



## AUTISM

Receiving a diagnosis of Autism Spectrum Disorder (ASD) or another related disorder may alter your dreams for your son or daughter. Even considering the possibility that your child may have ASD can be a difficult process. You will be receiving information from many sources and may feel overwhelmed and confused. Remember to maintain your determination, obtain the support you need, and don't lose hope. Matrix Parent Network is here to help support you as you begin your journey into this new world. When considering your options for helping your child, keep in mind that this is a marathon, not a sprint. You don't have to do everything at once. Take good care of yourself and your family, and remember to eat, drink, sleep, and most importantly, *breathe*.

There are few guidelines for predicting outcomes for children with ASD. However, research into causes and interventions is currently growing at an amazing rate. Much has been learned in the last ten years about ASD. For example, more adults with ASD are describing their experiences and providing us with incredible insight. There are many 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.

We invite you to use the information in this packet to begin to understand autism, the treatments and interventions available, the importance of family support and to obtain guidance on navigating your way through the many, many resources you will find in print, on the internet, through broadcasts (television and radio) and from the many professionals and parents you will meet.

*The library at the Novato Matrix office offers a wealth of articles, books, videos, magazines and other materials related to this topic. Additionally, our website offers resources and links to other websites of interest. Please check with us regarding workshops, support groups and other opportunities.*

***Matrix Parent Network and Resource Center***  
*Empowering families of children with special needs to understand and access the systems that serve them.*  
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[www.matrixparents.org](http://www.matrixparents.org)

# Frequently Asked Questions About Autism Spectrum Disorders

## What is an Autism Spectrum Disorder?

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 the American Psychiatric Association, 4<sup>th</sup> Edition (DSM-IV). 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** – Autism Spectrum Disorders can occur by themselves or in combination with other disabilities. Children may have symptoms of Attention Deficit Hyperactivity Disorder (ADHD). They may also experience learning disabilities (LD), anxiety disorders, obsessive-compulsive disorders (OCD), blindness, deafness, epilepsy, or mental retardation.

## What do children with ASD look like?

Children with ASD often look no different than any other typical child. At first glance, people may not recognize a person has ASD. Watching behavior is the best way to tell. 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 pretend 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.

### Other 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, like hitting or biting self
- Seizure disorder
- Discrepancy between verbal and non-verbal IQ
- IQ falling within range of mental retardation

If you would like to see what some of these behaviors look like in other children, go to <http://www.firstsigns.org/> and click on Video Glossary to see short clips of a variety of common behaviors.

## **How many children have ASD?**

The number of children born with, or who develop ASD, is estimated to be 1 in 150 births. It is the third most prevalent developmental disorder. It is four times more likely to occur in males than females for unknown reasons.

## **How are Autism Spectrum Disorders diagnosed?**

ASD cannot, at this point, be diagnosed using any type of medical test, like a blood test, genetic test, or 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.**

**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.

## **What causes Autism Spectrum Disorders?**

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. Studies have shown that if you have one child with autism, you are at some increased risk of having another child with autism.

# The Importance of Family Support

Parents of children with ASD need educational and emotional support, as well as physical recreation or relaxation, in order to function well as parents and as individuals. If your child is a Regional Center client (see information below), you can seek respite care services that can provide free of charge supervision for your child while you take a break, spend time with a sibling of your child with ASD, or simply run errands by yourself.

## Helpful Suggestions for Families:

- If you are sharing the responsibility of parenting a child with ASD with a partner, be sure to make a concentrated effort to spend quality time alone with your partner. Fostering your own adult relationships is crucial to keep your family together through difficult times.
- Provide information about your child's disability to siblings and friends. There are excellent books geared toward children that explain ASD in easy to understand language.
- Model ways the family can unite and interact positively with their family member with ASD:
  - Arrange structured conversation times at home when children talk about age-appropriate subjects to help generalize language and social skills.
  - Host structured "play dates" or "games nights" when siblings can model taking turns, sharing and negotiating in order to teach appropriate social behavior
  - If appropriate, engage siblings to coach adolescents with ASD about non-verbal nuances of social behavior regarding "cool" school age dress, behavior or social cues
- Balance time spent with all of the siblings, and don't forget to make time for an occasional visit with your own friends and family. You need their support.
- Encourage siblings to seek after school activities unique to their interests as a break from their family responsibilities.
- Call Matrix. We are here to help you.

Some of the services **Matrix Parent Network** provides are:

- ◆ **HELP Line – (800) 578-2592** staffed by Parent Advisors for general advice, information, support and referrals
- ◆ **In-depth Consultation** – support from a designated Parent Advisor
- ◆ **Parent Support Groups** – where parents of children with special needs meet and support each other
- ◆ **Trainings and Workshops** – on Individual Education Plans (I.E.P.), transition to preschool/kindergarten and special education processes
- ◆ **Information Packets** – on a variety of topics, such as Individual Education Plans, assessments, behavior, and transition to preschool and kindergarten
- ◆ **The Networker** – bi-annual publication with in-depth information
- ◆ **Networker Express** – monthly e-mail newsletter
- ◆ **Lending Library** – disability related books, magazines, video tapes
- ◆ **Website** – [www.matrixparents.org](http://www.matrixparents.org) with information and links

## How do I get services for my child with ASD?

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. Matrix Parent Network and Resource Center can help connect you with many of these agencies.**

### How to Get Help for Your Child (From Birth to Age 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 Golden Gate Regional Center, for Marin County, or North Bay Regional Center, for Napa, Solano, and Sonoma counties. Many therapeutic services and supports are available to residents of these areas.

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)*
- *Nutrition counseling*
- *Occupational therapy*
- *Physical therapy*
- *Psychological services*
- *Respite*
- *Service coordination (case management)*
- *Speech/language pathology 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 will ensure that services and community support 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. Most children diagnosed with ASD will continue to need services past their third birthday. A transition plan will be developed which will ensure that your child continues to receive needed services. Your Regional Center 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 your Regional Center**, 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. Different Regional Centers serve different counties.

**Golden Gate Regional Center serves Marin County:**  
**(888) 339-3305**

**North Bay Regional Center serves Napa, Solano, and Sonoma Counties:**  
*Birth to Age 3 (800) 646-3268      Age 3 and up (707) 256-1181*

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

If your child receives a diagnosis of autism spectrum disorder after their third birthday, you should contact your local school district to determine if s/he is eligible for special education preschool services. Children from age three and up receive educational and therapeutic services from the local school district. You should also contact your Regional Center (see listings above), since they can provide case management and other family support services.

Special education is guided by 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.

**Special Education Department Contacts:**

Marin County Special Education Local Planning Area (SELPA): (415) 499-5850  
Marin County Office of Education: (415) 472-4110  
Solano County SELPA: (707) 399-4460  
Vallejo SELPA (707) 556-8921  
Solano County Office of Education: (707) 399-4400  
Sonoma County SELPA: (707) 524-2750  
Sonoma County Office of Education: (707) 524-2600

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. Timelines apply to the response that a district must provide. **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.**

## **Treatments available for ASD**

While there are no cures for autism, there are many therapies available. One of the best ways to learn about each one is to go to your library or come to Matrix and speak with a Parent Advisor and use the many resources available in the Matrix library. Below is a list of some of the most commonly used treatments for ASD. **This listing is informational only and not an endorsement of any particular treatment.** Some of these techniques are well researched, while others are based on limited evidence. Please contact Matrix Parent Network for more detailed information about these therapies.

### **Applied Behavioral Analysis (ABA):**

ABA is used to teach new behaviors, decrease inappropriate behaviors, and generalize skills. It includes Discrete Trial Training (DTT) and Pivotal Response Training (PRT). ABA has well-documented evidence of effectiveness with some children.

### **Auditory Integration Therapy (AIT):**

AIT was developed to treat disorders of the auditory system such as hearing loss. It has been used to treat auditory processing issues in children with ASD in order to regulate the hearing of an individual who is over or under sensitive to sound. Present studies include differing opinions relating to a lack of scientific substantiation.

### **Floor Time:**

Floor Time is based on the Developmental, Individual Difference, Relationship-based (DIR) model. This approach views ASD as a biological disorder in which sensory processing difficulties work to prevent the normal development of skills. It is used as a method to enhance relationships and language. While Floor Time has not been systematically and independently validated, it does share important features with other forms of treatment that have received validation.

**Medications:**

Many doctors treat some symptoms of ASD with pharmacological agents (drugs). A variety of drugs are currently used to treat self-injurious behavior, hyperactivity, seizures, obsessive-compulsive disorder, aggression and anxiety or depression in children with ASD. Parents can consult with their medical doctor to target specific symptoms of ASD that could be helped by medications. Treatment may increase their child's ability to benefit from other services and to remain at home or in the community.

**Music Therapy:**

Music Therapy uses music as a therapeutic tool to further growth and development in the child. Although parents and practitioners have reported that significant improvements have been fostered in sensory integration, behavior, and play, as yet well-controlled scientific studies have not been completed upon children with ASD.

**Nutritional Treatments:**

A variety of nutritional treatments may be used by parents to treat physical and behavioral issues of children with ASD. Treatments include special diets such as the wheat and dairy free diet (gf/cf), anti-yeast therapy, vitamin B supplements, digestive enzymes and many others. Most of these therapies have not been proven in peer-reviewed studies, but have strong anecdotal evidence to support them.

**Occupational Therapy:**

Occupational Therapy (OT) attempts to increase a child's ability to function in everyday life activities such as: self-help skills, appropriate play activities, fine motor and school readiness skills. The effectiveness of OT has been demonstrated through research in peer-reviewed journals.

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

Based on the principles of ABA, this technique offers an alternative communication system. It is a functional form of communication that allows children to meet their needs, make choices, and engage with people. Early research indicates that children using PECS often use spoken language after a period of time. There are a limited number of publications in peer-reviewed journals demonstrating effectiveness with people with ASD.

**Pivotal Response training (PRT):**

Based on the principles of ABA, this method identifies certain (pivotal) behaviors for treatment that will produce changes in many other behaviors. The two important pivotal behaviors addressed using PRT are motivation and responsiveness to multiple cues. This method has been researched in peer-reviewed journals.

**Rapid Prompting Method (RPM):**

RPM is a method used for teaching by eliciting responses through intensive verbal, auditory, visual, and/or tactile prompts. This low tech method uses paper and pencil and rapid prompting to compete with self-stimulatory behaviors. It was developed by a mother to treat her son with autism. Research is not yet complete on the effectiveness of the method for all children.

**Relationship Development Intervention (RDI):**

The RDI program is a parent-based clinical treatment modeled after the way children typically become competent in emotional relationships. The primary goal is to systematically teach the motivation for the skills of experience sharing, leading to a better quality of life for the child as they mature. The method has not been systematically researched by a peer-reviewed source.

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

SCERTS offers a framework to address social communication and emotional self-regulation. It focuses on building a child's capacity to communicate with a conventional, symbolic system from pre-verbal to conversational levels of communication. It is guided by research on child development.

**Sensory Integration Therapy (SIT):**

Sensory Integration Therapy emphasizes the importance of the relationship between sensory experiences and motor and behavioral performance that support the learning of higher-level skills. There is no standardized SIT approach, so it is difficult to find a comprehensive review of research in this area.

**Social Stories:**

Since children with ASD have deficits with social cognition, this method provides stories about difficult social situations so children can practice and learn about appropriate social response in a structured format. Despite widespread acceptance of this technique, there have been limited publications in peer-reviewed journals.

**Speech and Language Therapy:**

Interventions take place in the form of one-on-one, group sessions, home programs, and social groups. Therapy works to improve various deficits, including receptive and expressive language, articulation, and oral motor disorders. There have been many studies in peer-reviewed journals that support the use of speech therapy for children with ASD.

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

TEACCH is a structured teaching method emphasizing the visual mode of processing for ASD children, using a daily schedule of pictures, instructions, and visual organization for discrete skills. TEACCH comprises specific interventions that have been empirically validated as effective. However, independent studies of its comprehensive program have not been done.

## Where can I get support?

Matrix Parent Network Information and Resource Center is a great place to start. Several Parent Advisors have direct experience raising children with ASD, and everyone who answers our **Helpline at (800) 578-2592** can give you information and support. We provide a range of family support activities such as resource and referrals, support groups, parent training and education, phone help, web sites, written materials, and other supports. Matrix sponsors one support group specifically for parents of children with Asperger's Syndrome, and plans are underway for more groups for parents of children with ASD. Below is a list of a variety of support groups throughout the area that are ASD specific. Remember that Matrix can provide information about an even wider variety of support groups that are more general, for parents of children with any kind of special needs.

### **ASD Related Support Groups in the North Bay**

Asperger's Support Group meets monthly at Matrix in Novato: (415) 475-2182

AutismHOPE meets the 3<sup>rd</sup> Monday of the month in Petaluma: (707) 344-4387

Solano FEAT (Families for Effective Autism Treatment) restarting meetings in Solano County in January 2008: (707) 410-6004

Talk About Curing Autism (TACA) meets the 2<sup>nd</sup> Tuesday of the month in Santa Rosa: (707) 524-6677

## Where can I find resources to learn more?

As ASD becomes more common, information is more readily available. Keep in touch with other parents to keep up to date on the latest resources. Below are some to get you started.

### **Internet Resources**

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)  
Autism Speaks, [www.autismspeaks.org](http://www.autismspeaks.org)  
Cure Autism Now (CAN) [www.cureautismnow.org](http://www.cureautismnow.org)  
Families for Early Autism Treatment (FEAT), [www.feat.org](http://www.feat.org)  
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)  
Organization for Autism Research, [www.researchautism.org](http://www.researchautism.org)  
TACA -Talk About Curing Autism, [www.talkaboutcuringautism.org](http://www.talkaboutcuringautism.org)  
M.I.N.D. Institute, University of California, Davis, [www.ucdmc.ucdavis.edu/mindinstitute](http://www.ucdmc.ucdavis.edu/mindinstitute)  
Schafer Autism Report, [www.sarnet.org](http://www.sarnet.org)  
Valerie Saraf's Newsletter, [ValeriesList@aol.com](mailto:ValeriesList@aol.com)

### **Books for Parents**

The Autism Book: Answers to your Most Pressing Questions (2005), Jhoanna Robledo and Dawn Ham-Kucharski  
Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorders, and Other ASDs (2004), Chantal Sicile-Kira  
The Complete Guide to Asperger's Syndrome (2006), Tony Attwood  
Living With Autism: The Parents' Stories (1995), Kathleen M. Dillon  
The New Social Story Book (2000), Carol Gray  
The World of the Autistic Child: Understanding and Treating Autism Spectrum Disorders (1996), Bryna Siegel  
Thinking in Pictures: and Other Reports of my Life with Autism (1995), Temple Grandin  
Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share their Wisdom (2006), Cindy N. Ariel and Robert A. Naseef

### **Books for Children and Siblings**

Siblings of Children with Autism: A Guide for Families (1995), S. Harris  
Everybody is Different: A Book for Young People Who Have Brothers or Sisters with Autism (2002), Fiona Bleach  
The Autism Acceptance Book: Being a Friend to Someone with Autism (2006), Ellen Sabin