



Autism Resource Guide for Pima County

**Compiled by the Autism Society of America,
Pima County Chapter**

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Disclaimer: This guide was compiled by parents and volunteers of the Autism Society of America, Pima County Chapter (ASA-PCC) and funded by a grant from the Governor's Council on Developmental Disabilities to better support and inform local families and professionals involved with autism. The treatments, doctors and organizations mentioned in this guide are for informational purposes only to aid families in deciding the best treatments and services for their loved one affected by autism; the Autism Society of America does not assume any liability for consequences that may result from services mentioned herein.
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THE DIAGNOSIS

Receiving a diagnosis of autism can be devastating to some families, but for others it can be a relief to have a label for their child's symptoms. Many parents can be overwhelmed by fear and grief for the loss of the future they had hoped for their child. No one expects to have a child with a developmental disability. Most parents go through a denial stage, then a time of depression and grief. Most parents, in hindsight, wish their denial stage had been shorter because precious time was lost; the sooner you get informed about autism, you can intervene and help your child get better.

We encourage you to join parent support groups and begin NOW to act upon the diagnosis. Many parents fear having 'a label' placed on their child. The diagnosis and 'label' is important because it can open the doors to many services, and help parents learn about treatments that have benefited similar children.

Most importantly, autistic individuals have the potential to grow and improve, and in some cases become indistinguishable from their peers. Contrary to what you may hear from outmoded professionals or read in outmoded books, **autism is treatable**. It is important to find effective services, treatments and education for autistic children as soon as possible. The earlier these children receive appropriate treatment, the better their prognosis.

WHAT IS AUTISM?

Autism is a developmental disability that typically involves delays and impairment in social skills, language, and behavior. Autism is a spectrum disorder, meaning that it affects people differently. Some children may have speech, whereas others may have little or no speech. Less severe cases may be diagnosed with Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS) or with Asperger's Syndrome (these children typically have near-normal speech, but they have many "autistic" social and behavioral problems).

Left untreated, many autistic children will not develop effective social skills and may not learn to talk or behave appropriately. Without any intervention, few individuals recover completely from autism. **The good news is that there are a wide variety of treatment options which can be very helpful.** Some treatments may lead to great improvement, whereas other treatments may have little or no effect. Some children, but not all, with intensive enough early intervention, have been known to become indistinguishable from their peers and lose their autism label.

ONSET OF AUTISM: Early Onset vs. Regression

Autism develops sometime during pregnancy and the first three years of life. Some parents report that their child seemed different at birth. These children are referred to as early-onset autism. Other parents report that their child seemed to develop normally and

then had a major regression resulting in autism, usually around 12-24 months. These children are referred as late-onset or regressive autism.

Prior to 1990, approximately two-thirds of autistic children were autistic from birth and one-third regressed sometime after age one year. Starting in the 1990's, the trend has reversed — fewer than one-third are now autistic from birth and two-thirds become noticeably autistic in their second year.

CAUSES and GENETICS OF AUTISM

There is no simple answer to the question, 'what caused my child's autism?' One thing is certain; it is **not** the fault of the parents. Many mothers blame themselves for not taking prenatal vitamins the first trimester or for 'that one drink' during pregnancy or for not eating enough fish during pregnancy. A few decades ago, mothers were blamed for their child's autism and labeled 'refrigerator mothers'. The mothers were placed in therapy to 'learn to love and bond' while the children didn't receive intervention. Thank goodness for modern science and the brilliance of one father and scientist, Dr. Bernard Rimland in California who authored 'Infantile Autism' after having an autistic child, and shattered beliefs that the mothers were to blame.

There have been numerous studies to determine the causes of autism, all of which have been inconclusive. Some studies show that genetics appear to play an important role in causing some cases of autism. Several studies have shown that when one identical twin has autism, the other co-twin often has autism. In contrast, when one fraternal twin has autism, the co-twin is rarely autistic. As the rates of children diagnosed with autism keep increasing, the instances of having more than one child with autism in the same family has also increased.

Studies trying to identify specific genes associated with autism have been inconclusive. Currently, it appears that 20 or more genes may be associated with autism. This is in contrast to other disorders, such as Fragile X or Rett's syndrome, in which single genes have been identified.

A large number of studies have found that autistic individuals often have compromised immune systems. Often a child with autism can have allergies, food intolerances, asthma, blood platelet disorders, or sometimes thyroid problems. In fact, autism is sometimes described as an autoimmune system disorder. One working hypothesis of autism is that the child's immune system is compromised genetically and/or environmentally, that may predispose the child to autism. Then, exposure to an environmental 'trigger' (perhaps a toxic exposure or possibly a vaccine) may lead to autism.

If parents have a child with autism, there is an increased likelihood that their future children will also develop autism. Statistics show only a 5 to 10% likelihood of having another child with autism, but many agree this statistic should be higher. Even in Arizona there are families with two, three and even four children with autism. Many studies have identified cognitive disabilities in siblings of autistic children. Siblings should be evaluated for possible developmental delays and learning disabilities.

POSSIBLE ENVIRONMENTAL 'Triggers' OF AUTISM

Although genetics play an important role in autism, environmental factors seem to also be involved. There is no general consensus on what those environmental factors are at this point in time. Since the word "autism" is only a label for people who have a certain set of symptoms, there are likely to be a number of factors that **could** cause those symptoms.

◇ Childhood vaccinations: We encourage you to make your own decisions regarding vaccinations; it is a very heated subject among parents and professionals.

There are many Internet sites on this topic, and a book entitled 'What Your Doctor May NOT Be Telling You About Childhood Vaccinations' can be ordered on Amazon.com and is written by Stephanie Cave, MD who is also a mother of a child with autism, AND a DAN! Doctor. A DAN! Doctor (Defeat Autism Now) is a physician specializing in alternative and mainstream medical treatments for children with autism. This is not an anti-vaccine book but advocates safe vaccine schedules for small children. If you decide not to vaccinate, your children's schools are required to allow vaccine waiver forms - a religious or personal beliefs waiver or a medical waiver form. If your doctor won't cooperate with a medical waiver, your DAN! doctor probably will, or just sign the personal beliefs waiver if you feel it appropriate. See a list of DAN! Doctors in Arizona, in the **Treatments** section of this guide.

◇ Excessive use of oral antibiotics is another possible environmental trigger which can cause gut problems (which affects immune function), such as yeast/bacterial overgrowth. A healthy gut is essential to vitamin and mineral absorption. A large number of children with autism have gut disturbances, which are not always apparent by diarrhea or discomfort. Seeing a gastroenterologist to rule out ulcers, Celiac's disease or blockages is advised. Supplements of probiotics (bought at health food stores) help the gut. See more in the Treatments section of this guide.

◇ Maternal exposure to mercury (e.g., consumption of seafood high in mercury, mercury dental fillings, thimerosal in RhoGam shots and Flu shots). These are considered POSSIBLE triggers, not proven.

◇ Dietary intolerances and/or lack of essential vitamins and minerals: many children with autism have dietary intolerances or allergies. These can be immediate response allergies (rash or throat swelling or hives) or delayed response allergies up to hours later (red cheeks, dark circles under eyes and/or behavioral changes). In addition, the average child with autism has gut issues which may inhibit full absorption of essential vitamins and minerals. The constant introduction of dietary intolerances or the continued lack of essential vitamins and minerals may be a trigger for autism. Another intolerance may be nitrite

preservatives in meat, MSG, Nutrasweet and food dyes. Try to feed your child as naturally as possible. DAN! Doctors can test for intolerances and elimination of these offenders can help.

◇ Environmental toxins such as yard treatments or fertilizers, pesticides, pressure-treated wood with arsenic (some wood play equipment), mold in carpets or walls, stain-resistant coatings and flame retardant clothing and bedding, to name a few.

PREVALENCE OF AUTISM

There has been a rapid increase in the number of children diagnosed with autism. The most accurate statistics on the prevalence of autism come from California, which has an accurate and systematic centralized reporting system of all diagnoses of autism. The California data show that autism is rising rapidly, from 1 per 2,500 in 1970 to 1 per 150 in 2007. Similar results have been reported for other states by the US Department of Education. Whereas autism once accounted for 3% of all developmental disabilities, in California it now accounts for 45% of all new developmental disabilities. Other countries report similar increases.

We do not know why there has been a dramatic increase in autism over the past 15 years, but there are several reasonable hypotheses. Since there is more than one cause of autism, there may be more than one reason for the increase. A small portion of the increase of autism where speech is delayed may be due to improved diagnosis and awareness, but the report from California reveals that this only explains a minute part of the increase. However, the increase in the milder variant called Asperger's Syndrome may be due to increased diagnosis. In Asperger's Syndrome, there is no significant speech delay and early childhood behavior is much more normal. Some possible environmental factors were discussed in the previous section, and an increased occurrence of one or several of those factors probably accounts for the rapid increase in autism.

COMMON CO-OCCURRING CONDITIONS IN AUTISM

Mental Retardation: Although it has been said that many people with autism have mental retardation, research studies have frequently used inappropriate IQ tests, such as verbal tests with nonverbal children and, in some cases, estimating the child's intelligence level without any objective evidence. Parents should request non-verbal intelligence tests that do not require language skills, such as the Test for Nonverbal Intelligence (TONI). Furthermore, regardless of the result, realize that autistic children will develop more skills as they grow older, and that appropriate therapies and education can help them reach their true potential.

Seizures: It is estimated that 30% of autistic individuals also develop seizures, some in early childhood and others as they go through puberty (changes in hormone levels may trigger seizures). These seizures can range from mild (e.g., gazing into space for a few seconds) to severe, grand mal seizures.

Some autistic individuals have subclinical seizures which are not easily noticeable but can significantly affect mental function. A short one or two hour EEG may not be able to detect any abnormal activity, so a 24-hour EEG is recommended (your doctor will try to order a two hour test - be persistent in your request for a 24 hour EEG!). Although drugs can be used to reduce seizure activity, the child's health must be checked regularly because these drugs can have effects. For seizures that cannot be controlled with medication, Vagal Nerve Stimulation Therapy may be used, where a generator device (sort of a brain defibrillator) is implanted and the electrode wrapped around the vagus nerve to control or shorten seizure activity when activated. To learn more about seizures visit these websites: www.epilepsyfoundation.org and www.epilepsy.com.

Chronic Constipation and/or Diarrhea: An analysis of the Autism Research Institute's database of thousands of cases show over 50% of autistic children have chronic constipation and/or diarrhea. Diarrhea may actually be due to constipation—i.e., only liquid is able to leak past a constipated stool mass in the intestine. Manual probing often fails to find an impaction. A flat abdomen X-ray or colonoscopy may be the best way to check for this problem. Consultation with a pediatric gastroenterologist is required.

Sleep Problems: Many autistic individuals have sleep problems, the most popular being night waking. Night waking may be due to reflux of stomach acid into the esophagus. Placing bricks under the head of the bed may help keep stomach acid from rising and provide better sleep. Melatonin has been very useful in helping many autistic individuals fall asleep and is available over-the-counter. In some cases Melatonin helps the child to fall asleep, but also causes the child to wake up refreshed at a very early hour. Dietary intervention (gluten free/casein free) has helped many children with sleep (see Treatments section). Vigorous exercise will help a child sleep, and other sleep aids are a weighted blanket or tight fitting mummy-type sleeping bag. There are also prescription medications available if needed.

Pica: 30% of children with autism have moderate to severe Pica. Pica refers to eating non-food items such as paint, sand, dirt, paper, fecal material, etc. Pica can expose the child to heavy metal poisoning, especially if there is lead in the paint or in the soil. Behavioral intervention can help with Pica, but often there is an underlying deficiency which can be helped with supplementation or dietary changes. Occasionally, Pica is related to obsessive/compulsive behavior (e.g. the child is obsessed with finding and eating strings from clothes, carpets, furniture) for which psychotropic medications such as Zoloft can eliminate the obsessive behavior.

Low Muscle Tone: A study conducted by Jim Adams, Ph.D. found 30% of autistic children have moderate to severe loss of muscle tone, and this can limit their gross and fine motor skills. That study found that these children tend to have low potassium levels. Increased consumption of fruit may be helpful.

Sensory Problems: Many autistic children have unusual sensitivities to sounds, sights, touch, taste, and smells. High-pitched intermittent sounds, such as fire alarms or school bells, may be painful to autistic children. Scratchy fabrics may also be intolerable, and some children have visual sensitivities such as to the flickering of fluorescent lights. If the child often has tantrums in large supermarkets, it is possible that he/she has severe sensory oversensitivity. Sensory sensitivities are highly variable in autism, from mild to severe. In some children, the sensitivities are mostly auditory, and in others, mostly visual. It is likely that

many individuals who remain non-verbal have both auditory and visual processing problems, and sensory input may be scrambled. Even though a pure tone hearing test may imply normal hearing, the child may have difficulty hearing auditory details and hard consonant sounds.

Some children have very high pain thresholds (i.e., be insensitive to pain), whereas others have very low pain thresholds. Interventions designed to help normalize their senses, such as sensory integration, Auditory Integration Training (AIT), and Irlen lenses, are discussed later in the treatments section.

What is the difference between Asperger's Syndrome and Autism?

Asperger's syndrome is usually considered a subtype of high-functioning autism. Most of the individuals with Asperger syndrome are described as "social but awkward." That is, they want to have friends, but they do not have the social skills to begin and/or maintain a friendship. While high-functioning autistic individuals may also be "social but awkward," they are typically less interested in having friends. Teaching the Asperger's child social skills and arranging play dates, and role playing are helpful. Support groups for adults with autism are recommended and do exist in Tucson (see Support Group section of this guide).

In Arizona, getting services for a child with an Asperger's label is more difficult than an autism label. If the child is under six, a diagnosis of 'developmental delay' in three of the seven categories (see State Services section of this guide) should qualify you to receive the services that are needed, but beyond age six, Asperger's is not one of the four qualifying diagnoses (mental retardation, autism, cerebral palsy, epilepsy) needed to receive services from the Division of Developmental Disabilities.

Treatments

Remember, **Autism is treatable**. Most professionals agree on one thing: EARLY INTERVENTION IS KEY. Below are several treatment options. Do not feel overwhelmed. Most parents do not try all treatments at once, but one at a time. Do the best you can, but start quickly.

Applied Behavioral Analysis (ABA): Educational/behavioral therapies are often effective in children with autism, with Applied Behavioral Analysis (ABA) being the most effective. These methods can and should be used together with biomedical interventions (discussed below), 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 pre-school aged children learn primarily by play, and the importance of play in teaching language and social skills cannot be overemphasized. In most cases, children with autism fail to learn socialization, play and educational skills independently, so a structured environment needs to be 'set up' to teach them. Often the child has lost the desire and ability to play, which can be taught and 'rediscovered' through ABA. Ideally, many of the techniques used in ABA and other interventions can and should be extended throughout the day by family and friends.

ABA generally involves therapists or 'trainers' 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 picture color card when its name is given; and then, after some time, there is a shift towards generalizing skills to other situations and environments. Other teaching categories may be oral motor, verbal imitation, receptive labels, expressive labels, gross motor, fine motor, independent play, colors, shapes, drawing, coloring, self help, etc. depending on the program.

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. Most parents who have an ABA program in their home agree that the sooner you get moving on ABA to stop the regression, the better. Parents need to learn how to generalize what is being taught, in the home. Suggested reading is '*Behavioral Interventions for Young Children with Autism*' by Catherine Maurice, ordered through bookstores or available on Amazon.com which has excellent programming ideas so you can get moving, until you get a program in place (the ASA library, at the TAFA center, also has this book for check-out). Catherine has written another book about her childrens' voyage through ABA called 'Let Me Hear Your Voice' which is also a must-read. A listserve of parents implementing ABA programs throughout the world is also helpful, called the ME-list.

In Tucson, contact Home Based Services, at the Division of Developmental Disabilities (DDD) at 520-628-6800 to inquire about funding a program and the approval process. Please read the Government Services section of this guide prior to calling. There are a few consultants (below) who are approved through DDD to supervise ABA Programs. These consultants may use different methods to structure their ABA programs; a couple of examples are: Floortime method (www.floortime.org), or the TEACCH method (www.teacch.com).

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| True Potential, PLLC Daniel Quinones, MS 2201 N. Camino Principal Suite B Tucson, AZ 85715 (915) 887-8753 info@truepotentialtherapy.com | Counseling and Consulting Services Victoria Cannon, M.S.W. 2430 E. 6 th St. Tucson, AZ 85719 VCannon@cpes.com |
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| Angels in Autism, LLC (also provides summer, afterschool, hab and respite providers) Michelle Mastrangelo 1326 S. Camino Seco Tucson, AZ 85710 520-820-3650 angelinautism@cox.net | Autism Partnership 200 Marina Drive, Suite C Seal Beach, CA 90740-6057 562-431-9293 Contact: Julie McEaschin x 141 |
| Center for Autism & Related Disorders, Inc. Contact: Sarah Niehoff Gilbert, AZ 85297 Phoenix, AZ 85008 (602)325-2485 s.niehoff@centerforautism.com | Liberty Center Consulting Stephanie Crawford Genteman, MA Deborah Killion, BA 5315 E. Broadway Ste. 203 Tucson, AZ 85713 sgenteman@cox.net 520-991-0867 |
| Liz Anderson, MS, MCABA Consulting Behavior Analyst 9419 Silverfox Dr. Fort Wayne, IN 46805 260-348-7007 Andersonliz@aol.com | Head, Heart, Hands Journey, Inc. Barbara Rosenberg, RN, MA, LAC 3817 E. Calle Ensenada Tucson, AZ 85716 520-403-5611 rosenjones22@msn.com |
| HOPE Group Erin Ganier, M.Ed., BCBA Behavioral Consulting Manager 480-610-6981 eganier@hopegroupaz.com | FABAS, Inc. Fernando Armendariz 4262 W. Tombolo Trail Tucson, AZ 85745 520-795-2680 or 520-240-3746 Director@FABASinc.org |
| Melissa McIntosh, MA (615) 479-5336 mdmac2b@hotmail.com (480)-610-6981 | Cynthia Dee Wing 1390 S. Desert Crest Dr. (520) 624-4240 cyndeew@earthlink.net |

After selecting a consultant, you will need to hire the trainers either by calling from a DDD master list or by posting your needs on the Tucson autism listserv (email asa-pcc@googlegroups.com), or many have advertised at churches or at the U of A to great success. Another option is calling H.O.P.E. Group in Phoenix, who recruits habilitation workers in the Tucson area. Their number is 480-610-6981. Another agency is Liberty Group, phone number 520-991-0867. You can also call the Blake Foundation at 520-792-2636 or Angels in Autism at 520-820-3650 or UCP at 520-795-3108. If you recruit your own workers and want to get them certified to do habilitation or respite through DDD, call Home Based Services at DDD, phone number 520-628-6800.

If a child is approved for ACCSS (which is government paid healthcare), and they meet certain other requirements, this ABA program can be funded through DDD in Arizona, which is uncommon in other states. The family must pay for the consultant under most circumstances. Often military families can get their consultant fees paid for. For any questions regarding 'getting approved for ABA therapy' please contact Home Based Services at DDD (520-628-6800), AFTER reading the Government Services section of this guide.

An insurance bill was passed this year, stating that Insurance agencies will be required to fund ABA treatment (and other mainstream medical treatments) for children with autism. This is supposed to go into effect in July of 2009. Contact your insurance provider for details and fight for this, especially if your child cannot qualify for DDD services.

Dietary Interventions: Cleaning up the diet is essential to good health. In Tucson, there are many health food stores that sell organic food, such as Trader Joe's, New Life Health, Whole Foods, Sunflower Market, Aqua Vita, just to name a few. In addition, it has been found that most children with ASD have food intolerances and allergies, including delayed-response allergies (such as red cheeks and ears, dark circles under the eyes, stimmy (self-stimulatory behavior)). Many ASD children benefit greatly by adhering to a gluten free/casein free diet, even though there may be no visible signs of gut distress.

Gluten and Casein are proteins in wheat and milk. Research suggests they are not digested normally in many people with autism, but are broken down into compounds which act like opiates, which are addictive and destructive to developing brain tissue. Specialized testing can be done to determine the necessity of this diet (consult a DAN! doctor or Dr. McCandless' medical intervention book listed in the resource section) Most DAN! doctors recommend a six month trial of the GF/CF diet instead of testing. Many parents report their children were less agitated, slept better and behaved less autistic by simple elimination of these foods. Additional lab testing can be done to find other intolerances which should be eliminated, such as soy, corn, peanuts, etc. with supervision of your autism doctor. Gluten/casein free pretzels, cookies and other products can be found at New Life Health Center, Wild Oats, and Trader Joe's. Some products can also be found at your regular market. Products can also be purchased from specialty stores online. Name brands can be found on www.gfcdiet.com. Also a local chef created her own GF line of baked goods 'Miracle Munchies' sold at local farmer's markets - phone 744-1174 for info. Web sites and books to help you:

- *Special Diets for Special Kids* by Lisa Lewis
- *Is This Your Child? Discovering and Treating Unrecognized Allergies in Children and Adults* by Dr. Doris Rapp, M.D.

- www.gfcfdiet.com contains a list of Gluten and Casein free foods and items
- www.autismndi.com ANDI: Autism Network for Dietary Intervention also has a newsletter for families about the GF/CF diet.
- www.onelist.com/community/GFCFkids Favorite snacks compiled by GFCF kids
- www.gluten-free.org, www.celiac.com, www.Gfrecipes.com

Enzyme Therapy - a few companies are now producing enzymes for the autistic child to help break down the offensive proteins such as gluten and casein. Kirkman Labs as well as Houston Nutraceuticals sell these enzymes; some parents swear by them and others find no change. See www.houstonni.com or www.kirkmanlabs.com for more information.

Exercise - perhaps the most overlooked medical treatment. Find something your child can do on a daily basis to be physically active. Most children with autism love water which can be very good for them but also dangerous. See the 'Recreation' section for swimming instructors. A salt-filter pool is preferable and more natural than a chlorinated pool if you have an option.

Many parents have said a large trampoline was the best purchase they ever made for their child. Make sure to buy the safety net since autistic children's balance is often compromised.

Medical Testing and Biomedical Treatments - Finding the right doctor for your child is crucial. Most physicians don't understand the medical aspects of autism primarily because it is a very complicated disorder and keeping up with all the latest treatments is monumental. We encourage you to find a specialist who understands autism and will help you treat your child.

A small but growing number of physicians (many of whom are themselves parents of autistic children) are involved in trying safe and innovative methods for treating the underlying biomedical basis of autism -- the Defeat Autism Now! (DAN!!) program. Parents and physicians can learn about this approach by attending DAN!! conferences (audio and videotapes are also available), visiting the Autism Research Institute's website (www.Autism.com), and reading biomedical intervention books. One parent-friendly book is 'Children With Starving Brains' by Jaqueline McCandless M.D., the grandmother of a child with autism and a DAN!! doctor in California. A listing of doctors who subscribe to the DAN!! approach to autism can be found on the ARI website, but below are the official Arizona DAN! Doctors:

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| <p><u>Matthew Baral, N.D.</u> International Child Development Resource Center 1620 N. 48th St. Phoenix, AZ 85008 ph: 321-259-7111</p> <p><u>Cindy Schneider, M.D.</u> Center for Autism Research and Education 4045 E. Union Hills Drive, Suite 116 Phoenix, AZ 85085 ph: 602-277-2273 fax: 602-277-2283</p> <p><u>Geoffrey P. Radoff, M.D., M.D.H.</u> Alternative Medical Care of AZ 2525 West Greenway Rd., Ste. 210 Phoenix, AZ 85023 ph: 702-755-6475 fax: 602-993-0207</p> <p><u>Alan K. Ketover, M.D., M.D.H.</u> The Valley Clinic 10595 N. Tatum Blvd., Ste. E-146 Paradise Valley, AZ 85253 ph: 602-381-0800 fax: 602-381-0054</p> <p><u>Jessica Tran, ND</u> 8010 E. McDowell Rd., Ste. 111 Scottsdale, AZ 85257 ph: 480-970-0000 fax: 480-970-0003</p> | <p><u>Martha M. Grout, M.D., MD(H)</u> The Cross Roads Clinic 9328 E. Raintree Drive Scottsdale, AZ 85260 ph: 480-240-2600 fax: 480-240-2601</p> <p><u>Eli Ber, NMD</u> 10752 N. 89th Place B213 Scottsdale, AZ 85260 ph: 480-634-6172 fax: 480-634-6975</p> <p><u>Joel Morgan, NMD</u> Total Wellness Medical Center 9887 West Bell Rd. Sun City, AZ 85351 ph: 623-977-0077 fax: 623-977-0057</p> <p><u>Maureen Schwehr, N.D.</u> Rising Moon Natural Health Care 621 N. 6th Ave. Tucson, AZ 85705 ph: 520-623-1033 fax: 820-742-3846</p> |
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Routine medical tests are usually performed by traditional doctors, but they rarely reveal problems in autism that can be treated. Genetic testing for Fragile X syndrome (which is a genetic disorder which often has autistic symptoms - see www.FragileX.org) can help identify one possible cause, and this testing is typically recommended when there is mental retardation in the family history. Many physicians do not conduct extensive medical testing for autism, mainly because they are not familiar with these specialized labs and testing procedures, and are not trained in the DAN! protocol. Again, we urge you to consult a DAN! specialist; unfortunately, insurance often does not cover these visits.

Psychiatric Medications - It is generally recommended to try treating the symptoms of autism with biomedical approaches as listed above. Often when diets are changed or offending foods removed, or metals removed from a child, the behavior radically changes for the better. There are times, however, when parents and physicians chose to use psychiatric medications to treat the symptoms of autism, such as obsessive/compulsive behavior, sleep disturbances or seizures.

For some classes of drugs the doses which are successful for reducing symptoms, such as aggression or anxiety, are much lower for those with autism than for normal people. For the SSRI drugs, such as Prozac (Fluoxetine), Zoloft (Sertraline), and other and other antidepressants, the best dose may be only one-third of the normal starting dose. Too high a dose may cause agitation or insomnia. If agitation occurs, the dose must be lowered. The low dose principle also applies to all drugs in the atypical or third generation antipsychotic drug class, such as Risperdal (Risperidone). The effective dose will vary greatly between individuals. Start low and use the lowest effective dose, per the suggestion of your physician. Other classes of drug, such as anticonvulsants, will usually require the same doses that are effective in individuals without autism.

There are always concerns over the use of medications, mainly because there is relatively little research on their use for children with autism. There are almost no studies on the long-term effects of their use, especially for the newer medications, and there is a concern that their long-term use in children may affect their development. DAN! doctors suggest using the natural biomedical approaches first, then turning to medications as a final resort.

Speech Therapy - If your child's language is diminishing or has been lost, fight for as much speech therapy as you can get for your child. If you are approved for DDD funding, most likely you will get only 1 to 2 hours of therapy a week, but you can ask for 'homework' every week to incorporate into your home life or other programming. Helping your child develop a way of communicating is a number one priority. The most common question asked by parents is, will my child ever talk?

An analysis of data from the Autism Research Institute involving 30,145 cases indicated that 9% never develop speech. Of those who develop speech, 43% begin to talk by the end of their first year, 35% begin to talk sometime between their first and second year, and 22% begin to talk in their third year and after. With appropriate interventions, there is reason to hope that children with autism can learn to talk, at least to some extent.

There are several ways to help autistic children learn to talk, including:

- ◇ Teaching speech with sign language; it is easy for parents to learn a few simple signs and use them when talking to their child. This is referred to as 'simultaneous communication' or 'signed speech.' Research suggests that the use of sign language increases the chance of children learning spoken language.
- ◇ Teaching with the Picture Exchange Communication System (PECS), which involves using pictures or symbols on a board, then working up to building sentences on a word strip and exchanging pictures for desired items and needs. As with sign language, it can also be effective in teaching communication and visual sentence structure.
- ◇ Applied Behavior Analysis: discussed above
- ◇ Augmentative Communication Devices: these devices can talk for your child, and help them gain language. To learn how to apply and receive an appropriate augmentative communication device, call Donna Alvarado at DDD, the Provider Relations Rep for the Augmentative Communication Program: 520-519-1719.
- ◇ Music: encouraging child to sing with a videotape or audiotape. See, for example www.BabyBumbleBee.com for information on vocabulary building videos.
- ◇ Vestibular stimulation, such as swinging on a swing, while teaching speech
- ◇ Several nutritional/biomedical approaches have been associated with dramatic improvements in speech production. A local speech therapist conducted research using a Nordic Natural Essential Fatty Acid (Omega 3 and Borage Oil) supplement (www.nordicnaturals.com). Many children have shown improvement in speech and understanding with this supplement, some have not.

There seems to always be a shortage of speech therapists in Tucson. You can call DDD at 520-745-5588 and ask for the person in charge of speech and occupational therapists. If you are approved for DDD services already, work through your support coordinator to find an appropriate speech therapist.

Sensory Integration: 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 and knowing where the body is 'in space'). Many techniques are used to stimulate these senses in order to normalize them, such as:

- **Brushing** - a surgical brush is used and brushed roughly on the child's arms, legs and back, then followed by joint compressions. This stimulates blood flow and is thought to 'wake up' the body and help it get in sync. This technique should be repeated every two to three hours, and can be incorporated into the child's day or ABA program.
- **Weighted vests, blankets or ankle weights**, or pressure vests. Many ASD children have sensory impairment to some degree, and do not feel 'grounded' or in touch with their body. Many ASD children benefit from wearing a weighted vest of pressure (tight fitting) vest, or even weights on their ankles. Some children sleep much better with a weighted blanket. These can be purchased through Southpaw Enterprises (www.southpawenterprises.com) or Achievement Products (www.specialkidszone.com), or may be available through Adaptation Station here in Tucson at the DDD community resource center where they make inexpensive adaptive equipment and swings. Call 520- 519-1676 and ask for the Adaptation Station number.
- **Swinging** on a swing or bouncing on a therapy ball - many children can learn faster while in motion. Please see catalog list in the resource section to obtain this equipment.
- Other Tucson resources to help in sensory integration are swimming, sports, skating, karate, therapeutic horse riding, music therapy or piano lessons. Please refer to the Recreation section of this guide.

Occupational Therapy: 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. May include sensory integration (above).

Physical Therapy: Often children with autism have limited gross and fine motor skills, so physical therapy can be helpful. This may also include sensory integration (above).

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 (www.berardaitwebsite.com).

Computer-based auditory interventions have also received some empirical support. They include Earobics (<http://www.earobics.com/>) and Fast ForWord (www.fastforword.com). These programs have been shown to help children who have delays in language and have difficulty discriminating speech sounds.

Music Therapy – UCP of Southern Arizona offers music therapy in groups or individually. Often this therapy can be paid for by DDD. Contact your support coordinator or call UCP at 520-488-7391.

Computer Software: There are many educational programs available for typical children, and some of those may be of benefit for autistic children. There is also some computer software designed specifically for children with developmental disabilities. One major provider is Laureate (www.lsys.com). Another option is DTTrainer which is a discrete trial training program for those able to use a computer, see www.dtrainer.com

Vision Training and Irlen Lenses: Many autistic individuals have difficulty attending to their visual environment and/or perceiving themselves in relation to their surroundings. These problems have been associated with a short attention span, being easily distracted, excessive eye movements, difficulty scanning or tracking movements, inability to catch a ball, being cautious when walking up or down stairs, bumping into furniture, and even toe walking). A one- to two-year vision training program involving ambient prism lenses and performing visual-motor exercises may reduce or eliminate many of these problems. See www.AutisticVision.com More information on vision training can be found on Internet website of the College of Optometrists in Vision Development (www.pavevision.org).

Another visual/perceptual program involves wearing Irlen lenses. Irlen lenses are colored (tinted) lenses. Individuals who benefit from these lenses are often hypersensitive to certain types of lighting, such as florescent lights and bright sunlight; hypersensitive to certain colors or color contrasts; and/or have difficulty reading printed text. Irlen lenses can reduce one's sensitivity to these lighting and color problems as well as improve reading skills and increase attention span. See www.Irlen.com

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. See www.rdicconnect.com

Although young children with autism may seem to prefer to be by themselves, one of the most important issues for older children and adults is the development of friendships with peers. It can take a great deal of time and effort for them to develop the social skills needed to be able to interact successfully with other children, but it is important to start early. In addition, bullying in middle and high school can be a major problem for students with autism, and the development of friendships is one of the best ways to prevent this problem.

Friendships can be encouraged informally by inviting other children to the home to play. In school, recess can be a valuable time for teachers to encourage play with other children. Furthermore, time can be set aside in school for formal "play time" between children

with autism and volunteer peers – typical children usually think that play time is much more fun than regular school, and it can help develop lasting friendships. This is probably one of the most important issues to include in a student's Individualized Education Program (IEP, or education plan for the child). Children with autism often develop friendships through shared interests, such as computers, school clubs, model airplanes, etc. Encourage activities that the autistic individual can share with others. An excellent book on developing social skills is titled *Relationship Development Intervention with Children, Adolescents and Adults* by Steven E. Gutstein, Ph.D. and Rachelle K. Sheely.

Rapid Prompting Method (RPM): This form of teaching was developed by an Indian educator, Soma Mukhopadhyay who has a teenage son with severe autism, Tito. Soma taught Tito to spell and write at a very early age, although Tito is very severely autistic. Soma's teaching methods have appeared on Sixty Minutes and other documentaries. Visit www.halo-soma.org for more information.

Comprehensive Avoidance Program for Autistic Children by the Applied Science and Technology International, Inc. in Springfield, Virginia offers a comprehensive chemical avoidance program to aid in autism recovery. For more information, log on to www.specialfoods.com.

Pfeiffer Treatment Center is based in Illinois but has outreach services twice a year to Scottsdale, AZ. (check out www.hripts.org for the dates). The Pfeiffer Treatment Center is a non-profit medical research and treatment facility specializing in research and treatment of biochemical imbalances. Since the center opened in 1989, it has treated more than 16,000 patients who suffer from behavior dysfunction, depression, schizophrenia, bipolar disorder, autism, learning disorders, or anxiety by balancing body and brain chemistry. The Pfeiffer Treatment Center, the medical clinic of the Health Research Institute (HRI), is staffed by a team of physicians, chemists, and other professionals who specialize in the effects of biochemistry on behavior, thought, or mood. The on-site HRI Pharmacy compounds nutrients, hormones, and other biochemicals to reduce the number of pills in a prescription using customized methods and equipment.

GOVERNMENT SERVICES

Arizona Division of Developmental Disabilities (DDD): Services may be available for individuals diagnosed with autism who are residents of Arizona. Typical services for people with autism include respite, habilitation, speech therapy, and occupational therapy. In order to qualify for services, children or adults must be diagnosed with autism (not PDD or Asperger's, which do not qualify), cerebral palsy, epilepsy or mental retardation by a licensed psychiatrist or psychologist with expertise in autism. Also, the applicant must meet three of seven functional limitations:

1. self-care
2. receptive and expressive language
3. learning
4. mobility
5. self-direction
6. capacity for independent living
7. economic self-sufficiency

Infants and toddlers under the age of six years may be eligible for services if they exhibit a significant delay in one or more areas of development. If under the age of three, a child may be eligible if it's determined he/she is AT RISK of having a developmental disability if the supports and services are not provided. After age SIX, an autism diagnosis by a **licensed psychologist or psychiatrist** with expertise in autism will be needed. **The diagnosis report must describe the child's behaviors and compare them to the autism criteria listed in the DSM IV to justify the autism label.** The Tucson Alliance for Autism (TAAFA center) conducts multidisciplinary evaluations, on a sliding pay scale. Call 520-319-5857 to inquire.

After meeting the eligibility criteria for DDD, families must cooperate with the Arizona Long Term Care System (ALTCS) eligibility process. The child must pass a pre-admission screening test during which you will be asked many questions about the functioning of your child. Also, the child cannot have over \$2000 in assets (savings bonds, etc.); parent assets are not a factor. If you don't get approved for ALTCS, always appeal and try again. If that fails, you may get State-only funds which are at constant risk for budget cuts since there are over 7000 people in Arizona receiving these services. ABA services depend on eligibility for both systems.

To begin the intake process for ages 0 - 6, call (520) 519-1676 and ask for an intake worker. For ages 6 and older, call 520-519-1551 and ask for Intake. Once a child is determined to be eligible, they will be awarded service hours based on need. You will be assigned a support coordinator (request an 'autism specialist') who will help you attain the services your child needs.

School Programs and Services: For children over 3 years of age, there are pre-school and school programs available, which paired with a home ABA program are optimal for learning, in most cases. Parents should contact their local school district for information on their local programs. In some cases a separate program for special-needs children may be best, but for higher-functioning children, integration into a regular school setting may be more appropriate, provided that there is enough support (a part or full-time aide, or other accommodations as needed). It is important that parents work with their child's teacher on an Individual Education Plan (IEP), which outlines in great detail the child's educational program. You may want to hire an advocate to get the outcome you desire from your child's IEP (refer to the advocacy section in this guide). Additionally, meeting with the child's classmates and/or their parents can be helpful in encouraging other students to interact positively with the autistic child.

If you are not happy with your school placement, visit other sites and fight to get your child moved. Use the term 'appropriate placement' whenever you can and document all conversations, it helps to be as polite and kind as possible, take notes of any problems and/or events which might warrant a new placement.

One of the most frequently asked questions we hear, is 'which school is best for autism?' Every district and school is different in Tucson. What one family views as perfect for their child may be insufficient in your opinion, and of course, every child is different. We encourage you to visit different classrooms (with school permission) and speak with teachers and principals. Most of us have fought for what we want, and many have won.

There is a new program available called Chapel Haven West which serves men and women with disabilities 18 years of age and older. This is a residential program and is not appropriate for individuals with serious behavioral issues, but is staffed 24 hours a day, and is tuition based. Phone 1-877-824-9378 for more information, or visit www.chapelhaven.org

Social Security Assistance: Families with limited incomes (under about \$25,000-\$35,000/yr depending on family size and assets) can apply to the Social Security agency to obtain monies to help children with a disability. For more information, contact your local social security office by calling 1-800-772-1213.

FINANCIAL PLANNING

SPECIAL NEEDS TRUSTS: Many well-intentioned parents and relatives don't realize that an inheritance may cause many problems for their child. Under current federal law, an inheritance of over \$2,000 disqualifies disabled children from most federal and/or state assistance. However, most states allow "special needs trusts" to be set up for children with disabilities. These are irrevocable trusts in which a guardian decides how to spend the money on the child. A trust can hold cash, stocks, personal property, and real property. It can own and/or be the beneficiary of life insurance, can be used to protect personal injury settlements or judgments, and can help parents coordinate their estate plans.

For more information, contact a lawyer who specializes in special needs trusts. Below is a list of local attorneys and organizations whom can assist. In addition to working out the financial details, it is very useful to write up a description of suggestions of how you want your child cared for and/or supported.

| | |
|---|--|
| Paul D. Slosser 6750 N. Oracle Rd. Tucson, AZ 85704-5618 520-575-5555 | Robert Fleming 330 N. Granada Ave. Tucson, AZ 85701 520-622-0400 |
| Eugene Gieseler 3430 E. Sunrise Drive, Ste 200 Tucson, AZ 85718 520-792-1181 | Kay Richter 3615 N. Prince Village Place, Ste 101 Tucson, AZ 85719 520-318-1301 |
| Will Conway or Steven W. Phillips 405 W. Franklin Street Tucson, AZ 85701 520-798-3803 | |

ADVOCACY

If you need help with your child's IEP, or advocacy for DDD services, below are places to contact.

- www.wrightslaw.com Special Ed information including writing effective letters to schools and other officials. Pete and Pam Wright are both attorneys and write 'The Special Ed Advocate' newsletter. Sign up to receive it on the website.
- www.reedmartin.com Reed Martin is a lawyer who provides you with articles, a chat room, message board, resources, links and much more. He has written several manuals, including 'Getting Your Child with Autism What They are Entitled to Under Federal Laws'. He provides a free e-newsletter and Special Education articles.
- Pilot Parents: Individual support by parents for parents and various groups. #520-324-3150 www.pilotparents.org. They are located at Tucson Medical Center. They also have a program called Partners In Policymaking where parents are chosen to go through a free leadership training to help make a difference in government policy making and all travel, food, lodging and respite are paid.
- The ARC of Tucson #570-1295
- Pima Council on Developmental Disabilities #888-3304
- Arizona Center for Disability Law (see www.acdl.com), 100 N. Stone, Ste 100 in Tucson. Phone 520-327-9547 and fax is 520-884-0992. There is a Special Education Advocacy Hotline which is a free statewide legal hotline that provides information, advice and referrals regarding special education rights and remedies. 1-800-927-2260
- DIRECT 520-624-6844

- DDD Quality Advocacy, 400 W. Congress Suite 500 in Tucson, phone 520-628-6844, FAX 520-628-6809

RECREATION

Keeping your child 'busy' is essential to helping him/her improve. Most of the following are not specific to participants with autism but can help with inclusion efforts. Please check under the Sensory Integration section for other ideas:

- Blue Sky Fitness - outdoor sports, hiking and fitness for youth/adults 520-323-3146
- Fast Eddie Skate School 520-722-7434 www.fasteddiesskateschool.com
- Therapeutic Riders of Tucson (TROT) Call to receive an information packet and application at 749-2360. Program Director: Laura Brinkeroff. Physical Therapists are on staff. TROT is located on the eastside, near Tanque Verde and Catalina (Eastside). Child needs a medical release from his pediatrician. Child will receive a psychological evaluation by TROT. Number of instructors and assistants with the child is dependent on child's needs. The child learns balance, strengthening, trunk control and other skills on the horse.
- Recreational Horseback Riding and Animal Care: Rancho De Sonrisas, Kelly Goudielock, Riding Instructor, Linda Goudielock, COTA & Med, Christine Small, OTR Phone: 520-298-8431 Cell: 520-331-6254 Location is on the Eastside of Tucson
- Therapeutic Horseback Riding, Desert Rose Therapy. Call Luanne at 520-975-9103 or 520-572-7230 for more information. Location is on the Northwest side of Tucson. Individual lessons provided. Group lessons are an option with enough interested parties. Desertrosetherapy@earthlink.net
- Swimming Lessons - Scala's Sunshine Swim School 520-544-4976 (NW location) or 520-886-6005 (Eastside location). Private 1:1 lessons are available to teach water safety and advance to swimming lessons. The instructor determines if the child has skills to advance to a small group setting. Swim school is open from January through October. Pools are heated to ~ 90 degrees.
- Tucson Parks and Recreation has a therapeutic and recreational pool located at Reid Park. Children with autism can use this amazing and fun facility and buy a membership year-round and can be accompanied with an adult. Swimming lessons are also available. Call the pool at 520-791-5643
- Community Resource Center/ATPT Swimming Pool (Summer time only) 4710 E. 29th street (29th and Swan). Swim season from May to end of September. Call 520-745-5588 and ask for the lifeguard.
- Aqua Kids, Call 520-324-5423 for referral form and questions. The program is run by two physical therapists (PT). The therapeutic pool is located at Tucson Orthopedic Institute on the property of Tucson Medical Center. TMC Foundation funds part of class, parents responsible for rest. Each session is 8 weeks long. The child is allowed to do two consecutive sessions if space is available in the class. Parent or guardian must participate in the pool. Classes are on Tuesdays and Thursdays from 6:00 PM to 7:00 PM. Class choice is determined by the physical therapists. Age plays a factor in class choice too. The child learns balance, strengthening, and other gross motor skills in the water.
- VIP (Very Important Person) Soccer. Child needs to be at least 5 years old and plays with a 'buddy'. Games begin in the Fall. Games are played at Richardson Field (Camino de la Tierra between Ina Road & Orange Grove) behind Richardson Elementary School. Parent or guardian runs the field next to the child. Cost is \$45.00 for registration and uniform rental. Season: September through mid-November. Contact Person: Mary Ferber at 520-544-7704 or mferber@comcast.net
- Challenger Little League. Games are on Saturday mornings at a central location, every child plays with a 'buddy'. Child needs to be at least 5 years old. May need to transfer to another league after age 9. Season is March through mid-June. Cost involved for registration and uniform rental. Challenger hotline number: 712-9448 League President: Sam Hawtree: 520-886-5161 Mail all correspondence to: Challenger Little League c/o Hawtree Financial Services 6069 E. Grant Road Tucson, Arizona 85712
- Tennis - El Conquistador Country Club on Saturdays from 11:00 AM – 11:45 PM, from September through May. FREE. Classes switch to Wednesday evenings from 6:00 PM-7:00 PM, from June through August. Ages 4-18. Program is free for Special Needs children. Contact 520-544-1900
- Project A.M.O.R. Bilingual program for children birth to 3 who have developmental disabilities. Programs and social outings for families are available. Where: 4130 S. Fifth Avenue 520-573-2927
- Tucson Parks & Recreation Therapeutics 520-791-4504

- Horticulture Therapy - Horticultural Therapy (for facilities, not individuals) "Horticultural Therapy is a process utilizing plants and horticultural activities to improve the social, educational, psychological, and physical adjustments of persons thus improving their body, mind, and spirit." Other benefits include sensory stimulation, enhanced socialization, improvement with self-esteem, development of a sense of responsibility, improvement of motor skills, opportunity for self-expression and creativity. Where: Monthly gardening programs are offered at your facility. Specially trained Tucson Botanical Garden (TBG) docents instruct and conduct hands-on activities. Contact: 520-326-9686.
- Third Street Kids/Arts for all, Inc. www.artsforallinc.org Performing Arts company and school for children with and without disabilities. Weekly classes are available. Monthly performances are done throughout Arizona. Also has summer programs. Where: 516 N. Fifth Avenue, Tucson, AZ. 85702 phone 622-4100
- Pima County Special Olympics 520-207-0710 Year-round program of sports training, physical fitness, and athletic competition for children and adults with mental disabilities.
- Stagecoach Trails Guest Ranch just outside of Yucca, AZ. This is a completely wheelchair accessible summer camp that also caters to families with autism. There is horse riding, swimming, and many fun things for the non-handicapped family member. www.stgr.com 866-444-4471, FAX 866-728-3016

There are several other summer camps and vacations including Camp Civitan, Camp Tatiyee, Blake Foundation, Camp Hope, SAARC Family Camp, Kris' Camp, Camp Easter Seals New Mexico, Easter Seals Lake Powell Adventure Camp Trips, Search Beyond Adventures(trips) Blue Sky Fitness (trips), Angels in Autism, the Tucson Alliance for Autism. For updated information on summer camps, vacations and programs, contact the DDD Resource & Training Center at 519-1515. Yearly, DDD puts on a Summer Camp Fair with information on programs from which to choose.

LONG-TERM PROGNOSIS

The first few years of your child's life are crucial. Get busy with early intervention and that will greatly affect the outcome of your child's long-term prognosis. You are embarking on a bumpy road with many successes and some backtracking but it will be worth it. Celebrate the small successes and try not to dwell on the deficiencies.

Today, most adults with autism (who did not have much intervention when young) are either living at home with their parents or living in a group home. Some higher-functioning people live in a supported-living situation, with modest assistance, and some are able to live independently. Some are able to work, either in volunteer work, sheltered workshops, or private employment, but many do not. Adults with PDD/NOS and Asperger's generally are more likely to live independently, and they are more likely to work. Unfortunately, they often have difficulty finding and then maintaining jobs, not because of a lack of job skills, but rather due to their limited social skills. Thus, it is important to encourage appropriate social skills early on, so they are able to live and work independently as much as possible.

Some of the most successful people on the autism spectrum who have good jobs have developed expertise in a specialized skill that often people value. If a person makes him-/herself very good at something, this can help make up for some difficulties with social skills. Good fields for higher functioning people on the spectrum are architectural drafting, computer programming, language translator, special educator, librarian and scientist. It is likely that some brilliant scientists and musicians have a mild form of Asperger's Syndrome (Ledgin, 2002). The individuals who are most successful often have mentor teachers either in high school, college or at a place of employment. Mentors can help channel interests into careers. Untreated sensory oversensitivity can severely limit a person's ability to tolerate a workplace environment. Eliminating fluorescent lights will often help, but untreated sound sensitivity has caused some individuals on the spectrum to quit good jobs because ringing telephones hurt their ears. Sensory sensitivities can be reduced by auditory integration training, diets, Irlen lenses, conventional psychiatric medications and vitamin supplementation.

It should also be pointed out that the educational, therapy, and biomedical options available today are much better than in past decades, and they should be much better in the future. However, it is often up to parents to find those services, determine which are the most appropriate for their child, and ensure that they are properly implemented. Parents are a child's most powerful advocates and teachers. With the right mix of interventions, most children with autism will be able to improve or in some cases become indistinguishable. As we learn more, and with the increase of information, awareness of autism and better therapies, children with autism will have a better chance to lead happy and fulfilling lives.

Resources of Interest Websites and Books

Autism Society of America: 1-800-3-AUTISM; www.autism-society.org/ Publishes a magazine, sends monthly emails, hosts a national meeting and maintains a good website. Most importantly, they are the major lobbying body for people with autism, including efforts to increase research on autism, increase education opportunities, and generally improve the lives of people with autism. You can join ASA on the website and click on the JOIN tab in the upper blue bar.

Autism Research Institute: Founded by Bernard Rimland, a parent of an autistic adult and a leading advocate of research on autism. Publishes a quarterly newsletter summarizing current research on autism, and maintains a website full of relevant information about autism. ARI also has excellent Publication Packets of many topics that can be ordered inexpensively on topics ranging from Auditory Integration Training to Self Injury to Vaccination information. ARI also sponsors the Defeat Autism Now! approach to autism. DAN! conferences, held bi-annually, are the leading conferences on biomedical treatments for autism. Contact: www.AutismResearchInstitute.com, fax: 619-563-6840.

Families for Early Autism Treatment (FEAT): www.feat.org Provides valuable information regarding Applied Behavior Analysis. Tucson does not have a FEAT organization at this time.

Cure Autism Now! (CAN!) www.cureautismnow.org based in California raises thousands of dollars for research and programs and education.

UC Davis M.I.N.D. Institute - heavily involved in research and employs numerous well known scientists to study autism. www.mindinstitute.org

Southwest Autism Research & Resource Center (SARRC) in Phoenix phone 602-340-8717, involved in research, ABA training and early intervention services. Join their mailing list to receive the newsletter and receive information about the 'FRIEND program' to teach school children how to interact with your autistic child at www.autismcenter.org

The Children's Center for Neurodevelopmental Studies, The Temple Grandin School is located in Glendale, AZ. Special education services for preschool through high school. www.thechildrenscenteraz.org

CARE - Center for Autism, Research and Education founded by Dr. Cindy Schneider, a DAN! doctor in Phoenix. www.center4autism.org or 602-277-2273 An excellent place to get biomedical intervention and education.

The Parent Information Network (PIN), founded by the Arizona Department of Education, provides parents with information so they can actively participate in their child's special education. They have a quarterly newsletter and have parent consultants who can be contacted for consultation. Check out www.ade.az.gov/ess/pinspals

Other Useful Websites

Autism Speaks: www.autismspeaks.org

American Music Therapy Association: <http://www.musictherapy.org/>

Association for Science in Autism Treatment-ASAT: <http://www.asatonline.org/>

AutismAsperger.net: <http://www.autismasperger.net/>

Autism Community Store: <http://www.autismcommunitystore.com/>

AutismSpot (Online Videos): <http://www.autismspot.com/>

Dandee Child Safety Harness: <http://www.angelfire.com/in2/dandee/>

Defeat Autism Now (DAN!): <http://www.defeatautismnow.com/>

Doug Flutie, Jr. Foundation for Autism: <http://www.douglutiejrfoundation.org/>

Etsy: <http://www.etsy.com/>

First Signs: <http://www.firstsigns.org/>

Future Horizons: <http://www.futurehorizons-autism.com/>

GFCF Diet: <http://www.gfcfdiet.com/>

Generation Rescue: <http://www.generationrescue.org/>

Gluten-Free Choice: <http://www.glutenfreechoice.com/>

Healing Thresholds: <http://autism.healingthresholds.com/>

Individuals with Disabilities Education Act (IDEA): <http://idea.ed.gov/>

Kirkman Labs: <http://www.kirkmanlabs.com/>

Lost and Found Temporary Tattoos: <http://www.tattooswithapurpose.com/>

Medline Plus: <http://www.nlm.nih.gov/medlineplus/autism.html>

National Association Of Residential Providers for Adults with Autism: <http://www.narpaa.org/>

National Autism Association (NAA): <http://www.nationalautismassociation.org/>

National Institute of Neurological Disorders and Strokes: <http://www.ninds.nih.gov/disorders/autism/autism.htm>

Natural Cellular Defense, Waiora: <http://www.waiora.com/>

Natural Foods Education: <http://www.jennette-turner.com/>

Organization for Autism Research (OAR): <http://www.researchautism.org/>

PCI Education: <http://www.pcieeducation.com/>

SafeMinds: <http://www.safeminds.org/>

Sandbox Learning Company: <http://www.sandbox-learning.com/>

Surfer's Healing: <http://www.surfershealing.org/>

Talk About Curing Autism (TACA): <http://www.talkaboutcuringautism.org/>

Together In Autism: <http://www.togetherinautism.org/>

Train 4 Autism: <http://www.train4autism.org/>

Unlocking Autism: <http://www.unlockingautism.org/>

Wrightslaw: <http://www.wrightslaw.com/>

ZAC Browser: Zone for Autistic Children: <http://www.zacbrowser.com/>

BOOKS ABOUT AUTISM: Below are books related to autism. Many books are located in the Autism Resource Library at the Tucson Alliance for Autism Center at 1002 N. Country Club. To make an appointment to see the library and borrow resources, please call Stephanie Nardei at 520-990-2071. There is a huge assortment of newer books, conference notes and movies. Books can also be ordered through Amazon.com, Starfish Specialty Press (www.starfishpress.com), *Autism Asperger Publishing Company* www.asperger.net, Jessica Kingsley Press (www.jkp.com) and Future Horizons (www.futurehorizons-autism.com).

[Autism & Early Intervention: Real life Questions, Real life Answers](#) by Dr. James Ball, Ed.D. BCBA.
[Could it be Autism?](#) by Nancy Wiseman A Parent's Guide to the First Signs and Next Steps
[Engaging Autism: Helping Children Relate, Communicate and Think with the DIR Floortime Approach](#) by Stanley Greenspan
[The Child With Special Needs: Encouraging Intellectual and Emotional Growth](#) by Stanley Greenspan, Serena Wieder, Robin Simons
[The Functional Emotional Assessment Scale For Infancy and Early Childhood: Clinical and Research Applications](#) by Stanley Greenspan, Georgia DeGangi, Serena Wieder
[Right from the Start: Behavioral Intervention for Young Children With Autism: A Guide for Parents and Professionals](#) by Sandra L. Harris, Mary Jane Weiss
[Triumphs in Early Autism Treatment](#) by Ennio Cipani, PhD
[A Is for Autism F Is for Friend: A Kid's Book on Making Friends with a Child Who Has Autism](#) by Joanna Keating-Velasco
[Acting for Kids on the Autistic Spectrum](#) by Alisa Wolf
[Autism in the School-Aged Child: Expanding Behavioral Strategies and Promoting Success](#) by Carol Schmidt, Beth Heybyrne
[Bai and the Word Launcher: Space Age Asperger Adventures in Communication](#) by Pamela Victor
[Incorporating Social Goals in the Classroom: A Guide for Teachers and Parents of Children with High-Functioning Autism and Asperger Syndrome](#) by Rebecca A. Moyes
[No Strangers](#) by Sharrie Warner
[Teach Me Language: A Language Manual for Children with Autism, Asperger's Syndrome and Related Developmental Disorders](#) by Sabrina Freeman, Lorelei Dake
[Teaching Children with Autism: Strategies for Initiating Positive Interactions and Improving Learning Opportunities](#) by Robert L. Koegel, Lynn Kern Koegel
[Teaching Conversation to Children with Autism: Scripts and Script Fading](#) by Lynn McClannahan, Patricia Krantz
[The Autism Acceptance Book: Being a Friend to Someone with Autism](#) by Ellen Sabin
[The New Social Story Book: Illustrated Edition](#) by Carol Gray
[Trevor Trevor](#) by Diane Twachtman-Cullen
[Visual Strategies for Improving Communication : Practical Supports for School & Home](#) by Linda A. Hodgdon
[You're Going to Love This Kid!: Teaching Students with Autism in the Inclusive Classroom!](#) by Paula Kluth
[Adolescents on the Autism Spectrum: A Parent's Guide to the Cognitive, Social, Physical, and Transition Needs of Teenagers with Autism Spectrum Disorders](#) by Chantal Sicile-Kira
[The Life and Message of the Real Rain Man: The Journey of a Mega-Savant](#) by Fran Peek, Lisa Hanson
[Thinking in Pictures: My Life with Autism](#) by Temple Grandin
[Autism and Its Medical Management: A Guide for Parents and Professionals](#) by Michael G., M.D. Chez
[Autism, Brain, and Environment](#) by Richard Lathe
[Biological Treatments for Autism and PDD](#) by William Shaw
[Breaking the Vicious Cycle: Intestinal Health Through Diet](#) by Elaine Gottschall
[Changing the Course of Autism: A Scientific Approach for Parents and Physicians](#) by Bryan Jepson, MD
[Children With Starving Brains: A Medical Treatment Guide for Autism Spectrum Disorder](#) by Jaquelyn McCandless
[Diet Intervention and Autism: Implementing the Gluten Free and Casein Free Diet for Autistic Children and Adults: A Guide for Parents](#) by Marilyn Le Breton
[Enzymes for Autism and other Neurological Conditions](#) by Karen L. Defelice
[Evidence of Harm: Mercury in Vaccines and the Autism Epidemic: A Medical Controversy](#) by David Kirby
[Facing Autism: Giving Parents Reason for Hope and Guidance for Help](#) by Lynn M. Hamilton
[Healthy Child Healthy World: Creating a Cleaner, Greener, Safer Home](#) by Christopher Gavigan
[Special Diets for Special Kids, Two](#) by Lisa Lewis
[The Biology of the Autistic Syndromes](#) Christopher Gillberg, Mary Coleman
[The Neurology of Autism](#) by Mary Coleman
[Tourette Syndrome and Human Behavior](#) by David Comings
[Understanding Autism: From Basic Neuroscience to Treatment](#) by Steve Moldin, John Rubenstein
[What Your Doctor May Not Tell You About Children's Vaccinations](#) by Stephanie Cave
[Autism Journey Guide](#) by Talk About Curing Autism (TACA)
[Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research & Recovery](#) by Karyn Seroussi
[A Parent's Guide to Developmental Delays: Recognizing and Coping with Missed Milestones in Speech, Movement, Learning, and Other Areas](#) by Laurie LeComer
[A Regular Guy Growing up with Autism: A Family's Story of Love and Acceptance](#) by Laura Shumaker
[Awakening Ashley: Mozart Knocks Autism On its Ear](#) by Sharon Ruben
[Between Their World and Ours: Breakthroughs with Autistic Children](#) by Karen Zelan
[Blessed with Autism, The Workbook: The Interactive Guide to Securing Financial Support](#) by Christina Peck
[Born on a Blue Day: Inside the Extraordinary Mind of an Autistic Savant](#) by Daniel Tammet
[Brothers & Sisters: A Special Part of Exceptional Families](#) by Peggy Gallagher, Thomas H. Powell, Cheryl Rhodes
[Daniel Isn't Talking](#) by Marti Leimbach
[Dylan's Story: Overcoming Autism, A Childhood Epidemic](#) by Cristin Fergus, Joseph G. Fergus
[Hey! You Aren't the Boss of Me!](#) by Bob Fessler
[Hole in One: A Tale from the Iris Dragon Series](#) by Gayle Grass

[Improving Speech and Eating Skills in Children with Autism Spectrum Disorders](#) by Maureen A. Flanagan
[Kids Booklet on Autism: For Siblings and Peers](#) by New Jersey Center for Outreach & Services for the Autism Community
[Letters to Sam: A Grandfather's Lessons on Love, Loss and the Gifts of Life](#) by Daniel Gottlieb
[Making Peace with Autism: One Family's Story of Struggle, Discovery, and Unexpected Gifts](#) by Susan Senator
[Mother Warriors: A Nation of Parents Healing Autism Against All Odds](#) by Jenny McCarthy
[More Than a Mom](#) by Heather Fawcett, Amy Baskin
[The Other Kid: A Draw It Out Guidebook for Kids Dealing With A Special Needs Sibling](#) by Lorraine Donlon
[Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child's Life](#) by Lynn Koegel, Claire LaZebnik
[Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders](#) by Eric Schopler
[A Pebble to Polish](#) by Janet Lord Leszl
[Raising Brandon: Parenting My Son to Live Successfully with Autism, Epilepsy, and Learning Disorders](#) By Amalia Starr
[Rex: A Mother, Her Autistic Child, and the Music that Transformed Their Lives](#) by Cathleen Lewis
[Siblings of Children With Autism: A Guide for Families \(Topics in Autism\)](#) by Sandra L. Harris
[Strange Son: Two Mothers, Two Sons, and the Quest to Unlock the Hidden World of Autism](#) by Portia Iversen
[That's Life with Autism: Tales and Tips for Families with Autism](#) by Donna Satterlee-Ross, Kelly Ann Jolly
[The Autism Book: Answers to Your Most Pressing Questions](#) by S. Jhoanna Robledo, Dawn Ham-Kucharski
[The Autism Sourcebook: Everything You Need to Know about Diagnosis, Treatment, Coping, and Healing--from a Mother Whose Child Recovered](#) by Karen Siff Exkorn
[The Boy Who Loved Windows: Opening the Heart and Mind of a Child Threatened with Autism](#) by Patricia Stacey
[Toilet Training for Individuals with Autism or Other Developmental Issues](#) by Maria Wheeler
[Understanding Autism](#) by Susan Dodd
[Understanding the Nature of Autism: A Guide to the Autism Spectrum Disorders](#) by Janice Janzen
[Visual Perception Problems in Children With AD/HD, Autism, And Other Learning Disabilities: A Guide for Parents And Professionals](#) by Lisa Kurtz
[Voices from the Spectrum: Parents, Grandparents, Siblings, People With Autism, And Professionals Share Their Wisdom](#) by Cindy N. Ariel, Robert A. Naseef
[Asperger Syndrome and Bullying: Strategies and Solutions](#) by Nick Dubin
[Asperger's and Girls Featuring Tony Attwood and Temple Grandin, plus 7 more experts](#)
[Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome](#) by Stephen Shore, Foreword by Temple Grandin
[School Success for Kids With Asperger's Syndrome](#) by Stephan Silverman, Rich Weinfeld
[The Mom's Guide to Asperger Syndrome and Related Disorders](#) by Jan Johnston-Tyler
[Autism: Asserting Your Child's Right to Special Education](#) by David Sherman
[How To Compromise With Your School District Without Compromising Your Child: : A Practical Guide for Parents of Children with Developmental Disorders and Learning Disabilities](#) by Gary Mayerson
[How Well Does Your IEP Measure Up?: Quality Indicators for Effective Service Delivery](#) by Diane Twachtman-Cullen, Jennifer Twachtman-Reilly
[IEP and Inclusion Tips for Parents and Teachers](#) by Anne I. Eason, Attorney-at-Law, and Kathleen Whitbread, Ph.D.
[Autism Aspergers: Solving the Relationship Puzzle--A New Developmental Program that Opens the Door to Lifelong Social and Emotional Growth](#) by Steven E. Gutstein
[Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and Other ASDs](#) by Chantal Sicile-Kira
[Autism Spectrum Disorders from A to Z \(English Version\) : Assessment, Diagnosis...& More!](#) by Emily Doyle Iland, Barbara T. Doyle
[Autism's False Prophets: Bad Science, Risky Medicine, and the Search for a Cure](#) by Dr. Paul Offit
[Children with Autism: : A Parent's Guide](#) by Michael D. Powers, Temple Grandin
[Do-Watch-Listen-Say: Social and Communication Intervention for Children With Autism](#) by Kathleen Ann Quill
[How To Be A Para Pro: A Comprehensive Training Manual for Paraprofessionals](#) by Diane Twachtman-Cullen
[Pervasive Developmental Disorder: An Altered Perspective](#) by Barbara Quinn, Anthony Malone
[Relationship Development Intervention With Young Children: Social and Emotional Development Activities for Asperger Syndrome, Autism, PDD and NLD](#) by Steven E. Gutstein, Rachelle K. Sheely
[Teaching Individuals With Developmental Delays: Basic Intervention Techniques](#) by O. Ivar Lovaas
[The Autism Encyclopedia](#) by John T. Neisworth, Pamela S. Wolfe
[The Golden Bridge : A Guide to Assistance Dogs for Children Challenged By Autism or Other Developmental Disabilities](#) by Patty Dobbs Gross
[The Official Autism 101 Manual: Everything you need to know about autism from experts who know and care](#) by Karen L. Simmons with contributions by Temple Grandin, Anthony Attwood, Darold A. Treffert, Bernard Rimland, Jed E. Baker, and more
[Understanding Autism for Dummies](#) by Stephen M. Shore, MA and Linda G. Rastelli, MA
[Understanding Autism Spectrum Disorders](#) by The American Academy of Pediatrics (AAP) [Purchase from the AAP.](#)
[A Work in Progress: Behavior Management Strategies & A Curriculum for Intensive Behavioral Treatment of Autism](#) by Ron Leaf, John McEachin, Jaisom D. Harsh
[Activity Schedules for Children with Autism: Teaching Independent Behavior](#) by Lynn McClannahan, Patricia Krantz
[Behavioral Intervention for Young Children With Autism: A Manual for Parents and Professionals](#) by Catherine Maurice, Gina Green, Stephen C. Luce
[Let Me Hear Your Voice: A Family's Triumph over Autism](#) by Catherine Maurice

Equipment Resources - Below is a list of free catalogs you can order. We are lucky to have the Adaptation Station in Tucson, which is located at the Community Resource Center (29th and Swan). The Adaptation Station makes and sells swings and OT equipment which is MUCH cheaper than catalog prices. To inquire about ordering please call 745-5588 ext. 1272 and ask for Rhonda Chance at Adaptation Station.

You can get free catalogs from the following resource companies:

- *Different Roads to Learning* - an ABA catalogue of ABA supplies and educational materials. www.Difflearn.com
- *Great Ideas for Teaching* - speech and communication products www.greatideasforteaching.com
- *Attainment Company* - communication and educational resources www.AttainmentCompany.com
- *FlagHouse Special Populations* lots of adaptive and OT equipment, and learning materials 1-800-793-7900
- *Achievement Products for Children* sells sensory products and learning materials www.specialkidszone.com
- Southpaw Enterprises - sensory integration and developmental products www.southpawenterprises.com
- Integrations - a catalog for kids with learning and sensory differences www.integrationscatalog.com
- Abilitations - lots of OT and learning equipment www.abilitations.com

Safety equipment: If your child is a 'runner', you can look into tracking systems, alarm and locator systems for special needs kids. Check out Care Trak, 1202 Walnut Street, Murphysboro, IL 62966 1-800-842-4537. Another tracking supply company is Ion Kids at 888-846-6543 or www.ion-kids.com. You can order an ID bracelet for your child from MedicAlert, 1-800-ID-ALERT.

Assistance Dogs for children with autism: <http://www.northstardogs.com> (also a local organization, Handi Dogs of Tucson will train a dog to do almost anything. You provide the dog and they help train them to be certified service dogs to help your loved one with autism.) www.handi-dogs.org or call 520-326-3412

Dentists who are autism friendly: Dr. Laila Hishaw, pediatric dentist 520-544-4171 in NW Tucson. Great Grins pediatric dentistry 520-325-4746 at 1700 E. Fort Lowell Drive in Tucson. Dr. Richard Simoneaux on N. Oracle Road 520-297-4118. Dr. Robert Collier on N. Oracle Road at 520-297-7263. East side: Dr. Michael Wexler 520-888-7645. Dr. Richard Davis at 2777 N. Campbell Ave 520-795-9202.

Support Groups

Autism Society of America, Pima County Chapter – for parents, family and friends of persons with ASD. Meetings are the 1st Monday of every month at 6pm at the TAFE Center (1002 N. Country Club). Contact Peter at president@tucsonautism.org or 520-991-9237

Asperger Family Support Group – TucsonAspergerFamilies@yahoo.com – for parents and relatives of persons with Asperger Syndrome, high functioning ASD and PDD. Meets the 2nd Saturday of each month from 11:00 a.m. to 12:30 pm at the TAFE Center (1002 N. Country Club). Contact Ayn McNutt at 520-275-2869 or ayn138@yahoo.com

Adult Asperger's Syndrome Support Group – for adults with Asperger's Syndrome. Meets on the first and third Thursday of each month at 6 pm at 501 E. Roger Road in the community building. Call Barbara Nichols at 520-954-1490 or binichols@qwestoffice.net. Website for this group is www.aspergers-tucson.org

PASS Autism Support Group – for parents of children with ASD on the NW side of Tucson. For times call Bridgett at 481-5105 or mbmthead@aol.com

Spanish Speaking Autism Support Group – for families of persons with ASD. Meets the 2nd Thursday of each month at 6 p.m. at 3655 E. 2nd Street (DDD building). Contact Norma Torres at 318-3510.

Caregiver Support Group – for families of persons with special needs. Group is meeting on the 2nd Monday of each month at 11:30am – 1:00 pm at the MIKID office located at 4500 E. Speedway Blvd, #59. Contact person is Debbie at 520-882-0142

Raytheon Parents of Dependents with Special Needs (RPODS) Not only for Raytheon employees. Meets on the 3rd Tuesday of each month from 6:00 to 8 pm at Coco's on Broadway across from Park Mall. Contact Mary-Lisa Orth at 520-794-3866 or 520-663-8779

WHAT TO DO NEXT?

- Join the Autism Society of America, Pima County Chapter by calling Helen at 520-444-6538. To add yourself to our listserve to receive newsletters, updates and local autism information, visit www.tucsonautism.org, click on the 'google listserve' link and follow instructions. Attend the monthly meetings and support groups. We meet the first Monday of every month at 6 p.m., usually at the Autism Center at 1002 N. Country Club. Call Peter Earhart at 991-9237 to verify meeting place and time.
- Contact Tucson's Division of Developmental Disabilities and apply for services at 520-519-1676. Be persistent. If and when you are assigned a support coordinator through DDD, make sure you request an 'autism specialist'. DDD has gone to great lengths to specifically train these support coordinators in autism resources and needs.
- Contact your local school district and ask what school programs they have to offer. If your child is under Kindergarten age, most school districts have early intervention programs for 'at risk' children which cost you nothing.
- Find a physician, preferably one who is familiar with the Defeat Autism Now! Protocol, and plan out a series of medical tests and treatments. Some pediatricians will be open to these medical testing and biomedical treatments, but most will not – find one who is willing to help your child, as opposed to just monitoring the severity of your child's problems. Do not take your child to a physician who does not support you or respect your viewpoint regarding treatments.
- Attend local and/or national autism conferences. The Pima County Autism Society of America will send out mailings and announcements about upcoming events and conferences.

- Make sure you still find some time for your other children and spouse/significant other. Autism causes a huge strain on the family and marriage, and you need to be prepared for the long term. Autism can absorb your life IF YOU LET IT. Find joy in each small achievement your child makes and focus on the day at hand. Continue trying to learn all you can.

We urge you to become active in the Tucson autism community, and ASA. We need the help of parents, grandparents, doctors, educators and friends of families with autism to continue to build the support and help needed to improve the lives of loved ones with autism.

If you have any suggestions, additions or changes to this guide, please email hjcurtis@yahoo.com or call 520-444-6538.

Last updated 2/14/09