

Advice for Parents of Young Autistic Children (2004): Working Paper

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Temple Grandin, Ph.D. is an associate professor of Animal Science at Colorado State University and a person with autism. She is the author of *Emergence: Labeled Autistic* and *Thinking in Pictures* and a designer of livestock handling facilities. Half of the cattle in North America are handled in facilities she has designed. She is a popular speaker at colleges and autism conferences.

Bernard Rimland, Ph.D. is the director of the Autism Research Institute (ARI) in San Diego, which he founded in 1967, and the founder of the Autism Society of America, which he founded in 1965. He is also the co-founder of the Defeat Autism Now! (DAN!) Project, which is sponsored by ARI. Dr. Rimland is the author of the prize-winning book, *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, which is credited with debunking the "mother-blaming theories of autism prevalent in the 20th century. He is also the father of an autistic adult. His website is: www.AutismResearchInstitute.com

INTRODUCTION

This paper is geared toward parents of newly diagnosed autistic children and parents of young autistic children who are not acquainted with many of the basic issues of autism. Our discussion is based on a large body of scientific research. Because of limited time and space, detailed explanations and references are not included.

Receiving a diagnosis of autism can be devastating to some parents, 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. A diagnosis of autism can be very upsetting. Joining parent support groups may help. However, these strong emotions also motivate parents to find effective help for their children. The diagnosis is important because it can open the doors to many services, and help parents learn about treatments that have benefited similar children.

The most important point we want to make is that autistic individuals have the potential to grow and improve. 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. Their progress though life will likely be slower than others, but they can still live happy and productive lives.

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 (PDD) or with Asperger's Syndrome (these children typically have normal speech, but they have many "autistic" social and behavioral problems).

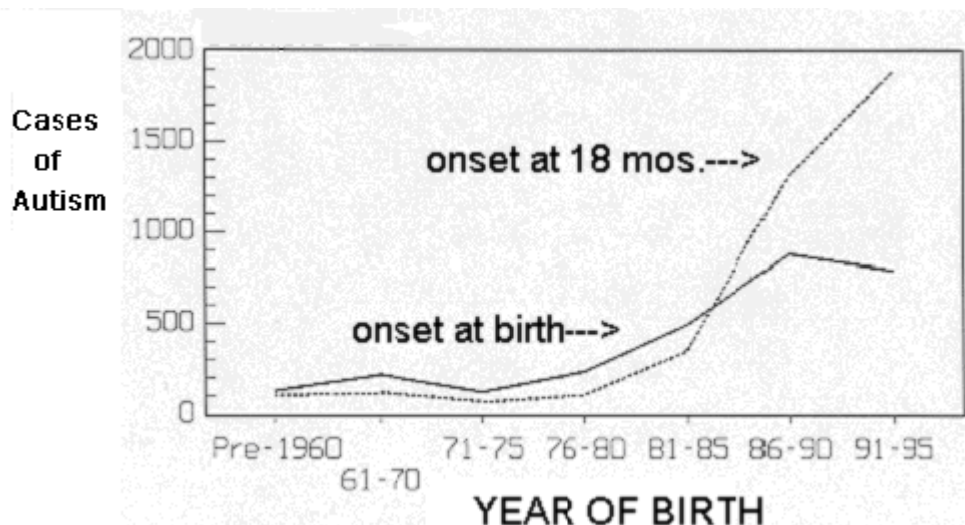
Left untreated, many autistic children will not develop effective social skills and may not learn to talk or behave appropriately. Very few individuals recover completely from autism without any intervention. The good news is that there are a wide variety of treatment options which can be very helpful. Some treatments may lead to great improvement, whereas other treatments may have little or no effect. No treatment helps everyone. A variety of effective treatment options will be discussed below.

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 to as late-onset or regressive autism. Some researchers argue that the regression is not real or the autism was simply unnoticed by the child's parents. However, many parents report that their children were completely normal (e.g., speech, behavior, social) until sometime between 1 and 2 years of age. The possible causative role of vaccinations, many of which were added to the vaccination schedule in the 1980's, is a matter of considerable controversy at present.

One recent study, conducted by the first author, compared 53 autistic children with 48 typical peers. The parents of the early-onset autism group reported a significant delay in reaching developmental milestones, including age of crawling (2 month delay), sitting up (2 month delay), walking (4-5 month delay), and talking (11 month delay or more). Thus, there appeared to be a delay in gross motor skills as well as of talking, so many children with autism also need physical therapy. In contrast, the late-onset autism group reached developmental milestones at the same time as typical children.

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 autistic in their second year (see figure below). The following results are based on the responses to ARI's E-2 checklist, which has been completed by thousands of autism families. These results suggest that something happened, such as increased exposure to an environmental insult, possibly vaccine damage, between ages 1 and 2 years.



Several brain autopsy studies have indicated that brain damage occurred sometime during the first trimester of pregnancy, but many of these studies involved individuals who were born prior to 1990. Thus, these findings may not apply to what appears to be the new population of regressive autism.

SPEECH DEVELOPMENT

One of the most common questions parents ask is: Will my child develop speech?

An analysis of ARI's data 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. A smaller, more recent survey conducted by the first author found that only 12% were totally non-verbal by age 5. So, 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 pointing to a set of pictures or symbols on a board. As with sign language, it can also be effective in teaching speech.
- Applied Behavior Analysis: described in more detail later
- Encouraging child to sing with a videotape or audiotape
- Vestibular stimulation, such as swinging on a swing, while teaching speech
- Several nutritional/biomedical approaches have been associated with dramatic improvements in speech production including dimethylglycine (DMG), vitamin B6 with magnesium, and the gluten-/casein-free diet. (To be discussed further below.)

GENETICS OF AUTISM

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. 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. 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 (e.g., exposure to chemicals). This may predispose the child to autism. Then, exposure to an (additional) environmental insult may lead to autism (e.g., the MMR vaccine) or mercury-containing vaccine preservatives (i.e., thimerosal).

If parents have a child with autism, there is an increased likelihood that their future children will also develop autism. Many studies have identified cognitive disabilities, which sometimes go undetected, in siblings of autistic children. Siblings should be evaluated for possible developmental delays and learning disabilities, such as dyslexia.

POSSIBLE ENVIRONMENTAL CAUSES OF AUTISM

Although genetics play an important role in autism, environmental factors are also 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. Some of the suspected environmental causes for which there is limited scientific evidence include:

- Childhood vaccinations: The increasing number of vaccines given to young children might compromise their immune system. Many parents report their child was normal until vaccinations.
- MMR Vaccine: Evidence of measles virus have been detected in the gut, spinal fluid and blood. Also, the incidence of autism began rising significantly when the MMR was introduced in the US (1978) and in the United Kingdom (1988).
- Thimerosal (a mercury-based preservative) in childhood vaccines. The number of vaccines given to children has risen over the last two decades, and most of those vaccines contained thimerosal, which is 50% mercury. The symptoms of mercury poisoning in children are very similar to the symptoms of autism.

- Excessive use of oral antibiotics: can cause gut problems, such as yeast/bacterial overgrowth, and prevents mercury excretion
- Maternal exposure to mercury (e.g., consumption of seafood high in mercury, mercury dental fillings, thimerosal in RhoGam shots)
- Lack of essential minerals: zinc, magnesium, iodine, lithium, and potassium may be especially important
- Pesticides and other environmental toxins
- Other unknown environmental factors

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 285 in 1999. 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. The major reason for the increase is certainly due to environmental factors, not genetics, since there is no such thing as a 'genetic epidemic.' 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 estimated that up to 75% of 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 25% 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.

Many 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 may be necessary. Although drugs can be used to reduce seizure activity, the child's health must be checked regularly because these drugs can be harmful.

There is substantial evidence that certain nutritional supplements, especially vitamin B6 and dimethylglycine (DMG), can provide a safer and more effective alternative to drugs, for many individuals. (Write to the Autism Research Institute for publication P-16).

- **Chronic Constipation and/or Diarrhea:** An analysis of the ARI's autism 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. An endoscopy may be the only way to check for this problem. Consultation with a pediatric gastroenterologist is required.

- **Sleep Problems:** Many autistic individuals have sleep problems. 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. Other popular interventions include using 5-HTP and implementing a behavior modification program designed to induce sleep. Vigorous exercise will help a child sleep, and other sleep aids are a weighted blanket or tight fitting mummy-type sleeping bag.
- **Pica:** 30% of children with autism have moderate to severe pica. Pica refers to eating non-food items such as paint, sand, dirt, paper, etc. Pica can expose the child to heavy metal poisoning, especially if there is lead in the paint or in the soil.
- **Low Muscle Tone:** A study conducted by the first author found that 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 Sensitivities:** 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. They are troubled by 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 this paper.

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

Asperger 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. In addition, high-functioning autistic individuals are often delayed in developing speech/language. Those with Asperger syndrome tend not to have speech/language delays, but their speech is usually described as peculiar, such as being stilted and perseverating on unusual topics.

MEDICAL TESTING AND TREATMENTS

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.AutismResearchInstitute.com), and studying the DAN! manual. The manual, titled *Biomedical Assessment Options for Children with Autism and Related Problems*, provides a comprehensive discussion of laboratory tests and interventions. A listing of doctors who subscribe to the DAN! approach to autism can be found on the ARI website.

A related description of medical testing and treatment is also available at <http://www.eas.asu.edu/~autism>

Routine medical tests are usually performed by traditional pediatricians, but they rarely reveal problems in autism that can be treated. Genetic testing for Fragile X syndrome 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, because they believe, incorrectly, that the only useful medical treatments are psychiatric medications to reduce seizures and behavioral problems.

Some of the major interventions suggested by DAN! practitioners include:

- Nutritional supplements, including certain vitamins, minerals, amino acids, and essential fatty acids
- Special diets totally free of gluten (from wheat, barley, rye, and possibly oats) and free of dairy (milk, ice-cream, yogurt, etc.)
- Testing for hidden food allergies, and avoidance of allergenic foods
- Treatment of intestinal bacterial/yeast overgrowth
- Detoxification of heavy metals

PSYCHIATRIC MEDICATIONS

The various topics covered in this overview paper for parents of young autistic children represent, for the most part, a consensus of the views, based on research and personal experience, of all four authors. However, the authors differ in their opinions on the role of psychoactive drugs should play. We will present you with the conflicting opinions, so you can decide for yourself.

Grandin has a relatively accepting position on the use of psychiatric medications in autistic children. She feels that it is worthwhile to consider drugs as a viable and useful treatment. Rimland and Edelson, on the other hand, are strongly opposed to the use of drugs except as a possible last resort, etc. – They feel the risks are great and consistently outweigh the benefits. Adams has an intermediate view.

Grandin

There are no psychiatric medications for “autism,” but there are many psychiatric medications used for treating specific symptoms often found in autism, such as aggression, self-injury, anxiety, depression, obsessive/compulsive disorders, and attention deficit/hyperactivity disorder (ADHD). These medications generally function by altering the level of neurotransmitters (chemical messengers) in the brain. There is no medical test to determine if a particular medication is called for; the decision is based on the psychiatrist’s evaluation of the patient’s symptoms. This is a “trial and error” approach, as dosages need to be adjusted differently for each person, and one medication may be ineffective or have negative effects while others are helpful.

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. Other classes of drug, such as anticonvulsants, will usually require the same doses that are effective in normal individuals.

Psychiatric medications are widely used to treat the symptoms of autism, and they can be beneficial to many older children and adults. However, there are concerns over their use. 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. They treat the symptoms, but not the underlying biomedical causes of autism. One must balance risk versus benefit. A drug should have an obvious positive effect to make it work the risk. In order to observe the effect of a drug, do not start a drug at the same time as you start some other treatment.

Rimland and Edelson

The Defeat Autism Now! (DAN!) approach to autism described above was developed by a group of advanced physicians and scientists (including a number of parents of autistic children) because the treatments offered as standard practice by traditional pediatricians, child psychiatrists and child neurologists is far from satisfactory. For the most part, traditional, non-DAN! doctors rely on psychoactive drugs, such as Ritalin, Risperdal, and Prozac. None of these drugs are approved by the FDA for autistic children, and like all drugs, may have serious side effects, including death. DAN! doctors rarely use drugs, relying instead primarily on nutritional supplements – safe substances that the human body routinely depends upon to keep the brain and body functioning smoothly and safely.

The Autism Research Institute (ARI) has collected data from many thousands of parents about their experiences with psychiatric medications and other treatments. In general, parents report that the medications are about equally likely to cause problems or to help, with some being worse than others. This is in contrast to other treatments for which the ARI has collected data, such as nutritional supplements, special diets, and heavy metal detoxification, which were more likely to help and very rarely caused problems. The results of this ongoing collection of parent survey data is available at www.AutismResearchInstitute.com

Here are the parent ratings of the three most often used drugs and the three most often used nutrients:

<u>Three most used drugs</u>	<u>Got Worse</u>	<u>No Effect</u>	<u>Got Better</u>	<u>Better: Worse</u>	<u>No. of Cases</u>
Ritalin	45%	26%	29%	0.7:1	3650
Benedryl	24%	51%	25%	1.1:1	2573
Risperdal	19%	28%	53%	2.8:1	401

<u>Three most used vitamins</u>	<u>Got Worse</u>	<u>No Effect</u>	<u>Got Better</u>	<u>Better: Worse</u>	<u>No. of Cases</u>
Vit. B6 & Mag.	4%	49%	46%	10:1	5284
DMG	7%	51%	42%	5.7:1	4725
Vit. C	2%	58%	39%	16:1	1408

We feel that psychoactive drugs should not be used at all on your children, and should be used only as a last resort, not as an initial treatment, on autistic teenagers and adults. ARI has collected information from parents of autistic children on their evaluation of various treatments, including drugs, since 1967.

Some adolescents and adults are helped by anti-psychotic drugs, such as Risperdal, or anti-depressants, such as Tofranil, but the risk of side effects is significant. Drugs should be the last resort, not the first choice. When psychoactive drugs are used with autistic teenagers or adults, it is often found that a very low dose, perhaps one-fourth or one-fifth of the normally-used dosage, is sufficient.

Adams

Psychiatric medications are not well-tested in young children with autism, especially for long-term use, and often have significant side-effects. DAN! approaches (nutritional support, diet changes, detoxification) are significantly safer and address core problems rather than symptoms. So, I think DAN! approaches should be tried first, especially in young children. However, there are some children and adults who have benefited from psychiatric medications, so they are reasonable to consider after DAN! approaches have been tried. In young children, they should be used only very cautiously, and beginning with low doses.

EDUCATIONAL/BEHAVIORAL APPROACHES

Educational/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 pre-school 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.

There is general agreement that:

- behavioral interventions involving one-on-one interactions are usually beneficial, sometimes with very positive results
- the interventions are most beneficial with the youngest children, but older children can benefit
- the interventions should involve a substantial amount of time each week, between 20-40 hours depending on whether the child is in school
- prompting as much as necessary to achieve a high level of success, with a gradual fading of prompts
- proper training of therapists and ongoing supervision
- regular team meetings to maintain consistency between therapists and check for problems
- most importantly, keeping the sessions fun for the children is necessary to maintain their interest and motivation

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.

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). Many techniques are used to stimulate these senses in order to normalize them.

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. As mentioned earlier, sign language and PECS may also be very helpful in developing speech. Speech therapists should work on helping the child to hear hard consonant sounds such as the “c” in cup. It is often helpful if the therapist stretches out and enunciates the consonant sounds.

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. 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' website (www.sait.org).

Computer-based auditory interventions have also received some empirical support. They include Earobics (www.cogconcepts.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. Earobics is less much expensive (less than \$100) but appears to be less powerful than the Fast ForWord program (usually over \$1,000). Some families use the Earobics program first and then later use Fast ForWord.

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).

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 can 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.connectionscenter.com

PREPARING FOR THE FUTURE

Temple Grandin: "As a person with autism I want to emphasize the importance of developing the child's talents. Skills are often uneven in autism, and a child may be good at one thing and poor at another. I had talents in drawing, and these talents later developed into a career in designing cattle handling systems for major beef companies. Too often there is too much emphasis on the deficits and not enough emphasis on the talents. Abilities in children with autism will vary greatly, and many individuals will function at a lower level than me. However, developing talents and improving skills will benefit all. If a child becomes fixated on trains, then use the great motivation of that fixation to motivate learning other skills. For example, use a book about trains to teach reading, use calculating the speed of a train to teach math, and encourage an interest in history by studying the history of the railroads."

DEVELOPING FRIENDSHIPS

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.

STATE SERVICES:

Most states will provide some services for children with autism, primarily funded by the federal Medicaid program. Many states have waiting lists for a limited number of slots. The quality of services varies widely state to state. Most states have one set of services for children under 3 years old (early intervention), and a second set of services for older children and adults.

State Services for Developmental Disabilities. Typical state 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) by a licensed psychiatrist or psychologist with training in childhood development. Furthermore, 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

Contact your local ASA chapter to obtain more information about the developmental disabilities services in your community.

Once a child is determined to be eligible, he/she may be awarded service hours. Many states have waiting lists for services, but some states provide services to everyone who qualifies. It is then up to the parent to choose a provider agency for each type of service. Speech therapists, occupational therapists, and physical therapists are in high demand, and the state pays only modest rates. Thus, it can be a challenge to find them. Similarly, it can be very challenging to find respite and habilitation providers (for an ABA program), and an even greater challenge to train and retain them. Often parents need to advertise for therapists, and then bring them to a provider agency for hiring. Often parents need to hire behavior consultants to train their habilitation (ABA) workers; this is very important and highly recommended if the parents can afford it.

SCHOOL PROGRAMS:

For children younger than 3 years old, there are early intervention programs. For children over 3 years of age, there are pre-school and school programs available. 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.

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.

In some states, home therapy programs (such as ABA and speech therapy) may be funded by the school district, rather than through the state. However, it may take considerable effort to convince the school district to provide those services. Check with your local ASA chapter and other parents about how services are usually provided in your state.

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.

SPECIAL NEEDS TRUSTS

Children who have assets over approximately \$2000 are ineligible to receive state and federal services. They must spend their money first. 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. They are the best way for relatives to leave funds to the child, because these monies do not count against the child when determining their eligibility for government services.

For more information, contact a lawyer who specializes in special needs trusts. 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. MetLife also has a special program for children with developmental disabilities.

LONG-TERM PROGNOSIS

Today, most adults with autism 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 a very few 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 a job. The major reason for chronic unemployment is not 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. As we learn more, children with autism will have a better chance to lead happy and fulfilling lives.

NATIONAL SOCIETIES

Autism Research Institute: Directed 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 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.

Autism Society of America: 1-800-3-AUTISM; www.autism-society.org/ Publishes a newsletter, 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. Parents should be encouraged to join and support the ASA.

Families for Early Autism Treatment (FEAT): www.feat.org Provides valuable information regarding Applied Behavior Analysis

SUGGESTED READING:

Facing Autism by Lynn Hamilton. This is one of the first books parents should read. It tells how one mother helped her child recover from autism, and it gives a good overview of testing, treatments, and resources.

Children with Starving Brains, by Jacquelyn McCandless, MD. This is probably the best book on the medical conditions of people with autism and how to treat them. Available from www.amazon.com.

Biomedical Assessment Options for Children with Autism and Related Problems by Jon Pangborn, Ph.D. and Sidney Baker, M.D.. Recommended series of tests and treatments for autistic individuals and those with related disorders. Available from the Autism Research Institute 4182 Adams Ave., San Diego, CA 92116, www.AutismResearchInstitute.com; fax: (619) 563-6840.

Biological Basis of Autism by William Shaw, Ph.D. Available from Great Plains Laboratory (913) 341-8949, www.greatplainslaboratory.com Covers many biological issues and treatments, including yeast/bacterial infections and casein-free/gluten free diets.

Relationship Development Intervention with Children, Adolescents and Adults by Steven E. Gutstein, Ph.D. and Rachelle K. Sheely.

Let Me Hear Your Voice by Catherine Maurice A story of how one mother helped her autistic child with ABA.

Autism, Handle With Care by Gail Gillingham. Book deals with the sensory issues often seen in people with autism.

Unraveling the Mystery of Autism & PDD: A Mother's Story of Research and Recovery by Karyn Seroussi. Discusses one mother's successful search for interventions for her child, with a focus on wheat-free, dairy-free diets.

Special Diets for Special Kids, by Lisa Lewis. Recipes for wheat-free, dairy-free foods. Available from www.autismndi.com

Emergence: Labeled Autistic by Temple Grandin and Margaret M. Scariano (contributor).

Thinking in Pictures: And Other Reports from My Life With Autism by Temple Grandin.

"Little Rainman" by Karen L. Simmons.

WHAT TO DO NEXT?

1) Attend one or more parent support groups: Parents can be a wonderful source of support and information. There are over 200 chapters of the Autism Society of America, over 70 chapters of FEAT, and other informal parent support groups. Consider joining at least one.

- 2) Contact your state's Developmental Disabilities program and apply for services. Be persistent.
- 3) Contact your local school district and ask about school programs. See what they have to offer.
- 4) Find a local physician, preferably one who is familiar with the Defeat Autism Now! Protocol, and plan out a series of medical tests and treatments. Some physicians will be open to medical testing and biomedical treatments, but others 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.
- 5) Attend local and/or national autism conferences.
- 6) Make sure you still find some time for your other children and spouse/significant other. Having a child with autism can result in many challenges, and you need to be prepared for the long term.
- 7) Continue trying to learn all you can. Good luck!

References -- On Request