

# **Autism Spectrum Disorder:**

## **An Introductory Guide from Early Diagnosis to Primary School Services**

**For Parents, Care Providers, Case Managers and Other  
Concerned Individuals**



***The East Bay Autism Campaign***

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## **Introduction**

The East Bay Autism Campaign is a group of individuals from public and private agencies and programs in Alameda and Contra Costa Counties who are working together to ensure the early identification and appropriate referral to services of young children with autism spectrum disorders. Membership has included: Alameda County Child Care Planning Council, Alameda County Developmental Disabilities Council, Alameda County Health Care Services Agency, Area Board 5 on Developmental Disabilities, California Children Services Alameda County, CARE Parent Network, Center for Autism and Developmental Disabilities Research and Epidemiology (CADDRE), Child Health and Disability Prevention Alameda County, Children's Hospital & Research Center Oakland, Contra Costa County Health Services Department, Developmental Disabilities Council of Contra Costa County, Every Child Counts Alameda County, La Familia, Oakland Unified School District, Regional Center of the East Bay, and Spectrum Center Schools.

This resource guide was written to assist parents who have a young child newly-diagnosed with autism spectrum disorder to understand and research the services their child may need. The guide contains an explanation of techniques and interventions commonly used to treat children with autism spectrum disorders, as well as information on local and national resources. This information supplements the support provided to families by the professionals who will be treating their child. Please note it is the intention of this group to publish and disseminate this guide, knowing that much of the information will change and evolve as research progresses.

## **Disclaimer**

This resource guide was developed to provide information only and does not recommend, endorse, guarantee, or promote the services and interventions described.

## **Acknowledgements**

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# Introduction to Autism Spectrum Disorders

## Definition:

An Autism Spectrum Disorder (ASD) is a developmental disorder that affects multiple aspects of a child's functioning. The disorder is characterized by delays in communication skills, impairment in social interaction and imaginative play, and behavioral symptoms involving repetitive behaviors and/or a restricted range of interest in activities.

Autism is often referred to as a spectrum disorder due to the variety of characteristics and the range of severity that is unique to each child. Even though children diagnosed with ASD share a common set of behavioral characteristics, no two individuals are alike. Each can act very differently from one another and have a varying set of skills. Toward the mild end of the spectrum children may relate comfortably with family members, whereas at the more severe end of the spectrum, children may be socially withdrawn in almost all situations. Children with ASD may also exhibit different symptoms over time, or from one situation to the next.

A variety of diagnoses may be used for children on this spectrum:

- **Autism Disorder** – children who meet full criteria for the disorder according to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association). Children in this group vary quite a bit; however, they each have characteristics in areas of communication, social interaction, and repetitive behaviors that are severe enough to meet criteria for the disorder.
- **Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)** – children with this diagnosis typically have many features of autism, such as severe and pervasive difficulties in social and communication behaviors, but do not meet the full criteria for Autistic Disorder.
- **Asperger's Syndrome** – this is diagnosed in school-aged children who have social and behavioral symptoms of autism without the language delay. Measured intelligence is in the average to above-average range. Frequently, these children show an almost obsessive interest that is unusual in intensity and focus.
- **Additional Disorders** – Pervasive Developmental Disorders can occur by themselves or in combination with other disabilities. Children usually have symptoms of Attention Deficit Hyperactivity Disorder (ADHD), which is part of the pervasive developmental disorder. They may also experience learning disabilities (LD), anxiety disorders, obsessive-compulsive disorders (OCD), blindness, deafness, epilepsy, or mental retardation. It is estimated that up to 70% of those diagnosed with ASD are also diagnosed with mental retardation ranging from mild to severe.

## **Characteristics:**

A child with ASD may display **only a few, or several** of the following characteristics.

### Communication

- No speech or delayed speech
- Lack of use of gestures for communication (no pointing)
- Repetitive speech or unusual use of language
- Echolalia (repeating exactly what has just been said)
- Speech of unusual quality such as high-pitched, 'sing-song' like, or monotone

### Social Interaction

- Attachment to parents, but difficulty relating to other adults
- Less interest in pointing, showing, sharing, or getting others' attention
- Below normal eye contact, poor use of eye contact for communication
- Not seeking comfort at times of distress
- Preference for solitary play, not initiating play with peers
- Difficulty in responding to teaching efforts, dislike of being directed in play, being read to, etc.
- Lack of imitation of others
- Lack of symbolic play

### Behavioral Symptoms

- Restricted range of interests or a preoccupation with parts of objects
- Strong attachment to particular objects
- Repetitive behaviors such as jumping, walking on toes, hand flapping, holding objects too close to eyes, etc.

### Associated Features

- Over-sensitivity to sound, light, or touch
- Lack of sensitivity (to hearing name, pain)
- Eating limited variety of foods
- Highly developed memory skills
- Abnormal sleeping patterns
- Self-injurious behavior
- Seizure disorder
- Discrepancy between verbal and non-verbal IQ
- IQ falling within range of mental retardation

### **Incidence:**

The number of children born with, or who develop ASD, is estimated to be 1 in 166 births. It is the third most prevalent developmental disorder. It is four times more likely to occur in males than females for unknown reasons.

### **Diagnosis:**

ASD cannot, at this point, be diagnosed using any type of medical test (e.g. blood test, genetic test, brain scan). Instead, it is diagnosed on the basis of a professional's assessment of the child's behavior.

**Parents are most likely to receive an accurate diagnosis from an evaluation done by an experienced professional that involves spending time with the child in both play and formal testing situations, combined with careful interviewing of the parents regarding developmental history and observation of behaviors seen in multiple environments.**

The behavioral characteristics typically used for diagnosis are listed in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (American Psychiatric Association).

**A clinical psychologist and/or a medical doctor who has had training and experience in understanding ASD and other developmental disabilities can make the initial diagnosis.**

Once an initial diagnosis or concern is raised, it will be helpful to obtain a multidisciplinary assessment that includes a psychologist, family members, and other professionals such as a speech therapist, an occupational therapist, and a neurologist.

### **Causes of ASD:**

There is no single known cause for autism. There are many theories about potential causes and it appears that multiple factors are involved. Autism Spectrum Disorders are physical disorders of the brain that are neurologically-based and are not emotional or behavioral disorders. Parents do not cause autism. The exact cause remains unclear, as we still do not understand how autism affects the structure of the brain, brain function, or brain chemistry. There is some evidence of a genetic component as studies have shown that if you have one child with autism, you are at some increased risk of having another child with autism. Autism has also been associated with a wide range of pre-, peri-, and post-natal difficulties.

### **Course of the Disorder:**

Receiving a diagnosis may alter your dreams for your son or daughter. Remember to maintain your determination, obtain the support you need, and don't lose hope. There are few guidelines for predicting outcomes for children with ASD. Research into causes and interventions is currently growing at an amazing rate. Much has been learned in the last ten years about ASD. More adults with ASD are describing their experiences and providing us with incredible insight. Certainly, there are successes that have been accomplished with hard work, creativity, and perseverance from individuals themselves, their family members, and the professionals and community members who are involved.

### **Obtaining Services:**

Once a diagnosis is obtained it will be important to begin to identify needed services and resources. **Each child with ASD is different and each family will have different needs.** This guide describes public and private agencies that may provide services for your child depending on your child's age, diagnosis, and needs.

Examples of services that individuals and families may require include:

- educational services
- speech therapy
- sensory integration therapy
- physical and occupational therapy
- behavioral consultation
- medical and dental care
- advocacy
- respite care
- parent education and family support
- sibling support and education
- socialization
- recreation
- employment training

## How to Get Help for Your Child (Birth to Three)

Help for children is available through California's **Early Start Program**, a coordinated, statewide program intended to provide family-centered services to children under three years of age with disabilities or developmental delays, including children with autism spectrum disorders. It is federally mandated by the Individuals with Disabilities Education Act (IDEA) and by the California Early Intervention Services Act. The purpose is to provide services early enough to make a difference in the child's development. Early intervention is not a cure for disabilities or developmental delays. It is an individualized program of coordinated services and supports that promotes the child's growth and development and supports families during the critical early years.

**Research shows that participation in family-centered, early intervention services during the first three years of life can have significant positive effects on the cognitive development, social adjustment, and the overall development of young children with disabilities, including children with autism spectrum disorders.**

Early Start includes supports and services for children from **birth to 36 months** and their families. Early Start services are free of charge to eligible children and families. Eligibility is determined after a referral is made and an evaluation is completed. You may refer your child yourself or have a professional (such as your child's pediatrician) assist you by making the referral. Services are accessed through the Regional Center of the East Bay, which serves Alameda and Contra Costa Counties. Many therapeutic services and supports are available to residents of Alameda and Contra Costa Counties. Services can include:

- *Assistive or adaptive technology devices/services*
- *Audiology services*
- *Behavioral training and intervention*
- *Family training, counseling and home visits*
- *Medical services (for diagnostic or evaluative purposes only)*
- *Nursing*
- *Nutrition counseling*
- *Occupational therapy*
- *Physical therapy*
- *Psychological services*
- *Respite*
- *Service coordination (case management)*
- *Social work services*
- *Speech/language pathology services*
- *Transportation services*
- *Vision services*



Upon determination of eligibility, an assessment will be done to determine what services are appropriate. The assessment process will result in the development of an overall service plan, called an **Individual Family Service Plan (IFSP)**. This plan, which must be developed within 45 days of the referral, will ensure that services and community support, including parent-to-parent resources, come together to meet your child's unique needs and the needs of your family to support your child's development. The IFSP is created by a multi-disciplinary team and includes the parents. You may work with many professionals from various agencies in the creation of your IFSP. Your IFSP will define the services that will best help your child and family. The IFSP is reviewed every six months, revised as needed, and **will be in place until your child turns 3 years old or no longer needs services.**

Before your child reaches the third birthday, a determination must be made whether s/he needs ongoing services. A transition plan will be developed which will ensure that your child continues to receive needed services. The Regional Center of the East Bay will work with you to develop an Individual Program Plan (IPP). If your child is eligible for special education services, you will be referred to your local school district for development of an Individualized Education Program (IEP).

Your first call should be to the **Regional Center of the East Bay**, a community-based agency funded by the State of California, designed to serve persons with developmental disabilities including children and families who are eligible for the Early Start Program. It is a private, non-profit agency under contract for provision of services through the California Department of Developmental Services. Regional Center of the East Bay serves both Alameda and Contra Costa Counties.

**Call 510-383-1355 (English and Spanish)**

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

## How to Get Help for Your Child (Three and Up)

If your child receives a diagnosis of autism spectrum disorder after the third birthday, you should refer your child to your local school district to determine if s/he is eligible for special education preschool services. Children from age three and up may receive educational and therapeutic services from the local school district. However, you should also refer your child to the Regional Center of the East Bay since they can provide case management and possibly other family support services.

The foundation for special education is the Individuals with Disabilities Education Act (IDEA), a federal law that provides six important protections and rights to eligible children. These are:

- All eligible children will have an **Individualized Education Program (IEP)**.
- Assessments must be non-discriminatory.
- Each child shall receive a free, appropriate public education at no charge.
- Children with disabilities will be educated in the least restrictive environment.
- Parents have due process rights and can challenge decisions of the school system.
- Parents and students can participate in educational planning.

When the school district receives a written referral from a parent requesting that their child be assessed for eligibility, they must conduct an evaluation of the child. **An educational assessment with a team of qualified professionals from your local school district will be needed to determine eligibility for special education and related services, even if you have received a diagnosis of autism elsewhere.**

Once the assessments are completed a meeting must be convened within 60 days to discuss eligibility and develop an Individualized Education Program (IEP). The IEP is a document containing a statement of the child's present levels of performance, a statement of annual goals and if appropriate, short-term objectives, and a statement of the special education and related services which the child needs, as well as the placement. The IEP team is comprised of the individuals who conducted assessments, special and regular education teachers, a school system representative, others with special knowledge about the child, and the parents. Once the IEP is written, it must be implemented as soon as possible afterwards.

## Contra Costa County

The contact numbers for each Special Education Department are listed below.

### West Contra Costa Unified School District SELPA

- Cameron School, 510-233-1955 (children aged birth to five)
- Special Education Department, 510-741-2840 (children five and up)

### Mt. Diablo Unified School District SELPA

- Preschool Assessment Services, 925-825-0144 (children aged birth to five)
- Special Education Department, 925-682-8000, Ext. 4048 (children five and up)

### Contra Costa SELPA (Special Education Local Planning Area)

- Antioch, 925-706-5343
- Brentwood, 925-513-6315
- Byron, 925-634-6644
- Canyon, 925-376-4671
- John Swett, 510-245-4300, Ext. 110
- Knightsen, 925-625-0073, Ext. 2076
- Martinez, 925-313-0480, Ext. 217
- Oakley, 925-625-7060
- Pittsburg, 925-473-4278

### San Ramon Valley Unified School District SELPA

- San Ramon, 925-820-5277

## Alameda County

The contact numbers for each Special Education Department are listed below.

### North Region SELPA

- Alameda, 510-758-4012
- Albany, 510-559-6536
- Berkeley, 510-644-6210
- Emery (Emeryville), 510-601-4909
- Piedmont, 510-594-2893

### Mid-Alameda County (MAC) SELPA

- Castro Valley, 510-537-3000, Ext. 1200
- Hayward, 510-784-2611
- San Leandro, 510-667-3507
- San Lorenzo, 510-317-4761

### Mission Valley SELPA

- Fremont, 510-659-2569 or 659-2515
- New Haven (Union City), 510-489-4141
- Newark, 510-818-4205

### Oakland Unified School District SELPA

- Oakland, 510-879-3070

### Tri-Valley SELPA

- Dublin, 925-828-2551, Ext. 8014 or 8037
- Livermore, 925-606-3208 or 606-3286
- Mountain House, 925-426-9114
- Pleasanton, 925-426-4293
- Sunol Glen, 925-862-2026

## Therapeutic Approaches

Parents of children who fall on the autistic spectrum are frequently overwhelmed when confronted with the many treatment/educational approaches suggested for their children. The following is an explanation of some of the most widely used techniques. This list is not exhaustive. Some of these techniques are comprehensive programs, while others are designed to target a specific area.

**This listing does not constitute an endorsement of any particular technique, but is intended to be informational only.** Some of these techniques have been well-researched, while others are based on very limited evidence. This guide will give you a brief description only. Please find out more about any techniques you decide to use with your child.

### Applied Behavior Analysis (ABA):

#### Theory

Applied behavior analysis is the implementation and evaluation of systematic environmental modifications for the purpose of producing socially significant improvements in behavior based upon an experimental analysis of behavior. It includes the identification of functional relationships between behavior and environments. ABA depends upon direct observation of behavior and the environment with an analysis of contextual factors, establishing operations, positive reinforcers, antecedent stimuli, and consequences in order to make a change in behavior.

#### Goals

The goal of ABA is to create socially significant change to a meaningful degree and to demonstrate that the interventions employed are responsible for the behavioral changes. More specifically, ABA is used to increase behaviors, teach new skills, maintain behaviors, generalize skills, decrease inappropriate behaviors, and modify contextual variables in the environment.

#### Technique

ABA includes but is not limited to the analysis of behavior through a functional analysis assessment and the development of behavioral intervention plans. ABA also includes the development of skills through the use of task analysis (breaking down into small parts), discrete trial training (DTT), and Pivotal Response Training (PRT). Specific techniques include (but are not limited to this list):

- Reinforcement to increase behaviors such as sitting in a chair, using words
- Teach new skills through shaping such as verbal language
- Maintain behaviors that have been acquired such as through self-monitoring
- Generalize skills to different environments, with new people, and across a variety of materials

- Reduce problematic behaviors such as self-injury and self-stimulation
- Teach the skill with awareness of natural cues to facilitate generalization and maintenance
- Use stimulus control to restrict the conditions under which problematic behaviors occur

### **Evidence**

ABA has evidence to support its effectiveness for people with disabilities including autism. The research has been well-documented in many scientific peer-reviewed journals including but not limited to Journal of Applied Behavior Analysis, Research in Developmental Disabilities, and Journal of Positive Behavior Interventions.

## **Discrete Trial Training (DTT):**

### **Theory**

Discrete trial training is based on applied behavior analysis (ABA) principles. This teaching method involved breaking tasks down into basic elements and teaching the child through repetition. An individualized program is designed for each child so that the child's specific strengths and weaknesses are appropriately addressed. It is recommended that treatment begins early in life and continues for an extended duration of time.

### **Goals**

The goal of the DTT program is to teach the child all that is required of a typically developing child of the same age. Optimally the gap between the child's chronological and mental age will be narrowed or eliminated. This method is designed to develop cognitive, play, social, and self-help skills.

### **Technique**

This program can consist of 10-40 hours per week of one-to-one discrete trial training. The instruction is most often performed in the home and at school with therapists and/or parents. Specific techniques include:

- Breaking a skill into smaller parts
- Teaching one sub-skill at a time until mastered
- Providing concentrated teaching
- Providing and fading prompts as necessary
- Using reinforcement procedures

Flexibility and patience are extremely necessary for DTT. Language, social, and play skills typically develop over months and years of intervention.

## **Floor Time:**

### **Theory**

According to proponents of this theory, children with ASD have a weak connection between their emotions and their behaviors or the words to communicate them. Floor Time focuses on the developmental milestones to encourage the introduction and mastery of multiple necessary skills for children. The developmental milestones are:

- Self-regulation and interest in the world
- Intimacy
- Two-way communication
- Complex communication
- Emotional ideas
- Emotional thinking

### **Intervention**

Floor Time should be fun and spontaneous play. The therapist/parent has assumed the role of an active play partner who follows the lead of the child in whatever he expresses interest in, while encouraging him to interact. Basing the Floor Time on a toy or game of the child's choice keeps him motivated and engaged, while promoting the connection between emotions and behaviors. Actively following the child's lead by building on what he does compels him to participate in two-way interaction. At the most basic level, this program involves helping the child open and close circles of communication. A circle of communication is opened and closed when a child evidences some interest or behavior and the parent responds to that interest in a way that is acknowledged by the child. The ideal program for a child with emotional and developmental challenges, according to proponents of this approach, would include speech therapy, sensory integration therapy, and an educational placement that includes interaction with typical peers.

### **Goals**

The four goals of Floor Time coordinate with the emotional milestones to assist the child in progressing and mastering necessary developmental skills.

- Attention, engagement, and intimacy (connect with the child and experience mutual joy)
- Two-way communication (encourage on-going, non-verbal interaction that occurs reciprocally)
- Feelings and ideas (help the child navigate the world of symbols and ideas, to use words and play to express emotion)
- Logical thinking (have the child make a bridge between his internal world and yours)

### **Guidelines**

The guidelines promote consistent and stable environment conducive for comfort and learning by the child. Emotions drive behavior, and emotions and behavior drive language by building on the child's emotions by following his lead and interacting. This is accomplished by:

- Uninterrupted 20-30 minutes, up to 8 times a day
- Empathize with the child's emotional tone
- Play at the child's developmental level
- Be aware of your own feelings
- Child's rules: no hitting, hurting, or breaking things

### **Evidence**

Floor Time has evidence as published in anecdotal reports from practitioners and parents. It does not have controlled studies that have been held up to scientific rigor. Specifically, it has been analyzed as a method to enhance relationships and language.

## **Music Therapy:**

### **Theory**

Music therapy seeks to use music as a facilitating agent, or therapeutic tool, to further growth and development in the child. Proponents of music therapy believe that music can be used successfully as a medium for helping individuals with developmental disabilities, including autism.

### **Goals**

The goals of music therapy are usually to improve various aspects of a person's physical and mental health and to foster desired change in behavior. Goals often include improving play, socialization, and sensory integration.

### **Evidence**

Music therapy has been reported by parents and practitioners to improve the child's behavior and learning. There have not been well-controlled scientific studies of the impact of music therapy upon children with autism.

## **Occupational Therapy (OT):**

### **Theory**

Occupational therapy benefits a child with ASD by attempting to improve the quality of life through successful and meaningful experiences. The intervention is based on developmental and learning theories.

### **Goals**

The goal of OT is to increase a child's ability to function in everyday life activities that provide meaning. OT targets performance and participation in tasks such as self-care, work, play, and school. This can be accomplished through the



maintenance, improvement, or introduction of skills required to be successful in these activities.

### **Techniques**

Children are assessed in terms of age appropriate life tasks. OT then addresses the areas that interfere with the child's ability to function independently by using a variety of play techniques to teach:

- Appropriate play activities
- Self-help skills
- School readiness skills
- Fine motor skills
- Coping skills

### **Evidence**

OT has been demonstrated to be effective for skill acquisition of motor skills. The effectiveness of OT has been demonstrated through research in peer-reviewed journals.

## **Picture Exchange Communication System (PECS):**

### **Theory**

PECS offers children a unique alternative communication system. It can be used in a variety of settings including the home, the classroom, and the community. The system is based on the principles of applied behavior analysis. According to the proponents of this system, it is more beneficial than other types of augmentative communication. Because natural reinforcers are used, there is no need to train prerequisite skills such as pointing or imitation. In other words, natural use of communication is built into the program, and children can learn the PECS system without needing to imitate.

### **Goals**

The goal of PECS is to teach children a form of communication that requires few prerequisite skills. Providing children with a functional form of communication allows them to get their needs met, make choices, engage with people, and form a sense of control over their environment. Early research indicates that children using PECS often also use spoken language after a period of time.

### **PECS Components**

Children using PECS are taught to give a picture of a preferred item to a communicative partner in exchange for the item. The initial communicative behavior is requesting and the preferred items serve as reinforcers for communication. The communication is motivating for the child because she is receiving reinforcement for her choice. Requesting is an extremely useful skill and may facilitate the development of other communicative intents. Physical prompts are faded quickly to insure independent communication. Once the

behavior of requesting with pictures is firmly established, the child is encouraged to verbalize the request.

### **Evidence**

Whereas PECS is widely used in ABA programs and ABA classrooms, it has not been widely researched. Studies have been conducted and presented at professional conferences; however, there are a limited number of publications in peer-reviewed journals demonstrating the effectiveness with people with autism.

## **Pivotal Response Training (PRT):**

### **Theory**

This intervention is also based on the principles of applied behavior analysis. This technique is used to identify certain behaviors ('pivotal' behaviors) for treatment that will produce simultaneous changes in many other behaviors. These pivotal behaviors are believed to be central to wide areas of functioning, so positive changes in pivotal behaviors should have widespread effects on many other behaviors. The two important pivotal behaviors addressed using PRT are motivation and responsiveness to multiple cues.

### **Goals**

PRT works to increase motivation in developing and acquiring new skills such as language acquisition, social interaction, and play.

### **PRT Techniques and Components**

The question/instruction/opportunity to respond should:

- Be clear, uninterrupted, and appropriate to the task
- Be interspersed with maintenance tasks
- Be chosen by the child
- Include multiple components when appropriate

The reinforcers should be:

- Contingent upon behavior
- Administered following any reasonable attempt to respond
- Related to the desired behavior in a direct way

Other important aspects of PRT include turn-taking, frequent task variation, allowing child choice, and natural consequences. This intervention is flexible and designed to be used in structured one-on-one teaching or a natural setting. This technique provides therapists, parents, teachers, and caregivers with a method of responding to the child with ASD, which provides teaching opportunities throughout the day. Integrating PRT into everyday living can facilitate generalization and maintenance of the desired behavior change.

### **Evidence**

PRT has been researched across a few different situations such as with peers, to increase play skills, and with parents. These studies have been published in peer-reviewed journals. PRT has been implemented and disseminated for about

one decade. Recently, this procedure has drawn more attention from practitioners and researchers. More studies are being conducted and have been presented at national conferences but have not yet been published.

### **Rapid Prompting Method (RPM):**

The Rapid Prompting Method was developed by Soma Mukhopadhyay (initially to teach her son with autism) and has been used to instruct many others. RPM is a method used for teaching by eliciting responses through intensive verbal, auditory, visual, and/or tactile prompts. RPM presumes competence to increase students' interest, confidence, and self-esteem.

#### **Techniques**

Prompting serves to compete with each student's self-stimulatory behavior and is designed to keep students focused and successful. Student responses evolve from picking up answers, to pointing, to typing and writing which reveals students' comprehension, academic abilities, and eventually to conversational skills. RPM is a low-tech approach, requiring only paper and pencil. But the science behind how and why it works for some individuals is much more complex.

#### **Evidence**

RPM is a technique that has been successful for educating one child with autism. The one student and his mother, who developed the technique, have received widespread attention (BBC television). This one student remains non-verbal and engages in self-stimulation. However, he communicates through writing and typing on a computer. The technique is currently being researched for other students. The research has the support and funding from CAN.

### **Relationship Development Intervention (RDI):**

#### **Theory**

The RDI program is a parent-based clinical treatment for individuals with autistic spectrum and other relationship-based disorders. RDI is modeled after the way typical children become competent in the world of emotional relationships. The model for intervention begins with the Relational Development Assessment, careful assessment to pinpoint the specific stage of readiness or the appropriate developmental place to begin working. RDI is based on the model of Experience Sharing Interaction developed by Steven Gutstein, Ph.D.

#### **Goals**

The primary goal of the RDI Program is to systematically teach the motivation for and skills of Experience Sharing Interaction.

## **Objectives**

Grouping of objectives is based on the RDI curriculum, composed of six levels and 28 stages. Each of the stages represents a dramatic development shift in the central focus of relationships. Objectives are divided into 'Functions' that are the reasons why we engage in an action, and 'Skills', the specific proficiencies needed to be competent. Along with social objectives, the RDI curriculum encompasses a number of non-social areas including flexible thinking, rapid attention shifting, reflection, planning, forethought, preparation, emotion regulation, improvisation, creativity, mistake management, and problem-solving. Individuals certified in RDI use an assessment to determine the level of need for the child and then use a specified curriculum developed by the authors of the program.

## **Evidence**

RDI has been widely marketed through books, workshops, and trainings by its originator, Dr. Gutstein. This method has not been systematically researched other than unpublished data collected by Dr. Gutstein. RDI has not had any empirical studies published in peer-reviewed journals.

## **Sensory Integration (SI)/Sensory Processing:**

### **Theory**

Sensory integration is an innate neurobiological process that refers to the integration and interpretation of sensory stimulation from the environment by the brain. It is the brain's process of organizing and interpreting information from sensory experiences that involve touch, movement, sight, sound, body awareness, and the pull of gravity. Most children develop and integrate this information naturally as they grow, but children with ASD may have a dysfunctional sensory system. It is believed that a problem with an individual's ability to process such information could manifest as learning and behavior disorders. The following are distinct behavioral characteristics of sensory integration dysfunction:

- Hyper- or hypo-sensitivity to touch, movement, sight, or sound
- Impulsivity
- Distractibility
- Inability to unwind or calm self
- Lack of a healthy self-concept
- Physically clumsy
- Socially and/or emotionally immature
- Difficulty with transition
- Delayed speech, language, or motor skills
- Delayed academic achievement

### **Goals**

The goals of sensory integration are to provide the child with sensory information that helps to organize the central nervous system, to assist him in modulating

sensory information, and processing more organized responses to sensory stimuli.

### **Intervention**

Interventions are designed to enhance growth and development by involving children in whole body activities that provide vestibular input. SI programs can involve sports activities, fine and gross motor play, creative thinking, interactive play, and even music. Specific techniques include brushing, deep pressure, joint compression, scooter board riding, swinging, jumping activities, etc.

### **Evidence**

Sensory integration itself has been widely researched and has many peer-reviewed publications that demonstrate effectiveness. There are very few studies that have been conducted on people with autism. There has been a call for well-designed, controlled studies of sensory integration for people with autism.

## **SCERTS Model (Social Communication, Emotional Regulation, and Transactional Support):**

### **Theory**

The SCERTS Model was developed out of 25 years of research and clinical/educational practice by a multidisciplinary team of professionals trained in communication disorders, special education, occupational therapy, and developmental and behavioral psychology. SCERTS is a comprehensive, multi-disciplinary approach to enhancing communication and social/emotional abilities, and for supporting families. It provides an individualized education/treatment approach based on a child's strengths and needs, guided by research on the development of children with and without disabilities.

### **Goals**

SCERTS offers a framework to directly address social communication and emotional regulation, the core challenges of ASD. It focuses on building a child's capacity to communicate with a conventional, symbolic system from pre-verbal to conversational levels of communication. It also focuses on the development of self and mutual regulatory capacities to regular attention, arousal, and emotional states.

### **Program**

The SCERTS Program is designed to be comprehensive and address the following areas:

- Social communication, including joint attention and symbolic behavior
- Emotional regulation, including self-regulation, mutual regulation, and the ability to recover from dysregulation
- Transactional support including educational supports, interpersonal supports, family supports, and collaboration among professionals

## **Social Stories:**

### **Theory**

Many persons with autism have deficits in social cognition, the ability to think in ways necessary for appropriate social interaction. This deficit is addressed using social stories in which individuals with autism “read” about difficult social situations. The idea is that the child can practice and learn about social events in a structured, safe format, before the event occurs.

### **Goals**

The goal of using social stories is to help a person predict and understand what may occur in a social situation, thereby increasing the person’s success in that situation and reducing behavior problems associated with it.

### **Intervention**

Social behaviors are presented in the form of a story. This can be done with words or pictures, be read by the individual or to the individual, or listened to via audiotape. Once the individual successfully enacts the skills or appropriately responds to the social situation in the story, the use of the story can be faded. Stories can be re-written to address variations in a situation and can be individualized to the specific needs of the person with autism.

### **Evidence**

Despite widespread acceptance of this technique there have been limited publications in peer-reviewed journals.

## **Speech and Language Therapy:**

### **Theory**

The acquisition and effective use of communication is an integral part of daily life. Language and speech is the primary and optimal form of communication as it allows for the most detail and specification. Assisting children to communicate through speech provides more opportunity for engagement with others as well as having needs met.

### **Goals**

There are many goals for speech therapy depending on the specific needs of the child. The treatment works to attain the best form of language or speech that the child can communicate. Therapy will address all areas of receptive and expressive language. Other areas of focus may be to expand vocabulary, teach direction-following skills, and organizing language.

### **Therapy Components**

Speech and language therapy intervention may take place in the form of one-on-one sessions, home programs, social groups, or computerized training programs. Therapy will work to improve:

- Receptive and expressive language
- Word retrieval
- Vocabulary development
- Comprehension/auditory processing
- Articulation
- Oral motor disorders
- Language organization

### **Evidence**

There have been many studies published in peer-reviewed journals that support the use of speech therapy for people with autism.

### **TEACCH (Treatment and Education of Autistic and Communication Handicapped Children):**

#### **Theory**

TEACCH is a state-funded public health program available in North Carolina, which provides services from the time of diagnosis, early intervention, and early counseling for parents and professionals. A hallmark of the TEACCH program is to provide “Structured Teaching”. This technique is based upon the observation that children with autism learn and integrate information differently than other children. TEACCH believes that many non-compliant behaviors of children with autism are a result of their difficulty understanding what is expected of them. TEACCH uses the children’s strength in visual processing as a cornerstone of the intervention.

#### **Goals**

The structured teaching technique is designed to help the children understand expectations, remain calm, focus on relevant information through visual cueing, achieve independence in tasks, and manage behavior.

#### **Technique**

Structured teaching places a heavy emphasis upon teaching through visual modes due to the difficulties most children with autism have with processing verbal information. Visual structure is provided at many levels, such as organizing areas of the classroom, providing a daily schedule using pictures or written words, visual instructions, and visual organization signaling the beginning and end of tasks.

### **Anti-Yeast Therapy:**

#### **Theory**

This theory is currently hotly debated in the field. Some medical professionals believe that there is a link between *Candida Albicans* and autism as well as other learning disabilities. *Candida* is a yeast-like fungus that is normally present in the body to some degree. Certain circumstances, however, may lead to an

overgrowth of yeast that a normal, healthy immune system would otherwise suppress. The more severe symptoms of yeast overgrowth may include long-term immune system disturbances, depression, and possibly autism.

### **Medical Complaints Associated with Candida Albicans**

- Intestinal problems (constipation, diarrhea, flatulence)
- Distended stomach
- Excessive genital touching in infants and young children
- Cravings for carbohydrates, fruits, and sweets
- Unpleasant odor of hair and feet, acetone smell from mouth
- Skin rashes
- Fatigue, lethargy, depression, anxiety
- Insomnia
- Behavior problems
- Hyperactivity

### **Treatment**

Treatment for Candida overgrowth usually includes a prescription of antifungal medication. In addition, certain herbal formulas are sometimes used. Along with antifungal medications, a diet that eliminates sugar, yeast, and many other foods is a critical part of the treatment. Symptoms may grow worse at the onset of treatment but may gradually improve if Candida overgrowth is in fact contributing to the patient's problems. Finally, it is important to note that Candida Albicans is not the only yeast that may cause problems. Stool analysis may reveal serious problems in various functions of the body.

### **Dietary Interventions:**

#### **Theory**

The role diet and allergies play in the life of a child or adult with autism is not yet well understood. This means that parents who wish to explore this avenue of treatment must really do their homework. There has not yet been extensive research in this area for autism. Some preliminary research studies have indicated that individuals with autism may have trouble metabolizing peptides into amino acids because of an enzyme deficit. Two sources of protein, gluten and casein, are particularly suspect. Some anecdotal success has been noted when diets were modified to exclude casein and gluten. There are ways to uncover allergies. Some tests are more effective than others at discovering intolerance to food and chemicals. Careful research and consultation with a professional who is skilled in this area are probably your best bets in determining which tests are most appropriate. Food intolerances can often be determined by beginning a rotation or an elimination diet and observing any changes in behavior.

#### **Treatment**

Dietary changes are the treatment for gluten and casein, or other allergies. Commitment and perseverance on the part of parents are required to make



dietary changes and stick with them. Although any food could be the offender, there are several foods that are considered prime suspects in relation to behavioral disturbances. Sugar is one, as some children are allergic to it, and they may also be unable to metabolize it properly. As a result the adrenal glands in the body become stressed and depleted and over time cease to function normally. The effects may include mood swings, irrational behavior, irritability, sleep disturbances, nervousness, etc.

Other foods that cause allergic reactions are, unfortunately, foods we often consume the most. Wheat is one such food. Milk has also been linked to behavior problems. Other common food offenders include corn, chocolate, chicken, tomatoes, and certain fruits. However, any food can cause an intolerance or sensitivity. There may be more than one food that causes difficulty. Other substances may also cause reactions in children. These include food additives such as phosphates and food colorings, molds, chemicals, perfumes, and other substances.

### **Vitamin/Nutritional Supplements Therapy:**

#### **B6/Magnesium Supplements**

The goal of vitamin therapy is to normalize the body metabolism and improve behavior. Studies have shown that vitamin B6 may help normalize brain waves and urine chemistry, control hyperactivity, and improve overall behavior. It may also help in reducing the effects of allergic reactions by strengthening the immune system. Although improvements vary considerably among individuals, other possible improvements from B6/magnesium therapy are speech improvements, improved sleeping patterns, lessened irritability, increased attention span, decrease in self-injury/self-stimulation, and overall improvements in general health.

#### **Dimethylglycine (DMG) Supplements**

Dimethylglycine (DMG) is a food substance. Its chemical make-up resembles that of water-soluble vitamins, specifically vitamin B15. Anecdotal reports from parents giving their child DMG indicate improvements in areas of speech, eye contact, social behavior, and attention span. Occasionally, if too much DMG is given, the child's activity level has been seen to increase; otherwise, there are no apparent side effects.

### **Medications for Treatment of Symptoms of Autism:**

No primary medication is used to treat autism. Medications are usually prescribed to decrease specific symptoms associated with autism. These symptoms may include self-injurious behavior, aggressive behavior, seizures, depression, anxiety, hyperactivity, or obsessive-compulsive behavior. Medications alone are not a solution to the problems associated with autism. Individuals with autism need well-rounded intervention, including behavior

management strategies, environmental modification, and positive support services. Parents wishing to try medications for their children should be given the support and knowledge necessary to maintain a safe level of treatment. Parents need to be aware of potential risks and harmful side effects, and should carefully weigh them against possible benefits before treatment begins. Dosage should be carefully considered and monitored. There must be good communication among parents, physicians, service providers, and school personnel to monitor treatment with any medication. Accurate data on the effects of medication are also essential.

Listed below are the various classifications of medications used to treat symptoms associated with autism.

- **Antipsychotics** – also known as neuroleptics or “major” tranquilizers, these are sometimes used to treat severe aggression, self-injurious behavior, agitation, or insomnia. Side effects may include tardive dyskinesia (an involuntary muscular twitching which may become irreversible), tremors, stiffness, and sleepiness. Medications include Mellaril, Haldol, Thorazine, and Risperdal.
- **Anticonvulsants** – given to control seizures. Side effects may include drowsiness, gum swelling, negative behavioral and cognitive performance. Medications include Tegretol, Depakote, and Dilantin.
- **Anti-anxiety** – sometimes used to relieve “nerves” or anxiousness. Medications vary in effectiveness for long-term anxiety. Side effects associated with Valium and Librium may include increased behavior problems. Some antidepressants are used to treat chronic anxiety. They include Trofranil, Elavil, and Paxil.
- **Antidepression, antimania** – these medications are used to treat disorders such as depression, compulsive behaviors, mania, panic, or anxiety. Lithium and Depakote are sometimes prescribed for bipolar (manic-depressive) disorders. Anafranil and Prozac are sometimes prescribed for compulsive behavior. Most antidepressants take two to three weeks before effectiveness is noted. Side effects may include agitation, insomnia, decreased appetite, and hyperactivity.
- **Beta blockers** – these medications are usually used to control blood pressure, but are sometimes given to individuals to decrease aggression or hyperactivity caused by a rush of adrenaline. The beta blockers help to prevent the adrenalin rush and allow the individual to control impulsive reactions. Medications include Inderal and Clonidine/Catapres. They may cause drowsiness, irritability, and lowered blood pressure.
- **Opiate blocker** – some researchers theorize that self-injurious behaviors may cause the brain to release endorphins (chemicals which produce an opiate-like “high”), which may cause the individual to continue the self-injury in order to feel good. Opiate blockers act to block the pleasurable sensation and allow the individual to feel the

pain. As a result, self-injury may diminish. Sometimes, a sedating effect has been noted. Naltrexone/Trexan is an opiate blocker. These drugs may also improve socialization and general well-being.

- **Sedatives** – are given to individuals who have difficulty sleeping. Often medication is gradually withdrawn when normal sleep patterns are established. If the medication is not suitable for an individual it can cause excitation or sleeplessness. Chloral Hydrate, Noctec, and Benadryl are examples of sedatives.
- **Stimulants** – sometimes prescribed for hyperactivity and attention or concentration problems. Side effects may include decreased appetite, sadness, tantrums, and hyperactivity after the medication wears off. Ritalin and Dexedrine are stimulants.

Medications can sometimes help an individual with autism by providing relief from specific symptoms that interfere with daily life. Their use should be carefully monitored both by parents and professionals caring for the individual with autism.

**Caution:** *The above list of treatment options represents a list of commonly-used practices and does not represent endorsement. Please contact a professional before beginning any treatment program.*

## **Legislation and Entitlements**

### **Part C of the Individuals with Disabilities Education Act (IDEA)– Early Intervention:**

Part C of IDEA, known as California's Early Start Program, outlines the regulations that specifically address the birth-to-three population. This amendment is for the population with qualifying disabilities or who have a diagnostic condition that places them 'at risk' for future or substantial delay. The purpose of Part C is to enhance the development of infants and toddlers with disabilities by minimizing potential for delay, while enhancing the capacity of families to meet these special needs.

#### **Definition of an Infant or Toddler with Disabilities**

A child who is younger than three years old that is experiencing developmental delays in:

- Cognitive development
- Physical and motor development (including vision and hearing)
- Delay in communication development
- Delay in social/emotional development or adaptive development

The diagnosis or determination of an existing developmental delay must be made by a professional such as a licensed psychologist, neurologist, or physician. The diagnosis will then lead to a referral requesting an assessment to identify the child's strengths, needs, and appropriate services. After the assessment (which must take place within 45 days of the referral) a multidisciplinary team including the parents develops an Individual Family Service Plan (IFSP) based on the unique needs of the child and the family's concerns, priorities, and resources. The IFSP defines the child's present level of development and structures an action plan to meet the special needs. The IFSP is reviewed every six months.

#### **Services Included Under Part C**

Services must be designed to meet the unique needs of each child and family and may include:

- Assistive technology devices
- Audiology
- Family training
- Counseling and home visits
- Health services
- Medical services
- Nursing services
- Nutrition services
- Occupational and/or physical therapy
- Psychological services

- Respite care
- Social work services
- Service coordination
- Special instruction
- Speech/language services
- Transportation services
- Vision services

### **Individuals with Disabilities Education Act:**

Special education programs are governed under this law and its recent amendments for students from birth to 22. IDEA requires school districts to provide each student with a disability with a free and appropriate public education (FAPE). FAPE means special education and related services are to be provided at public expense and without charge, meet appropriate standards, include preschool through secondary education, and conform to an Individualized Education Program (IEP). Special education must be provided in the least restrictive environment: to the maximum extent appropriate all students with disabilities will be educated with students who do not have disabilities.

### **Qualifying Areas for Eligibility**

- Autism
- Deaf-blindness
- Deafness
- Hearing impairment
- Mental retardation
- Multiple disabilities
- Traumatic brain injury
- Orthopedic impairment
- Other health impairment
- Serious emotional disturbance
- Speech or language impairment
- Specific learning disability
- Visual impairment

The local school district is responsible for providing special education services to children. The IEP requires related services that may include:

- Speech/language therapy
- Audiology services
- Orientation and mobility instruction
- Home/hospital instruction
- Adapted physical education
- Physical therapy
- Occupational therapy
- Vision services
- Counseling

### **Section 504 :**

Section 504 of the Rehabilitation Act of 1973 outlines modifications for special education eligibility. A child who may have trouble learning may not be found eligible for special education services because the deficit may not fit into the criteria, or be severe enough to qualify for eligibility under IDEA. Such a child may qualify for special services and program modifications under the federal anti-discriminatory law Section 504. This law was designed to implement regulations that will appropriately accommodate students' needs and conditions as adequately as the needs are met of students without disabilities. Section 504 protections are available to students who can be regarded in a functional sense as having a physical or mental impairment that substantially limits a major life activity.

### **Lanterman Act:**

The Lanterman Developmental Disabilities Services Act establishes the rights of persons with developmental disabilities to services and supports they need and choose. These services are arranged by local regional centers which were established through the Lanterman Act. Persons who are eligible for regional center services are persons with a developmental disability, which is defined as mental retardation, cerebral palsy, epilepsy, autism, or other conditions closely related to mental retardation or requiring treatment similar to that required by persons with mental retardation. The condition must have occurred before age eighteen and it must constitute a substantial disability, which is defined as the existence of significant functional limitations in three or more of the following areas of major life activity, as determined by a regional center and as appropriate to the age of the person: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency. The condition cannot be solely psychiatric, solely a learning disability or solely physical in nature. There is no citizenship requirement. A client must be a resident of the State of California.

## Resource Information

### Family Support and Support Groups:

California's Early Start Program has established peer family resource and support programs throughout California. These resource centers provide a range of family support activities such as mentor parent programs, resource and referrals, support groups, parent training and education, "warmlines", web sites, written resource directories, and other supports. The Alameda and Contra Costa County peer support family resource centers serve parents who have children through age 22. Services are available in Spanish and English. Below is the contact information for the peer support programs in both Alameda and Contra Costa Counties.

In Alameda County, contact:

**Family Resource Network**, 5232 Claremont Avenue, Oakland, CA 94618  
510-547-7322, [www.frnoakland.org](http://www.frnoakland.org)

In Contra Costa County, contact:

**CARE Parent Network**, 1340 Arnold Drive, Suite 115, Martinez, CA 94553  
800-281-3023, [www.careparentnetwork.org](http://www.careparentnetwork.org)

### Support Groups in Alameda County

The Umbrella Club, Starbucks, Dublin  
[kmgwin@pacbell.net](mailto:kmgwin@pacbell.net)

Fremont Autism Support Group  
[katew@frnoakland.org](mailto:katew@frnoakland.org)

Angelitos del Futuro con Autismo  
[valescas@frnoakland.org](mailto:valescas@frnoakland.org)

### Support Groups in Contra Costa County

Special Kids Parent Support Group

925-516-9690

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

Autism Spectrum Disorder & Non-Verbal Learning Disabilities Support Group

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

Autism Family Support Project, We Care Services for Children, Concord

925-671-0777, Ext. 25

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

National Autism Alliance, California Chapter, San Pablo

510-237-9454

[www.freewebs.com/calnaa/](http://www.freewebs.com/calnaa/)

For additional information on special education advocacy, contact:

**Disability Rights Education Defense Fund (DREDF)**, Parent Training and Information Center, 2212 – Sixth Street, Berkeley, CA 94710

510-644-2555, [www.dredf.org](http://www.dredf.org)



### **Gluten and Casein Free Diets:**

Autism Educational Services, 732-473-9482

Ener-G Foods, 800-331-5222

The Gluten Free Pantry, 860-633-3826, [www.glutenfree.com](http://www.glutenfree.com)

The Gluten-Free Baker Newsletter, 361 Cherrywood Drive, Fairborn, Ohio  
45324-4012

Trader Joe's and Whole Foods offer a variety of items that are gluten free.

The Gluten Free Casein Free Diet  
[www.gfcfdiet.com](http://www.gfcfdiet.com)

Feingold Dietary Program  
[www.feingold.org](http://www.feingold.org)

Edward & Sons Trading Company, Inc.  
[www.edwardandsons.com](http://www.edwardandsons.com)

### **Vitamin Therapy:**

Center for the Study of Autism  
[www.autism.org/vitaminb6.html](http://www.autism.org/vitaminb6.html)

### **Internet Resources:**

Association for Science in Autism Treatment, [www.asatonline.org](http://www.asatonline.org)  
Autism National Committee, [www.autcom.org](http://www.autcom.org)  
Autism Research Institute, [www.autism.com](http://www.autism.com)  
Autism Society of America, [www.autism-society.org](http://www.autism-society.org)  
Beach Center on Families and Disability, [www.beachcenter.org](http://www.beachcenter.org)  
California Department of Developmental Disabilities, [www.dds.ca.gov/autism/](http://www.dds.ca.gov/autism/)  
Centers for Disease Control and Prevention, [www.cdc.gov/ncbddd/autism](http://www.cdc.gov/ncbddd/autism)  
Disability Resource Catalog, [www.disabilityresource.com](http://www.disabilityresource.com)  
Families for Early Autism Treatment (FEAT), [www.feat.org](http://www.feat.org)  
Interdisciplinary Council on Developmental and Learning Disorders,  
[www.icdl.com](http://www.icdl.com)  
MAAP Services for Autism & Asperger Syndrome, [www.asperger.org](http://www.asperger.org)  
National Dissemination Center for Children with Disabilities, [www.nichcy.org](http://www.nichcy.org)  
OASIS (Online Asperger Syndrome Information and Support),  
[www.udel.edu/bkirby/asperger/](http://www.udel.edu/bkirby/asperger/)  
Organization for Autism Research, [www.researchautism.org](http://www.researchautism.org)  
Resources in Autism Education, [www.autismmed.com](http://www.autismmed.com)

TEACCH Program, [www.TEACCH.com](http://www.TEACCH.com)  
University of California, Davis, M.I.N.D. Institute,  
[www.ucdmc.ucdavis.edu/mindinstitute](http://www.ucdmc.ucdavis.edu/mindinstitute)

### **Listservs**

Schafer Autism Report:, [www.sarnet.org](http://www.sarnet.org)  
Valerie Saraf's Newsletter, [ValeriesList@aol.com](mailto:ValeriesList@aol.com)

### **On-Line Forums/Chats**

[www.WrongPlanet.net](http://www.WrongPlanet.net)  
[www.groups.yahoo.com/group/eastbayautism](http://www.groups.yahoo.com/group/eastbayautism)

## **Books and Journals:**

### **Introductory Books**

Asperger's Syndrome (1998), Tony Attwood, Jessica Kingsley (publisher)  
Autism Spectrum Disorders (2000), Wetherby & Prizant  
Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorders, and Other ASDs, Chantal Sicile-Kira, Perigee Book  
Autism Treatment Guide (1996), Elizabeth Gerlach, Four Leaf Press  
The Child With Special Needs (1998), Stanley I. Greenspan  
Keys to Parenting the Child With Autism (1994), Marlene Brill, Barron's Education Series  
The World of the Autistic Child: Understanding and Treating Autism Spectrum Disorders, Bryna Siegel

### **Families and Personal Accounts**

Eating an Artichoke: A Mother's Perspective on Asperger Syndrome (2000), Echo R. Fling  
Eric's Story: Autism and the Autoimmune Connection, Ray Gallop  
For Parents and Professionals: Autism in Adolescents and Adults (1998), Kathie Harrington  
Just This Side of Normal (1993), Elizabeth Gerlach  
Let Me Hear Your Voice (1993), Catherine Maurice, Random House  
Living With Autism: The Parents' Stories (1995), Kathleen M. Dillon  
Love, Hope and Autism (1999), Joanna Edgar, National Autistic Society  
Pretending to be Normal, Liane Holliday Wiley  
There's a Boy in Here (1993), Judy and Sean Barron, Chapman  
Thinking in Pictures: and Other Reports of my Life with Autism (1995), Temple Grandin

## **Siblings**

Brothers & Sisters: A Special Part of Exceptional Families (1993), Thomas Powell and Peggy Ogle  
Brothers, Sisters, and Special Needs (1990), D. Labato, Paul Brookes  
Mori's Story: A Book About a Boy With Autism, Zachary M. Gartenberg and Jerry Gray  
Siblings of Children With Autism: A Guide for Families (1995), Sandra Harris, Woodbine House

## **For Children**

Are You Alone on Purpose? (1994), Nancy Werlin  
Having a Brother Like David (1985), Cindy Dolby Nollette  
Ian's Walk: A Story About Autism, Lears, Mathews, and Ritz  
Joey and Sam, Lilana Katz and Edward Rivoto  
Kristy and the Secret of Susan, (1999), Ann M. Martin, Econo-Clad Books  
My Brother Mathew (1992), Becky Edwards and David Armitage  
My Brother Sammy (1999), Becky Edwards and David Armitage, Millbrook Pr Trade  
Russell is Extra Special (1992), Charles Amenta

## **Education and Treatment**

Behavioral Intervention for Young Children With Autism (1996), ed. Maurice, Green, and Luce  
Educating Children With Autism (2001), National Research Council  
The New Social Story Book, Carol Gray  
Play and Imagination in Children With Autism (1999), Pamela Wolfberg  
The Out-of-Sync Child (1998), Carol Stock Kranowitz  
Reaching Out, Joining In: Teaching Social Skills to Young Children With Autism, Mary Jane Weiss and Sandra L. Harris  
Teach Me Language: A Language Manual for Children With Autism, Asperger's Syndrome, and Related Developmental Disorders, Sabrina Freeman and Lorelei Dake  
Teaching Children With Autism: Strategies to Enhance Communication and Socialization (1995), Kathleen Ann Quill  
Work in Progress: Behavior Management Strategies and A Curriculum for Intensive Behavioral Treatment of Autism, Ron Leaf, John McEachin, Jaisom D. Harsh

## **Laws and Advocacy**

Advocacy, Self-Advocacy, and Special Needs (1995), ed. Philip Garner, Richard Joss, and Sarah Sandow, Open University Press

Autism: Asserting Your Child's Right to a Special Education, David A. Sherman, AboutAutismLaw.com

Creating a Win-Win IEP for Students With Autism: A How-To Manual for Parents and Educators, Beth Fouse, Future Horizons, Inc.

The Complete IEP Guide: How to Advocate for Your Special Education Child, Lawrence M. Siegel

## **Monthly Publications and Journals**

Journal of Autism and Developmental Disorders

Focus on Autism and Developmental Disorders

Autism: An International Journal

## **Research Opportunities:**

California CADDRE

[www.ehib.org/caddre/SEED](http://www.ehib.org/caddre/SEED)

Kaiser Permanente, Division of Research

[www.dor.kaiser.org/studies/active/neuro.shtml#TopOfPage](http://www.dor.kaiser.org/studies/active/neuro.shtml#TopOfPage)

Stanford University, Center for Integration of Research on Genetics and Ethnicity

[www.cirge.stanford.edu/activities/autism.html](http://www.cirge.stanford.edu/activities/autism.html)

Stanford University, Center for Interdisciplinary Brain Sciences Research

[www.spnl.stanford.edu/disorders/autism.htm](http://www.spnl.stanford.edu/disorders/autism.htm)

University of California, Davis, M.I.N.D. Institute

[www.ucdmc.ucdavis.edu/mindinstitute](http://www.ucdmc.ucdavis.edu/mindinstitute)

## **Charities and Foundations:**

ACT-Today for Autism, [www.act-today.org](http://www.act-today.org)

Autism Family Resources, [www.autismfamilyresources.org](http://www.autismfamilyresources.org)

Autism Research Institute, [www.autismwebsite.com/ari/index.htm](http://www.autismwebsite.com/ari/index.htm)

Autism Speaks, [www.autismspeaks.org](http://www.autismspeaks.org)

Doug Flutie, Jr. Foundation for Autism. Inc., [www.dougflutie.org](http://www.dougflutie.org)

National Autism Foundation, [www.nationalautismassociation.org](http://www.nationalautismassociation.org)

United Healthcare Children's Foundation, [www.uhccf.org](http://www.uhccf.org)

## Sibling Issues

### Developmental Considerations:

The following is helpful information for parents. What do you tell . . . ?

- **Preschoolers (under age 5)** – Children in this age group are unable to articulate their feelings, so they will likely show their feelings through behaviors. They will be unable to understand the special needs of their sibling, but they will notice differences and may try to teach their brother or sister. Children of this age are likely to enjoy their sibling because they have not learned to be judgmental and their feelings toward their siblings will likely be linked to typical sibling interactions.
- **Elementary school age (6 to 12)** – These children start venturing out into the world and become acutely aware of the differences between people. They have the ability to understand a definition and explanation of their sibling's special need as long as it is explained to them in terms that they can understand. They may worry that the disability is contagious or wonder if something is different about them, too. They may also experience guilt for having negative thoughts or feelings about their sibling as well as guilt for being the child who is not disabled. Some typical responses of children in this age are to become over-helpful and well-behaved or to become non-compliant in order to attract a parent's attention. Throughout this age span, the children will have conflicting feelings about their sibling. This happens in sibling relationships that do not include a disability, too.
- **Adolescents (13 to 17)** – Adolescents have the capability of understanding more elaborate explanations of the particular disability. They may ask detailed and provocative questions. The developmental task of adolescence is to begin discovering oneself outside of the family. At the same time, conformity with peer groups is important. Therefore, for children this age, having a sibling who is different may be embarrassing in front of friends and dates. They may feel torn between their desire for independence from the family and maintaining a special relationship with their sibling. They may resent the amount of responsibility, and they may begin worrying about their sibling's future.

### Educate Your Children

Provide information to the child about how the condition is evaluated, diagnosed, and treated.

- Children need to know what the disability is and what to expect.
- Explain the strengths and weaknesses of the child with a disability.
- Demonstrate ways to interact with the sibling.
- Explain ways to help the sibling.

### **Balance Time Spent with Children**

Encourage children to have activities unique to him/her. Parental participation in activities outside the disability world/community with the child is important. Parental recognition of the sibling's strengths and accomplishments can build feelings of self-worth. Open discussion in the family should allow members to express both positive and negative feelings. It is helpful to have discussion of ways to cope with stressful events such as the public reaction of peers as well as unexpected changes in family plans, or extra home responsibility.

Participation in a group for siblings allows them to meet others in the same circumstance. A group also provides children with the chance to discuss feelings that may be difficult to express within the family.

### **Warning Signs (Depression, Anxiety)**

- Changes in a child's sleeping or eating habits
- Sense of helplessness or hopelessness
- Irritability
- Mentions hurting self
- Difficulty making decisions or concentrating
- Lack of pleasure in activities
- Social withdrawal
- Low self-esteem
- Excessive worry
- Increased energy without a purpose
- Tearful
- Difficulty separating from parents
- School phobia
- Somatic symptoms
- Perfectionism

If your child displays a number of these symptoms for a prolonged period of time (two weeks or more), it may be advisable to discuss the situation with the child's pediatrician or a local mental health professional.

## Glossary and Abbreviations

**ABA** – Applied behavior analysis

**Adapted Physical Education (APE)** – Instruction to develop a student’s motor skills, physical fitness, and self-image.

**Advocate** – An individual who works to secure the rights and services of a person with a disability.

**AIT** – Auditory integration training

**Assessment** – A process used to develop an accurate and thorough understanding of a child’s strengths and weaknesses in the following areas: cognition/developmental levels, social/emotional skills, sensory regulation, motor skills, behavior, play/leisure skills, pre-academic/academic skills, self-help/adaptive skills, independent living skills, prevocational/vocational skills, and community-based skills.

**Assessment Team** – Those who gather information for decision-making including psychologists, speech therapists, nurses, teachers, administrators, other therapists, parents.

**Case Manager (aka Service Coordinator)** – Primary person responsible for coordinating a child’s services, working in partnership with the family and providers of special programs.

**CCS** – California Children Services

**CH** – Communicatively handicapped

**Cognitive** – A term describing the mental process people use for remembering, reasoning, understanding, and using judgment.

**Community Advisory Committee (CAC)** – Mandated committee comprised of parents of children with disabilities, school district representatives, and representatives of other public and private agencies concerned with the needs of children with disabilities who meet to review the special education local plan and programs.

**Curriculum** – The specific features of a master teaching plan which reflect the skills, tasks, and behaviors that a school or program has decided are important for children to acquire.

**DB** – Deaf-blind

**Designated Instruction and Services (DIS)** – Supplementary or support services determined through the IEP process. (Also called Related Services.)

**DHH** – Deaf and hard of hearing

**Discrete Trial Training (DTT)** – Specific training procedures based on principles of applied behavior analysis that simplifies learning into small segments that the child can more easily master. Helps to eliminate unwanted behaviors as well as encouraging positive behaviors.

**Due Process** – The legal principles and practices that exist to ensure that each child is treated in a manner that guarantees his/her rights to equal education opportunities.

**Early Intervention Services of Programs** – The program or services designed to identify and treat a developmental problem as early as possible.

**Echolalia** – Immediate and involuntary repetition of words or phrases just spoken by others.

**ESL** – English as a second language

**Evaluation** – Collecting information about a student's learning needs, strengths, and interests. Part of the process of determining if a student qualifies for special education programs and services.

**Expressive Language** – That which is said or written to communicate an idea or question.

**FAPE** – Free and appropriate public education

**Fine Motor** – Use of the small muscles of the body, especially the hands and fingers.

**Floor Time** – A method for actively engaging children and families in a process that fosters social/emotional and cognitive development using a child's natural motivations and emotions to fuel development and relationships.

**Gross Motor** – Use of the large muscles of the body for activities such as running, climbing, throwing, and jumping.

**HI** – Hearing impaired



**Home Visit** – A professional visiting the home to talk with parents about their child’s progress, demonstrating activities and sharing ideas and materials.

**IA** – Instructional aide

**IDEA** – Individuals with Disabilities Education Act

**Inclusion** – The placement of students with disabilities in classrooms with typically developing peers of the same age.

**Individualized Education Program (IEP)** – A document outlining your child’s unique education plan by defining broad goals and specific objectives for the school year, the services needed to implement those goals and objectives, and a method of evaluating your child’s progress. Includes child’s present performance, and the specified instructions and services required by achieve the goals.

**Individual Family Service Plan (IFSP)** – A written plan for providing early intervention services to eligible children (birth to three) and their families. Includes a statement of the child’s present levels of development and the specific early intervention services needed to meet the unique needs of the child and family.

**Individualized Program Plan (IPP)** – A written plan including the goals identified by the consumer and actions needed to achieve the goals. Plan development is done by the consumer, family, Regional Center staff, and others as appropriate.

**Integration** – The mixing of students with disabilities with their non-disabled peers in education and community environments.

**Intervention** – A design to change an individual’s behavioral, educational, medical, or health status or a change in the program itself.

**Language** – A structured system of symbols, spoken or written, used in interpersonal communication including phonology, syntax, semantics, and pragmatics.

**Lanterman Act** – California law that establishes the right of persons with developmental disabilities to services and supports they need and choose. The intent is to support consumers to live independent and productive lives in the community.

**LD** – Learning disabilities

**Least Restrictive Environment (LRE)** – The placement or program that best meets the student’s needs which provides maximum integration with non-disabled peers.

**Mainstreaming** – Refers to the placement of children with disabilities into educational programs for typically developing children.

**Master Plan** – State plan for implementing special education services for individuals with exceptional needs.

**MH** – Multiply handicapped

**Occupational Therapy (OT)** – Therapy or treatment provided by an occupational therapist that helps the development of physical skills that will aid in daily living.

**O & M** – Orientation & mobility

**OHI** – Other health impaired

**OI** – Orthopedically impaired

**PECS** – Picture Exchange Communication System

**Perception** – Organizing or interpreting the information obtained through the five senses.

**Perceptual Motor** – The interaction of the various channels or perception with motor activities.

**PH** – Physically handicapped

**Physical Therapy (PT)** – Services provided by a physical therapy to help the person improve the use of bones, muscles, joints, and nerves.

**Pivotal Response Training (PRT)** – A training that offers a way to interact with the child with autism during the daily routine in a structured yet comfortable manner.

**Placement** – Unique combination of facilities, personnel, location, and equipment necessary to provide instructional services to a student with special needs as specified in the IEP.

**Receptive Language** – Language that is spoken or written by others and received by the individual (listening and reading).

**Reverse Mainstreaming** – Placing typical children in classrooms for children with disabilities.

**SED** – Seriously emotionally disturbed

**Sensorimotor Integration** – The combination of the input of sensation and the output of motor activity.

**SGI** – Small group instruction

**SH** – Severely handicapped

**Social Stories** – Personalized short stories written by teachers, therapists, or family members which utilize the child's strength as visual learner and are an approach to the complex area of developing social skills.

**Special Day Class (SDC)** – Classes for students with more intensive needs that cannot be met in the general education classroom.

**Special Education** – Educational programs or services designed to meet the needs of individuals with special needs that cannot be met in the general education classroom.

**Special Education Local Planning Area (SELPA)** – The organization of school districts into regional units to facilitate the delivery of special education services to children through the educational system.

**Speech/Language Therapy (ST)** – A planned program to improve and correct speech and/or language or communication problems.

**TEACCH** – Acronym for Treatment and Education of Autistic and Communicatively Handicapped Children, a broad-based program that uses visual cues to help a child comprehend tasks.

**VH** – Visually handicapped

**VI** – Visually impaired