

Autism: Finding Success the First Year

**Designed by Parent Mentors
Cynthia Macluskie
Katie Wride**



Join a local support group in your area. We have support group meetings in the East, North and West Valley. We also have online Facebook Group and Yahoo Group.

EAST VALLEY MEETING:

We are partnering with EVAN (East Valley Autism Network) for this meeting each month

TIME: 6:30 to 8:30pm

WHEN: 4th Tuesday of each month

WHERE: Mi Amigo's Mexican Restaurant-1264 S Gilbert Rd, Mesa, 85204

NORTH VALLEY MEETING:

TIME: 6:30 to 8:00pm

WHEN: 3rd Wednesday of the month

WHERE: Paradise Valley Community Center-17402 North 40th St. Phoenix, 85032

WEST VALLEY MEETING

AZA NOW- the Arizona Autism Network of the West Valley will be primarily assisting families in the West Valley seek services, networking opportunities, support, community events and much much more!

TIME: 6:30 to 8:30 PM

WHEN: 2nd Thursday

WHERE: Autism Academy Peoria 6810 W Thunderbird, Peoria 85381

Mom's Meet Ups

WHEN: Friday from 9:30 to 11:00 AM

NORTH VALLEY: Paradise Bakery at Desert Ridge, 21001 N. Tatum Blvd., Suite 48-1520
Phoenix, 85050

EAST VALLEY: Paradise Bakery at San Tan Village, 2156 E Williams Field Rd #101, Gilbert, AZ
85295

Facebook Group

Autism Society of Greater Phoenix Closed Group

<https://www.facebook.com/groups/526180957472727/>

Yahoo Group

Autism Society of Great Phoenix Family Support

<https://groups.yahoo.com/neo/groups/ASA-GPCFamilySupport/info>

Get a diagnosis

To qualify for services in Arizona you will need a risk of autism diagnosis (before age 6) or a diagnosis of Autism Spectrum Disorder (after age 6) by a psychologist, psychiatrist or developmental pediatrician. We have a list of professionals on our website at www.phxautism.org. School psychologists may not diagnose for the state and their diagnosis may only be accepted by the school district.

Contact Division of Developmental Disabilities

In order to be eligible for DDD you must:

1. Be a resident of Arizona
2. Be at risk of having a developmental disability (before the age of 6); after the age of 6 you must have a diagnosis of : epilepsy, cerebral palsy, Autism, or cognitive disability
3. Must be diagnosed before the age of 18
4. Must have functional limitation in 3 of 7 major life areas: Self-care, receptive/expressive language, learning, mobility, independent living, self-direction, economic self-sufficiency

Contact DDD at:

Arizona Division of Developmental Disabilities

602.542.0419

www.azdes.gov/ddd/

https://ddd.azdes.gov/ddd/EligibilityReferral/frm_ContactInformation.aspx

Arizona Early Intervention Program for children 0-3 years old

www.azdes.gov/azeip/azeipinfo.asp

Contact ALTCS

Contact ALTCS at the same time as you contact DDD. ALTCS must process your application within 45 days.

Arizona Long Term Care to qualify for federal funding for services: (ALTCS)

602-417-6600 –Phx office; 602-417-6400- Mesa office

<http://www.ahcccs.state.az.us/Services/Programs/ALTCS.asp>

- You will first have a financial interview over the phone to make sure that your child does not have more than \$2000 in his/her name to qualify.
- Next you will have an interview to determine if your child is at risk for institutionalization. The interviewer will ask you questions from the PAS tool and you will need 40 points to qualify for services.
- Contact an AS-GP Parent Mentor to help you through this process.

Arizona's Health Care Cost Containment System AHCCCS (state Medicaid and Medicare insurance) Once you are approved for ALTCS and DDD you will select a health plan. Currently there are three choices. You read the member handbook, check out the plans and the formularies and search for providers:

<https://des.az.gov/services/disabilities/developmental-child-and-adult/altcs-home>

Contact your local school district

In order to get appropriate services for your child in school, contact your local school district and ask in writing for a complete Educational evaluation to be completed on your child. They will have 60 days to evaluate your child.

To find your school district look up Arizona Department of Education at: www.ade.az.gov or call 602-542-5393

Once your child is evaluated for Special Ed services you will have an IEP meeting to determine goals and what placement is appropriate for your child's needs.

For more information on IEP's and Special Education Law visit:

www.wrigtswlaw.com

We have a list of advocates and lawyers on our website in the event that you additional help navigating the process.

www.phxautism.org

You can also contact Raising Special Kids and attend one of their parent IEP trainings.

www.raisingpecialkids.org

Begin therapies

Even before you are approved for therapies through the state, check your insurance company to see if they cover OT, Speech, and Physical therapy for your child. Your insurance may also cover ABA therapy as well. DDD (funded by ALTCS) often covers behavioral therapies including ABA, speech, OT, PT, music therapy, habilitation and respite. Contact the AS-GP Parent Mentors for help if you are having trouble accessing therapies.

Behavioral therapies are often effective in children with autism, with Applied Behavioral Analysis (ABA) usually being the most effective. These methods can and should be used together with biomedical interventions, as together they offer the best chance for improvement. Parents, siblings, and friends may play an important role in assisting the

development of children with autism. Typical preschool children learn primarily by play, and the importance of play in teaching language and social skills cannot be overemphasized. Ideally, many of the techniques used in ABA, sensory integration, and other therapies can be extended throughout the day by family and friends.

Applied Behavior Analysis:

Many different behavioral interventions have been developed for children with autism, and they mostly fall under the category of Applied Behavioral Analysis (ABA). This approach generally involves therapists who work intensely, one-on-one with a child for 20 to 40 hours/week. Children are taught skills in a simple step-by-step manner, such as teaching colors one at a time. The sessions usually begin with formal, structured drills, such as learning to point to a color when its name is given; and then, after some time, there is a shift towards generalizing skills to other situations and environments. A study published by Dr. Ivar Lovaas at UCLA in 1987 involved two years of intensive, 40-hour/week behavioral intervention by trained graduate students working with 19 young autistic children ranging from 35 to 41 months of age. Almost half of the children improved so much that they were indistinguishable from typical children, and these children went on to lead fairly normal lives. Of the other half, most had significant improvements, but a few did not improve much. ABA programs are most effective when started early, (before age 5 years), but they can also be helpful to older children. They are especially effective in teaching non-verbal children how to talk. Parents are encouraged to obtain training in ABA, so that they provide it themselves and possibly hire other people to assist. Qualified behavior consultants are often available, and there are often workshops on how to provide ABA therapy.

Speech Therapy:

This may be beneficial to many autistic children, but often only 1-2 hours/week is available, so it probably has only modest benefit unless integrated with other home and school programs. Sign language and PECS may also be very helpful in developing speech.

Occupational Therapy:

This can be beneficial for the sensory needs of these children, who often have hypo and/or hyper sensitivities to sound, sight, smell, touch, and taste. Many autistic individuals have sensory problems, which can range from mild to severe. These problems involve either hypersensitivity or hyposensitivity to stimulation. Sensory integration focuses primarily on three senses — vestibular (i.e., motion, balance), tactile (i.e., touch), and proprioception (e.g., joints, ligaments). Many techniques are used to stimulate these senses in order to normalize them.

Physical Therapy:

Often children with autism have limited gross and fine motor skills, so physical therapy can be helpful.

Auditory Interventions:

There are several types of auditory interventions. The only one with significant scientific backing is Berard Auditory Integration Training (called Berard AIT or AIT) which involves listening to processed music for a total of 10 hours (two half-hour sessions per day, over a period of 10 to 12 days). There are many studies supporting its effectiveness. Research has shown that AIT improves auditory processing, decreases or eliminates sound sensitivity, and reduces behavioral problems in some autistic children. Other auditory interventions include the Tomatis approach, the Listening Program, and the SAMONAS method. There is limited amount of empirical evidence to support their efficacy. Information about these programs can be obtained from the Society for Auditory Intervention Techniques' website www.sait.org.

Relationship Development Intervention (RDI):

This is a new method for teaching children how to develop relationships, first with their parents and later with their peers. It directly addresses a core issue in autism, namely the development of social skills and friendships. Website: www.rdiconnect.com

Floortime:

Floortime meets children where they are and builds upon their strengths and abilities through interacting and creating a warm relationship. It challenges them to go further and to develop who they are rather than what their diagnosis says. In Floortime, you use this time with your child to **excite her interests, draw her to connect to you, and challenge her to be creative, curious, and spontaneous**—all of which move her forward intellectually and emotionally

Social Thinking:

Social Thinking is a treatment framework and curriculum developed by Michelle Garcia Winner that targets how to enhance and improve social thinking abilities, regardless of diagnostic label (often there isn't a diagnosis). Professionals and parents alike are using these methods to build social thinking and related social skills. Social Thinking concepts and strategies are designed for people with social learning challenges with *near average to way above average language skills and IQ*. The teachings of Social Thinking also are widely used to help educate parents and professionals as to how to systemize and teach about information that we traditionally have never taught before. Given the explicit nature of these social emotional teachings, they are also being adopted for use with all students to encourage improved social problem solving.

Check for Co Morbid Conditions

Children with autism often have other co-occurring medical conditions, including intellectual disability (about 50%), seizures (25%), subclinical seizures (60-80%), low muscle tone (about 30%), sensory sensitivities (about 50%), gastrointestinal problems (chronic, diarrhea, acid reflux, abdominal pain in about 50%), and sleep problems (about 50%). Some abnormal behaviors of children with autism are actually caused by medical issues. Once these medical

issues are addressed the behaviors stop. It is impossible to learn effectively if you do not feel well. Some children actually lose skills or do not retain skills because of a medical condition.

What are the most common co-occurring medical conditions for children with Autism?

Gastrointestinal Disorders:

- According to an article in the Journal of Medical Microbiology in 2005 “Children with ASD tend to suffer from severe gastrointestinal problems. “ It found that “GI problems were significantly more frequent in ASD patients than in controls demonstrating a significant association between GI symptoms and autism.”
- It is important to see a GI specialist if your child experiences any constipation, diarrhea, vomiting, reflux, or abdominal pain.
- There are several easy treatments that the doctors can give to relieve these symptoms

Seizure Disorders:

- According to a study published in Epilepsy and Behavior 10 to 30 percent of children with a autism have Epilepsy. Autism and epilepsy: Cause , consequence, co morbidity or coincidence? By Lidia Gabis, John Pomeroy and Mary R. Androla
- Epilepsy is a well-known co morbidity of children with autism spectrum disorder (ASD), with about one third of these children developing seizures over their lifetime.
- Seizures do NOT always present exactly the same way in every individual. They can be different from a major convulsion on the floor to minor seizures which look like rapid eye movement or a period of “zoning out.”

Immune Disorders:

- Approximately 25% of children on the spectrum have immune deficiency and dysfunction.
- Most children with autism do not have symptoms so it is important to run the lab work to rule this disorder.
- Children who have gastrointestinal disorders are very likely to have immune deficiency.

Other co morbid conditions are:

ADHD

Eosinophilic Gastrointestinal Disorders (EGIDs)

Mitochondrial Diseases

Tuberous Sclerosis

Primary Immunodeficiency Diseases

Hypothyroidism

Feeding Issues

Obsessive Compulsive Disorder

Sensory Processing Disorders

Tourette Syndrome

Dyspraxia

Central Auditory Processing Disorders

Hyperlexia

Inflammatory Bowel Diseases

Celiac Disease

Inborn Errors of Metabolism

Fragile X Syndrome

Anxiety Disorders

Food and Environmental Allergies

Dyslexia

Mood Disorders

Apraxia

Depression

Rett Syndrome

Educate yourself on co morbid conditions and how to navigate insurance. Learn the co-morbid conditions and the specialists in the valley that will rule these out. If you would like to learn more contact one of our parent mentors.

Nutritional and Dietary Interventions: There is growing evidence that many children with ASD have nutritional and metabolic problems, and often benefit from a combination of special diets and nutritional supplements. For more information, see “Summary of Dietary, Nutritional, and Medical Treatments for Autism” at <http://autism.asu.edu>

Ensure that you have time for yourself and your marriage.

- Be sure to use respite (babysitters) to get out and do the things you loved before you entered on the Autism journey.
- Remember that marriage support is key-(Over 85% of marriages of parents of children with Autism end in divorce.)
- Remember your other children – they need your love and attention too.
- Be sure to have a hobby of your own, exercise, and even read for pleasure!
- Even though there is a lot to handle with a child with Autism, you have to remember that this is a marathon and not a sprint.

We offer goal setting classes that are helpful in setting priorities, staying focused and learning how to manage time in the most effective ways possible. If you are interested in this class please contact us and we will schedule one for you.

We offer a variety of classes and workshops. Make sure you sign up for our newsletter so you are up to date on the social, educational and family activities.

MOST IMPORTANTLY DO NOT GIVE UP HOPE!

You must never forget that there is hope, even when others may say there is not. With treatments like biomedical interventions, ABA, RDI, AIT, etc. children with Autism are getting better and recovering skills many never thought possible.

YOU CAN DO IT!

