successfully implemented with children as young as two. Some parents worry that the using a communication system other than speech will interfere with the development of speech; however, research demonstrates that the opposite is true. The implementation of the PECS enhances the person's language development.

Advantages of PECS—

- The communication exchange is clearly understood.
- The individual initiates the interaction, therefore eliminating prompt dependency.
- The communication is meaningful and highly motivating.¹³

Dietary Interventions

The theory is that many, if not all, children with autism have a damaged intestine/gut. The damage may be there from birth but more likely comes from some immunological injury like a bad reaction to an immunization (keep in mind this is mostly theory). Children with autism seem to have weaker immune systems, and a lot seem to have digestive problems.

This "leaky gut" allows some food proteins to pass through into the bloodstream only partially digested, particularly the gluten from wheat/oats/rye/barley, and the casein from milk and other dairy products. These partially digested proteins form peptides, which have an opiate-like affect

(opioids is another term for them). They can bind to the receptors and cause harmful effects in the brain just like a regular opiate.

Opiates can either cause or magnify autistic symptoms. The opiates are a type of narcotic. The opiates bind to receptors in the brain to reduce pain and induce pleasure, but they also have harmful side effects. Until doctors and scientists can figure out how to heal the “leaky guts,” many parents are putting their children on the gluten free/casein free diets.

The parents who have tried this diet are reporting good success. “Leaky gut” is not like an allergy that can be diagnosed by routine allergy testing. The peptide level must be identified with a special urine test to determine the need for the gluten and casein free diet.¹⁴

Allergy Treatment

Evidence is growing that children on the autistic spectrum have weak immune systems, leading to multiple food and environmental allergies. Physical symptoms that may indicate allergies include—

- Pink or black circles around the eyes
- Bags under the eyes
- Rosy cheeks or ears
- Rapid heartbeat
- Shallow breathing
- Fluid in the ears (a cause of ear infections)
- Excessive perspiration

Several methods can be used to determine whether a person is sensitive to a specific food substance, the most common approach being a blood test. It is important to evaluate both the IgE and IgG antibody levels to get a complete picture of the body’s response to the allergens being tested.

After determining the specific allergens involved, some choose to completely remove the substances from the diet, especially in the case of gluten and casein. Other options may be rotation, provoked neutralization, or systematic elimination through NAET.

NAET (Nambudripad’s Allergy Elimination Technique) is a system designed for eliminating allergies. It is a natural, drugless, painless, non-invasive method. The technology is not new, but a combination of knowledge and techniques that use much of what is already known from allopathic (western medical knowledge), chiropractic, kinesiology, acupuncture (Oriental medical knowledge), and nutrition.

The NAET diagnosis uses a simple muscle response test. Then, a systematic treatment procedure is begun in which the central nervous system is mildly stimulated in the presence of each allergen, reprogramming the brain with the new message. Retesting is performed after an avoidance period of 25 hours. If clearance is still effective after the avoidance period, it is lasting and should be permanent¹⁵

Medications

No medication can correct the brain structures or impaired nerve connections that seem to underlie autism. Scientists have found, however, that drugs developed to treat other disorders with similar symptoms are sometimes effective in treating the symptoms and behaviors that make it hard for people with autism to function at home, school, or work. It is important to note that none of the medications described in this section has been approved for autism by the Food and Drug Administration (FDA).

Medications used to treat anxiety and depression are being explored as tools to relieve certain symptoms of autism. These drugs include fluoxetine (Prozac™), fluvoxamine (Luvox™), sertraline (Zoloft™), and clomipramine (Anafranil™). Some scientists believe that autism and these disorders may share a problem in the functioning of the neurotransmitter serotonin, which these medications apparently help.

One study found that about 60 percent of patients with autism who used fluoxetine became less distraught and aggressive. They became calmer and better able to handle changes in their routine or environment. However, fenfluramine, another medication that affects serotonin levels, has not proven to be helpful.

People with an anxiety disorder called obsessive-compulsive disorder (OCD), like people with autism, are plagued by repetitive actions they can't control. Based on the premise that the two disorders may be related, one NIMH research study found that clomipramine, a medication used to treat OCD, does appear to be effective in reducing obsessive, repetitive behavior in some people with autism. Children with autism who were given the medication also seemed less withdrawn, angry, and anxious. More research needs to be done to see if the findings of this study can be repeated.

Some children with autism experience hyperactivity, the frenzied activity that is seen in people with attention deficit hyperactivity disorder (ADHD). Since stimulant drugs like Ritalin™ are helpful in treating many people with ADHD, doctors have tried them to reduce the hyperactivity sometimes seen in autism. The drugs seem to be most effective when given to higher-functioning children with autism who do not have seizures or other neurological problems.

Because many children with autism have sensory disturbances and often seem impervious to pain, scientists are also looking for medications that increase or decrease the transmission of physical sensations. Endorphins are natural painkillers produced by the body, but, in certain people with autism, the endorphins seem to go too far in suppressing feeling. Scientists are exploring substances that block the effects of endorphins, to see if they can bring the sense of touch to a more normal range. Such drugs may be helpful to children who experience too little sensation, and once they can sense pain, such children could be less likely to bite themselves, bang their heads, or hurt themselves in other ways.

Chlorpromazine, thelidazine, and haloperidol have also been used. Although these powerful drugs are typically used to treat adults with severe psychiatric disorders, they are sometimes given to people with autism to temporarily reduce agitation, aggression, and repetitive behaviors; however, since these tranquilizers are powerful medications that can produce serious and sometimes permanent side effects, they should be prescribed and used with extreme caution.¹⁶

Vitamins and Minerals

Dr Bernard Rimland, director of the Autism Research Institute, and other scientists investigated claims from parents on improvements seen in their children after taking certain vitamins.

A vitamin and mineral therapy was developed, which is now considered an effective treatment for some individuals with autism. Researchers concluded that large doses of Vitamin B6 (pyridoxine), with magnesium and other vitamins and minerals, are an effective treatment for 45-50% of individuals with autism.

It is important to take Vitamin B6 in combination with other vitamins and minerals, in order to help metabolize the vitamin B6 and magnesium.

Studies have shown that vitamin B6 helps to control hyperactivity and improve overall behavior. Although improvements vary considerably among individuals, other possible benefits are: speech improvements, improved sleeping patterns, lessened irritability, increased attention span, decrease in self-stimulation, overall improvement in general health.

In some cases, behavioral improvements can be seen in a matter of days. However, the vitamins often take 60-90 days to show any effects. Dosage is an important consideration. The Autism Research Institute provides a form letter on B6/magnesium therapy that includes a detailed description of the treatment, a dosage chart, a table of scientific research data, and an extensive bibliography. Reading this report before beginning the megavitamin therapy is recommended.¹⁷

Neurofeedback

Neurofeedback, often known as brainwave biofeedback or EEG biofeedback, is a form of biofeedback that has been demonstrated to be highly effective in treating many physical and psychological disorders. Biofeedback is like eavesdropping on the body's own internal conversations. When inside-the-skin events are detected and fed back through electrical signals (using light, sound or touch), this information can help a person to change unwanted patterns that are contributing to poor physical and/or mental health. Neurofeedback allows direct access to the central processing system of the brain, rather than the peripheral systems of skin and muscle.

The healthy brain has the ability and versatility to change states of arousal and attention. As each new situation in a person's life demands a specific

level of arousal and awareness, the healthy brain can quickly move to the appropriate level of alertness. In contrast, the unhealthy brain may be under-aroused and sluggish or over-aroused and anxious. Either way, the disregulated brain has a diminished ability to respond to specific demands. The disordered brain seems to be stuck or “parked” at the wrong place.

Neurofeedback enables people to alter their own brain waves by making them aware of their brain wave characteristics. It is, simply, exercise for the brain. The training is painless and non-invasive. Neurofeedback allows the brain to begin to operate at optimal levels appropriate for the individual, assisting many of those on the autism spectrum to reduce confusing delta, theta, and alpha brain states, and encouraging the use of beneficial beta and SMR frequencies.

Chiropractic

Chiropractic care can be included in a sensory integration treatment plan. Chiropractors directly influence the nervous system by eliminating interference originating at the spinal column. Messages leaving or entering the spinal cord can be inhibited by a subluxation occurring at the spinal level, thus altering messages to and from the brain pertaining to the sensory system.



A subluxation occurs when a segment of the spine consisting of two vertebrae and a disc between them, has lost their juxtaposition. In between the two vertebrae is a foramen (opening) in which the nerve exits. Juxtaposition of the vertebrae causes irritation of the nerve root resulting in altered messages being sent and delivered.

A chiropractor removes the subluxation by applying pressure to the spine with his or her hands. This deep pressure can activate the spinothalamic tract of the nervous system and significantly diminish tactile defensiveness. Fortunately, due to the fact that people with autism often crave deep pressure, the adjustments are usually welcomed.¹⁸

Complementary Approaches

Art and music are particularly useful in sensory integration – providing tactile, visual and auditory stimulation. Music therapy is good for speech development and language comprehension. Songs can be used to teach language and increase the ability to put words together. Art therapy can provide a nonverbal, symbolic way for the child with autism to express him or herself.

Animal therapy may include horseback riding or swimming with dolphins. Therapeutic riding programs provide both physical and emotional benefits, improving coordination and motor development while creating a sense of well-being and increasing self-confidence. David Nathanson, a psychologist who believed that interactions with dolphins would increase a child’s attention and enhance cognitive processes, first tried dolphin therapy in the 1970s. In a number of studies, he found that children with

disabilities learned faster and retained information longer when they were with dolphins compared to children who learned in a classroom setting.¹⁹

One of the most under-utilized yet effective treatments for individuals with autism is exercise. Obviously, exercise is important for everyone, but it can be especially helpful for those with autism. Several research studies have shown that vigorous or strenuous exercise is often associated with decreases in stereotypical (self-stimulatory) behaviors, hyperactivity, aggression, self-injury, and destructiveness. These benefits have also been observed in the cognitively impaired population.

Vigorous exercise refers to a 20 minute or longer aerobic workout, three to four days a week. Mild exercise has little effect on behavior.

Since stereotypical behaviors interfere with teaching, a physical exercise program may also improve the student's attention in the classroom. Parents and teachers can include a rigorous exercise program in the student's Individualized Education Program (IEP). Mid-day recess may not provide an adequate amount of exercise.

Physical exercise is inexpensive, safe, and healthful. It makes more sense to try an exercise program to reduce behavior problems in the classroom and at home rather than to use more expensive and/or harmful treatments.²⁰

Activities that encourage brain/body communication, like Karate, swimming, jumping on a trampoline, swinging, dancing, beading, knitting, sewing, dressing dolls and "action figures," etc. can help regulation and coordination issues as well as improve fine and gross motor skills. These activities can even encourage social and verbal interaction, when performed in a small group setting.



At School

Positive Behavioral Supports

Traditional behavior management views the individual as “the problem” and tries to “fix” the individual. Positive behavior support views systems, settings, and lack of skills as “the problem” and works to change those. The traditional behavior goal, too, has been to eliminate challenging behavior (as quickly as possible), while positive behavior support (a long-term approach) strives to reduce the behavior, teach a more appropriate behavior, and provide the supports necessary for an attractive lifestyle.²¹

Positive Behavior Supports is a strategy designed to encourage positive behaviors in schools, homes, and other social situations. It is based on three key principles—

- All children have inherent value, dignity, and worth.
- Behaviors are learned responses to environmental and experiential conditions and factors.
- Behaviors can be changed when their function is understood and positive supports are provided for the change.

*Children with autism are easy targets for cruel teasing and bullying because of their immature social communication skills. Teachers and classroom aides must be vigilant and prevent them from becoming victims of aggressive, thoughtless classmates. If the child were **physically disabled**, no one would dream of allowing the other students to ridicule him or her. The child with a **developmental disability** needs the same protection. Learning to accept differences and show respect for each other are good lessons for **all** the children.*

If we truly believe that all children have value, then our goal must be to maximize each child’s capacity to have positive social relationships with others. If someone is struggling with inappropriate behaviors, we can act as if the child is a problem – and negate their innate human value – or approach the situation by understanding that the child has a problem, and seek to help him or her address and solve that problem. In order to do so, we must understand that there is (usually) logic behind the behaviors of all children; our challenge is to understand its context. The behaviors in which children engage serve a purpose, fill a need; if those behaviors are inappropriate, we must help the child fill that need in a more acceptable way. It is also critical for us to understand that behaviors are reinforced. Behaviors that result in desirable consequences are likely to be retained or strengthened. Behaviors that result in undesirable consequences are likely to be avoided, rejected, or lessened. However, consequences alone do not result in development of appropriate skills, and punishment (i.e., suspension, firing, etc.) does not teach someone to be able to behave appropriately in the future, it merely delays the need to address the underlying problem or hands it over to someone else.

Positive behavior interventions, on the other hand, recognize the inherent value and dignity of all children and seek to support each child’s capacity to be an effective member of our society, school, workplace, and community. Positive behavior interventions take place before the onset of problem behaviors, before those behaviors escalate, and after problems occur to prevent them from reoccurring. They are positive, in that they are characterized by or display approval, acceptance, or affirmation. They recognize that behavior is something an organism does in response to its environment. And their purpose is to intervene, to enter a course of events so as to successfully change it.²²

When learning about positive behavioral support and challenging behavior the word “aversive” (from the Latin meaning to “turn away”) will probably turn up. Aversives might be understood as quick application of discomfort or pain in response to challenging behavior. Sharp criticisms, slaps, offensive sounds or sprays, social humiliation, removal or desired object, shock, and isolation are aversive applications. In practice, aversives often fail to work. When they do work, their effectiveness diminishes. Besides making the person avoid the punisher, potential harm, and other negative side effects, aversive actions do not teach desirable behavior.²³

Accommodations

The classroom environment should be structured so that the program is consistent and predictable. Students with autism or PDD learn better and are less confused when information is presented visually as well as verbally. Interaction with non-disabled peers is also important, for these students provide models of appropriate language, social, and behavior skills. To overcome frequent problems in generalizing skills learned at school, it is very important to develop school programs in cooperation with the parents, so that learning activities, experiences, and approaches can be carried over into the home and community.²⁴

Students with autism (or other disabilities) may need classroom accommodations, such as—

- A specific type of classroom that does not cause anxiety (for example, fewer students, quiet, not too many frivolous rules, etc.)
- Other specific types of environments, such as the availability of a “resource room” for certain subjects, mainstreaming for certain subjects, or an area for self-calming
- Changes to the classroom environment to accommodate the child's sensory difficulties
- Specific learning materials or methods to address the child’s specific needs
- A personal educational assistant, aide, or “shadow”—not a monitoring aide who simply helps with behavior control, but an inclusion or instructional aide
- Therapeutic services
- Adaptive communications equipment or procedures
- Classroom equipment that will help the child learn (for example, a microphone or sound field system to help the child with auditory processing problems, a slanted work surface, or pencils with an orthopedic grip)²⁵

A forward-thinking school district in central New Jersey has brought several students with autism (who were formerly placed in out-of-district special schools) back into the public school environment. During outings or special events, the students are paired with a “typical” student as a “buddy.” Parents of the disabled and typical participants have written letters to the school board applauding the program.

At Home

The words “These are the rules in *our* house!” can’t be a part of your vocabulary if you have a child with an autism spectrum disorder. You need to do whatever it takes to help your child keep from having tantrums, meltdowns, and aggressive outbursts. Your child may not be able to communicate his or her needs like a typical child, so you must work harder to find out what those needs are.

Many children with autism have extremely limited food preferences because they are oversensitive to the taste, smell, and/or texture of certain foods. This is not the time to try to force your child to eat “what’s on his or her plate.” Extreme sensory defensiveness diminishes over time with proper therapy.

A child with an autism spectrum disorder may have trouble getting to sleep and staying asleep through the night. Establishing a set “bedtime” (when the child gets into his or her PJs, gets in bed, and falls asleep) is not a law written in stone on some sacred tablet. If your child throws violent tantrums when asked to go to bed, try letting him or her fall asleep on the couch. You may need to stay with your child (reading, singing, hugging, etc.) until he or she falls asleep. Heavy (in weight, not warmth) blankets, music, soothing videos, or deep massage may help.

If your child tends to get overstimulated, don’t schedule too many activities one right after another. For example, if you take your child to a birthday party, don’t go to the mall immediately afterwards. Give the child some time to cool down — like reading at home for a half-hour or so. Learn what types of activities have a calming effect on your child and which ones cause your child to get overstimulated, so you can help your child stay regulated.

The ignorant comments sometimes made by the uninformed can make you angry, hurt, or both. In public places, it is helpful to bring another adult with you to discreetly explain to bystanders that your child is not a brat, doesn’t “need a little discipline,” but is disabled. Your helper can also explain the situation when your child has a “meltdown” and you need to carry him or her screaming to the car. If your child doesn’t have the ability to wait (e.g., for several other customers to go first), your ally can explain the situation and possibly get people to accommodate you.

Mostly, it’s a better idea to avoid these high-stress situations. Shop without your child, or order through catalogs. Shoes are the exception, unfortunately, and you might need to endure a screaming session trying to get the right fit for your child. Once you establish your child’s size, though, you can buy shoes, bring them home, and try them on your child yourself.

Since the child most likely has sensory issues, pay attention if he or she refuses to wear certain clothes or covers his or her ears every time a specific noise is encountered. If your child screams when you dress him or her in a particular article of clothing, don’t force him or her to wear

“Children with sensory processing issues are often over-controlling, so avoid power struggles by offering them choices whenever you can. My daughter, however, would sometimes respond ‘No! Nothing!’ when given, for example, a choice between milk and apple juice. We learned to get around her (about 85% of the time) by responding, ‘That is not a choice. If you will not choose, I will choose for you.’ It turned out that she valued the power to choose more than either the milk or the juice.”

*Janette Vance, mother of a girl with Asperger’s Syndrome
www.aspergersexpress.com.*

it. If your child is afraid of the vacuum, leave the dust where it is and vacuum when he or she is out of the house. Again, pay attention and try to understand the effects that certain situations and/or objects have on your child.

Children with ASD are likely to be *very* late learning to use the toilet and stay dry all night. The advice to parents of children with developmental disabilities is the same as the advice for the parents of typical children—they'll do it when they're ready. In the meantime, use the disposable daytime and nighttime underwear and relax. Tell your child, "If you have an accident, change."

The Willbarger brushing technique may help reduce tactile defensiveness. An occupational therapist, trained in sensory integration therapy, will recommend this procedure for your child and teach you to implement it.

Read [The Explosive Child](#) by Ross Greene. It will teach you how to address important issues, negotiate others, and ignore the rest.

An Occupational Therapist who specializes in Sensory Integration Therapy is a good source of suggestions for accommodating your child at home.

Evaluating Treatment Options for Autism

Parents and caregivers need to be cautious when deciding which course of treatment is best for their children.

Be suspicious of any treatment which makes grandiose claims, using words like “miraculous,” “amazing breakthrough,” “recovery,” or “cure.” Legitimate medical and educational professionals show respect for the uniqueness of each individual with autism and the feelings of that individual’s family. They never indulge in overstatements and boasts about what they will be able to accomplish. When they are particularly successful in helping a person, they do not solicit testimonials from the person’s family or encourage parents to make grandiose promises and claims to others.

Be suspicious of professionals who publicize and promote their method or program as if it were a packageable commodity. Since autism is not a “thing” a person “has,” but an attempt to capture in a single label a wide range of behavioral adaptations to a wide range of sensory and movement regulatory differences, there can be no such thing as a general treatment for autism. Likewise, beware of parent support groups dedicated to the promotion of a particular “miraculous” method. Enthusiastic testimonials from people who claim they have been helped by a product or treatment are no substitute for the evidence gathered through careful, unbiased investigation, and for considering the unique developmental profile of each individual child. Run for the hills if you are ever made to feel guilty or inadequate for failing to buy into a treatment or for questioning the eager rhetoric surrounding it.

Remember that many treatments are composed of an eclectic mix of active and inactive ingredients. The more clarity you can achieve about what really helps, the less time, energy, and money you will waste on inactive, incidental, and occasionally harmful treatment components. It is helpful to note the common features in many effective interventions, across many different disciplines—

- Using environmental accommodations which slow down interactions, setting a consistent pattern paced to the person's unique rhythms
- Eliminating unnecessary stimuli and distractions which may overwhelm and confuse
- Giving the person, on a daily basis, as much uninterrupted time and attention as possible
- Following the person's lead by building on his or her own enthusiasms and interests
- Utilizing typical home and community settings, and the friendship and support of typically-developing peers
- Sharing with the person a belief in their competence and delight in their companionship²⁶

Suggested Reading

- A DYNAMIC SYSTEMS APPROACH TO THE DEVELOPMENT OF COGNITION AND ACTION by Esther Thelen & Linda B. Smith
- A FOOT IN BOTH WORLDS by Mary Lapos, Ed.
- A SLANT OF SUN: ONE CHILD'S COURAGE by Beth Kephart
- AHEAD OF HIS TIME: SELECTED SPEECHES OF GUNNAR DYBWAD by Allard, Howard, Vorderer & Wells, Eds.
- AN ANTHROPOLOGIST ON MARS by Oliver Sacks
- ANTS IN HIS PANTS: ABSURDITIES AND REALITIES OF SPECIAL EDUCATION by Michael Giangreco
- AROMATHERAPY AND MASSAGE FOR PEOPLE WITH LEARNING DIFFICULTIES by Helen Sanderson & Jane Harrison with Shirley
- ASPERGER SYNDROME IN ADOLESCENCE: LIVING WITH THE UPS, THE DOWNS AND THINGS IN BETWEEN by Liane Holliday Willey
- ASSESSING AND TREATING INFANTS AND YOUNG CHILDREN WITH SEVERE DIFFICULTIES IN RELATING AND COMMUNICATING by Stanley I. Greenspan, et al.
- AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC): ISSUES AND STRATEGIES FOR PEOPLE INVOLVED IN DEVELOPMENTAL SERVICES by Anne M. Donnellan, Karen Strandt-Conroy, & Laurel A. Sabin.
- AUTISM – A NEW UNDERSTANDING: SOLVING THE ‘MYSTERY’ OF AUTISM, ASPERGERS, AND PDD-NOS, by Gail Gillingham
- AUTISM AND SENSING: THE UNLOST INSTINCT by Donna Williams

Suggested Reading

AUTISM SPECTRUM	by	Gail Gillingham and Sandra McClennan, eds
AUTISM SPECTRUM DISORDERS: A TRANSACTIONAL DEVELOPMENTAL PERSPECTIVE	by	Amy M. Wetherby & Barry M. Prizant, Eds
AUTISM, ADVOCATES AND LAW ENFORCEMENT PROFESSIONALS: RECOGNIZING AND REDUCING RISK SITUATIONS FOR PERSONS WITH AUTISM SPECTRUM DISORDERS	by	Dennis Debbaudt
AUTISM: AN INSIDE-OUT APPROACH	by	Donna Williams
AUTISM: HANDLE WITH CARE	by	Gail Gillingham
AWARENESS THROUGH MOVEMENT	by	Moshe Feldenkrais
BEYOND THE SILENCE	by	Tito Rajarshi Mukhopadhyay
BEYOND THE WALL: PERSONAL EXPERIENCES WITH AUTISM AND ASPERGER SYNDROME	by	Stephen Shore
BUILDING BRIDGES THROUGH SENSORY INTEGRATION	by	Ellen Yack, Shirley Sutton, Paula Aquilla
CAUGHT BETWEEN TWO WORLDS: MY AUTISTIC DILEMMA	by	Tomas S. Page
CHILDREN WITH AUTISM: DIAGNOSIS AND INTERVENTIONS TO MEET THEIR NEEDS	by	Colwyn Trevorthen
CHRISTMAS IN PURGATORY: A PHOTOGRAPHIC ESSAY ON MENTAL RETARDATION	by	Burton Blatt & Fred Kaplan
COGNITIVE COUNSELING FOR PERSONS WITH SPECIAL NEEDS	by	Herb Lovett
COMMUNICATION UNBOUND	by	Douglas Biklen

Suggested Reading

- CONFUSION, LONELINESS,
DEPRESSION: ASPERGER'S
SYNDROME – A JOURNEY by John & Patricia
Brine
- CONTESTED WORDS, CONTESTED
SCIENCE: UNRAVELING THE
FACILITATED COMMUNICATION
CONTROVERSY by Douglas Biklen &
Don Cardinal,Eds
- DEVELOPING THROUGH
RELATIONSHIPS by Alan Fogel
- DISCOVERING MY AUTISM:
APOLOIGIA PRO VITA SUA (WITH
APOLOGIES TO CARDINAL
NEWMAN) by Edgar Schneider
- ELIJAH'S CUP by Valerie Paradiz
- EMERGENCE: LABELED AUTISTIC by Temple Grandin
- EMOTIONAL INTELLIGENCE by Daniel Goldman
- EXPOSURE ANXIETY
– THE INVISIBLE CAGE: AN
EXPLORATION OR SELF-
PROTECTION RESPONSES IN THE
AUTISM SPECTRUM AND BEYOND by Donna Williams
- FACILITATED COMMUNICATION
TRAINING by Rosemary
Crossley
- FIGHTING FOR DARLA:
CHALLENGES FOR FAMILY
CARE AND PROFESSIONAL
RESPONSIBILITY by Ellen A.
Brantlinger, et al.
- FREAKS, GEEKS & ASPERGER
SYNDROME: A USER GUIDE TO
ADOLESCENCE by Luke Jackson

Suggested Reading

GREGORY'S STORY: A JOURNEY TO PEACE	by	Marijean Ginoble
HANDBOOK OF MENTAL HEALTH CARE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES	by	Ruth Ryan
I DON'T WANT TO BE INSIDE ME ANYMORE: MESSAGES FROM AN AUTISTIC MIND	by	Birger Sellin
"I HAD NO MEANS TO SHOUT!"	by	Mary Jane Hale & Charles Martel Hale, Jr.
IF YOU LOOK IN THEIR EYES YOU KNOW	by	Sue and Ben Lehr
LEARNING TO LISTEN	by	Herb Lovett
LIKE COLOR TO THE BLIND: SOUL SEARCHING & SOUL FINDING	by	Donna Williams
LISTENING WITH THE WHOLE BODY	by	Sheila m. Frick & Colleen Hacker
LIVING THE GOOD LIFE WITH AUTISM	by	Edgar R. Schneider
LUCY'S STORY: AUTISM AND OTHER ADVENTURES	by	Lucy Blackman
MOVEMENT DIFFERENCES AND DIVERSITY IN AUTISM/MENTAL RETARDATION	by	Anne Donnellan & Martha Leary
NO PITY	by	Joe Shapiro
NOBODY NOWHERE	by	Donna Williams
OUT OF SILENCE: A JOURNEY INTO LANGUAGE	by	Russell Martin
PAID FOR THE PRIVILEGE: HEARING THE VOICES OF AUTISM	by	Dan Reed
PLAY AND IMAGINATION IN CHILDREN WITH AUTISM	by	Pamela J. Wolfberg

Suggested Reading

PRETENDING TO BE NORMAL: LIVING WITH ASPERGER'S SYNDROME	by	Liane Holliday Willey
PROGRESS WITHOUT PUNISHMENT	by	Anne Donnellan, et al.
PUNISHED BY REWARDS	by	Alfie Kohn
REAL EYES: LESSONS IN HUMANITY, HUMILITY, AND HUMAN SERVICES	by	Ruth Ryan & Dave Hinsburger,
RESPONDING TO THE CHALLENGE: ESSAYS IN HONOR OF GUNNAR DYBWAD	by	Hank Bersani, Jr. Ed.
SEE US SMART: FACILITATED COMMUNICATION CASE STUDIES	by	Char Brandl
SOMEBODY SOMEWHERE	by	Donna Williams
SOON WILL COME THE LIGHT: A VIEW FROM INSIDE THE AUTISM PUZZLE	by	Thomas A. McKean
SPEECHLESS: FACILITATING COMMUNICATION FOR PEOPLE WITHOUT VOICES	by	Rosemary Crossley
TARGETING AUTISM	by	Shirley Cohen
TEACHING OLD LOGS NEW TRICKS	by	Michael Giangrecco
THE BOY WHO LOVED WINDOWS	by	Patricia Stacey
THE CHALLENGING CHILD	by	Stanley I. Greenspan, M.D.
THE CHILD WITH SPECIAL NEEDS: ENCOURAGING INTELLECTUAL AND EMOTIONAL GROWTH	by	Stanley I. Greenspan, M.D.
THE EXPLOSIVE CHILD	by	Ross. W. Greene
THE FEELING OF WHAT HAPPENS: BODY AND EMOTION IN THE MAKING OF CONSCIOUSNESS	by	Antonio Damasio

Suggested Reading

THE GROWTH OF THE MIND AND THE ENDANGERED ORIGINS OF INTELLIGENCE	by	Stanley I. Greenspan, M.D.
THE HIGHLY SENSITIVE PERSON: HOW TO THRIVE WHEN THE WORLD OVERWHELMS YOU	by	Elaine N. Aron
THE LIGHT WITHIN	by	Lincoln Grigsby (2001)
THE ORIGIN AND NATURE OF OUR INSTITUTIONAL MODELS	by	Wolf Wolfensberger
THE OUT-OF –SYNC CHILD HAS FUN	by	Carol Stock Kranowitz
THE OUT-OF-SYNC CHILD	by	Carol Stock Kranowitz
THE OUT-SYNCH-CHILD: RECOGNIZING AND COPING WITH SENSORY INTEGRATION DYSFUNCTION	by	Carol Stock Kranowitz
THE VIAL	by	Chammi Rajapatirana
THERE’S A BOY IN HERE	by	Judy Barron & Sean Barron
THINKING IN PICTURES	by	Temple Grandin
THROUGH THE EYES OF ALIENS: A BOOK ABOUT AUTISTIC PEOPLE	by	Jasmine Lee O’Neill
USING THE SUPPORTIVE PLAY MODEL	by	Sheridan, Foley & Radlinkski
WITHOUT REASON	by	Charles Hart
YOU, YOUR CHILD, AND SPECIAL EDUCATION	by	Barbara Coyne Cutler
YOU’RE GOING TO LOVE THIS KID!	by	Paula Kluth

Suggested Reading

Children's Books

- EVERYBODY IS DIFFERENT by Fiona Bleach
- IAN'S WALK: A STORY ABOUT AUTISM by Laurie Lears, Karen Ritz
- TREVOR, TREVOR by Diane Twatchman-Cullen
- ASPERGER'S HUH? A CHILD'S PERSPECTIVE by Rosina Schnurr
- THE STONKING STEPS:
A Journey Through Ing-Ong-Ung by Will Rogers
Illustrations by Honor Kever

Resources

National Institute of Child Health and Human Development (NICHD)
31 Center Drive
Bldg. 31, Rm. 2A-32
Bethesda, MD 20892
Voice: (301) 496-5133
Fax: (301) 496-7101
Internet: www.nichd.nih.gov/

National Institute of Mental Health (NIMH)
5600 Fishers Lane
Parklawn Bldg., Rm. 7C02
Rockville, MD 20857-8030
Voice: (301) 443-4513
Fax: (301) 443-0008
E-mail: nimhinfo@nih.gov
Internet: www.nimh.nih.gov

National Institute of Neurological Disorders and Stroke (NINDS)
31 Center Drive
Bldg. 31, Rm. 8A-06
Bethesda, MD 20892
Voice: (301) 496-5924
Fax: (301) 402-2186
Internet: www.ninds.nih.gov

American Speech-Language-Hearing Association (ASHA)
10801 Rockville Pike
Rockville, MD 20852
Voice: (301) 897-5700
TTY: (301) 897-0157
Toll-free: (800) 638-8255
FAX: (301) 571-0457
E-mail: actioncenter@asha.org
Internet: www.asha.org

Autism Network for Hearing and Visually Impaired Persons
7510 Ocean Front Avenue
Virginia Beach, VA 23451
Voice: (757) 428-9036
Fax: (757) 428-0019

Autism Research Institute
4182 Adams Avenue
San Diego, CA 92116
Voice: (619) 281-7165
Fax: (619) 563-6840
Internet: www.autismresearchinstitute.com

National Alliance for Autism Research (NAAR)
99 Wall Street
Princeton, NJ 08540
Voice: (609) 430-9160
Toll-free: 1-888-777-NAAR (6227)
Fax: (609) 430-9163
E-mail: naar@naar.org
Internet: www.naar.org

Resources, continued...

The Family Alliance to Stop Abuse and Neglect
P.O. Box 77238
West Trenton, NJ 08628
E-mail: pat.amos@verizon.net
Internet: www.thefamilyalliance.net
SPAN

Statewide Parent Advocacy Network
35 Halsey St. 4th Floor
Newark, NJ 07102
Voice: (973) 642-8100
Toll-free in NJ: (800) 654-SPAN
Fax: (973) 642-8080
E-Mail: span@spannj.org
Internet: www.spannj.org

TASH
29 W. Susquehanna Ave. Suite 210
Baltimore, MD 21204
Voice: (410) 828-8274
Fax: (410) 828-6706
E-mail: nweiss@tash.org
Internet: www.tash.org

Autism National Committee
P.O. Box 6175
North Plymouth, MA 02362-6175
Internet: www.autcom.org

New Jersey Parents' Caucus
486 Route 10 West
Randolph, NJ 07869
Voice: (973) 659-9922
Fax: (973) 659-9339
E-mail: njpc@njparentscaucus.org
Internet: www.njparentscaucus.org

Cerebral Palsy of New Jersey
354 South Broad Street
Trenton, NJ 08608-2502
Toll Free: (888) 322-1918
Fax: (609) 392-3505
TTY: (609) 392-7044
E-mail: info@cpofnj.org
Internet: <http://www.cpodfj.org>

Resources, continued...

CIBRA

Children Injured by Restraint and Aversives

E-mail: CIBRA@webtv.net

Internet: <http://users.1st.net/cibra/>

Federation of Families for Children's Mental Health

1101 King Street, Suite 420

Alexandria, Virginia 22314

Voice: (703) 684-7710

Fax: (703) 836-1040

E-mail: ffcmh@ffcmh.org

Internet: www.ffcmh.org

The Elizabeth M. Boggs Center on Developmental Disabilities

Robert Wood Johnson Medical School

335 George St.

P.O. Box 2688

New Brunswick, NJ 08903

Voice: (732) 235-9300

Fax: (732) 235-9330

Internet: <http://rwjms.umdnj.edu/boggscenter>

What is The Family Alliance to Stop Abuse and Neglect?

Mission:

The mission of the Family Alliance to Stop Abuse & Neglect is to create positive system-wide changes and promote best practices to guarantee the human rights and dignity of people with disabilities of all ages.

Goals:

The Family Alliance intends to stop abuse and neglect in two ways: through the identification and elimination of specific dangerous and demeaning practices, and through the promotion of positive reforms aimed at changing the culture of education and service delivery from one of coercion and segregation to one based on human rights and inclusion. Specific goals are—

To foster a social and legal structure in which all people, disabled and non-disabled, share in and mutually enjoy community-based options, full inclusion, true choices, and opportunities for self-determination and self-actualization.

To ensure that all children and adults with disabilities (regardless of the nature and degree of their challenges) receive the same protections from abuse and neglect enjoyed by non-disabled citizens, wherever they live, work, attend school, and/or receive services.

To inform the families of people with disabilities, policy makers, and the public at large about the dangerous and dehumanizing outcomes of the use of aversives and restraints to control behavior, and that tolerance of these practices leads to the segregation of people with disabilities from their communities.

To increase awareness of and access to positive approaches to the needs of people with disabilities, including assistive and augmentative communication, appropriate and flexible supports and accommodations, beneficial therapies, and consumer-directed services.

To work for fundamental change in the funding systems serving people with disabilities, so that resources are allocated to individuals rather than facilities.

To empower people with disabilities, their families and supporters with information about effective means to access and allot resources to achieve maximum therapeutic benefits, personal independence, and the preservation of families facing lifetime challenges.

Family Alliance Projects:

- Limiting restraints to emergencies
- Abolishing aversives
- Mandating caregiver training in positive behavioral supports and emergency procedures
- Professionalizing, compensating appropriately, and expanding career opportunities for direct care staff
- Requiring proper supervision of facilities
- Stipulating accountability for abuse, neglect, and crimes such as rapes, beatings, etc.
- Establishing a statewide registry of abusers, prohibiting re-hiring of abusive caregivers
- Providing resources for families attempting to design programs for their children

For additional information about the **Family Alliance to Stop Abuse and Neglect**, see www.thefamilyalliance.net.

References

- ¹ RENEE M. ROSSI-ROSEN, Attorney at Law
- ² Oregon Department of Education, Office of Special Education, <http://www.ode.state.or.us/sped/>
- ³ National Institute on Deafness and Other Communication Disorders, National Institutes of Health, <http://www.nidcd.nih.gov/>
- ⁴ Cindy Hatch-Rasmussen, M.A., OTR/L, Therapy Northwest, P.C., Beaverton, OR 97005, ©1995 Center for the Study of Autism. <http://www.autism.org/si.html>
- ⁵ AutismWeb, <http://www.autismweb.com>
- ⁶ Assessment of Sensory Processing, Praxis, and Motor Performance, G. Gordon Williamson, Ph.D., O.T.R., Marie E. Anzalone, Sc.D., O.T.R., and Barbara E. Hanft, M.A., O.T.R.
- ⁷ The National Autistic Society 393 City Road, London, EC1V 1NG, United Kingdom, <http://www.nas.org.uk/>
- ⁸ Sensory Integration International, <http://www.sensoryint.com>
- ⁹ Autism Society Ontario, <http://www.asohalton.org/ait.htm>
- ¹⁰ Floortime Foundation, <http://www.floortime.org/index.htm>
- ¹¹ Communication Crossroads, <http://www.commxroads.com/>
- ¹² Awares.org, http://www.awares.org/static_docs/ways_of_helping.asp?docSection=4
- ¹³ Center for Disabilities, 1400 West 22nd Street, Sioux Falls, South Dakota 57105 (605) 357-1439 1-800-658-3080 (Voice/TTY), <http://www.usd.edu/cd>
- ¹⁴ Autism Society Ontario, <http://www.asohalton.org/diet.htm>
- ¹⁵ Maribeth Mydlowski, D.C., 861 Whitehorse Ave., Hamilton Township, NJ 08610, 609-581-8484, fax: 609-585-0099
- ¹⁶ Support 4 Hope, http://www.support4hope.com/autism/autism_medications.htm
- ¹⁷ Autism Society Ontario, <http://www.asohalton.org/diet.htm>
- ¹⁸ Maribeth Mydlowski, D.C., 861 Whitehorse Ave., Hamilton Township, NJ 08610, 609-581-8484, fax: 609-585-0099
- ¹⁹ The Autism Society of America, <http://www.autism-society.org/>
- ²⁰ Stephen M. Edelson, Ph.D., Center for the Study of Autism, Salem, Oregon, <http://www.autism.org/exercise.html>
- ²¹ OSEP Technical Assistance Center On Positive Behavioral Interventions & Supports, http://www.pbis.org/english/Understanding_Challenging_Behavior.htm
- ²² Diana MTK Autin, Executive Co-Director, Statewide Parent Advocacy Network
- ²³ OSEP Technical Assistance Center On Positive Behavioral Interventions & Supports, http://www.pbis.org/english/Understanding_Challenging_Behavior.htm

²⁴ AUTISM and PERVASIVE DEVELOPMENTAL DISORDER, Fact Sheet Number 1 (FS1), 1997, National Information Center for Children and Youth with Disabilities, <http://www.nichcy.org>

²⁵ PATIENT-CENTERED GUIDES, http://www.patientcenters.com/autism/news/special_ed.html#fig4

²⁶ Autism National Committee, <http://www.autcom.org/redflags.html>