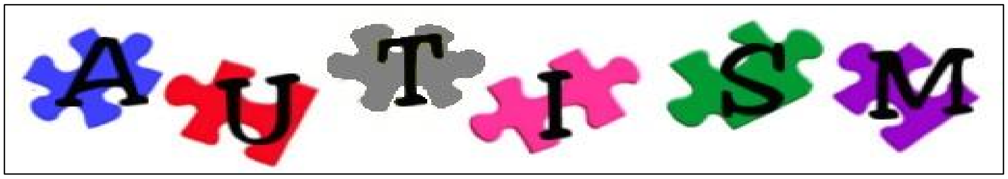
Utah Parent Center



UPC Connections

A Special Issue for Parents of Children with Autism Spectrum Disorders

Hope for Understanding the Causes of Autism: The Role of Research

Written by Bill McMahon M.D., Utah Autism Research Program

Autism is currently the focus of intensive research efforts. New clinical and lab methods, increasing numbers of scientists studying autism and increased support for autism research have emerged over the past decade. Parents and scientists have joined together to build systematic new research efforts. In response to parent advocacy, the National Institutes of Health and the Centers for Disease Control (CDC) have funded at least four multi-state research networks aimed at better understanding of autism and related disorders. Utah families are participating in these networks by volunteering to work with scientists at the University of Utah, Brigham Young University and the Utah Department of Health. These network projects promise discovery of new information in the genetics, immunology, brain imaging and epidemiology of autism.

Despite the increasing pace of research, much is not known about autism and the other Pervasive Developmental Disorders. A critical question is “What causes autism?” Genetic risk has been a known factor in autism for nearly thirty years, but no single gene has yet been established as a cause. Environmental factors may also contribute to the cause of autism but no chemical, viral or immune agent has been proven. Furthermore, the developmental course of autism over the lifespan remains a mystery. Some children with severe impairment at age 4 years continue to have lifelong severe impairment while other children with similar symptoms at an early age improve remarkably during later childhood and adolescence. Why do some children with autism improve while other children seem to fall further behind typical development with increasing age? Perhaps genetic markers or brain imaging will be helpful in predicting these developmental trajectories. Without clear understanding of one or more mechanisms causing autism, rational treatment is not possible. Current treatment research is hampered by the fact that autism is not one disorder, but probably is composed of many different subtypes, each with a different biological cause and each with a different developmental course. Knowledge of the underlying biology for each subtype of autism can make future treatment planning more effective by making it more tailored to the specific needs and strengths of each subtype of autism. Until such knowledge is available, intensive behavioral treatment and controlled trials offer some evidence for effective treatment.

Parents of children with autism face many challenges. First, they often struggle to identify what is wrong with their child. Obtaining a clear diagnosis may take months or years. Then, overcoming the shock of the diagnosis and obtaining services becomes a daunting task. Furthermore, confusing claims about autism causes or treatments continually plague parents with doubts about how to manage their child and the family’s financial and emotional assets. Finally, each year of development brings new needs for school, leisure and treatment planning. In the context of all of these challenges, why should families spend their time and energy volunteering for research? The simple answer is that research is the hope for the future. Without better understanding of the biology and neurodevelopmental course of autism, the current limitations on treatment will persist into the future. Precise drug or other treatments will not be possible. Prevention will remain an unachievable dream. The many mysteries about autism and Pervasive Developmental Disorders will be solved only if families invest their time and energy in a cooperative effort with the scientists who are trying to understand the biology of this neurodevelopmental disorder.

Inside this Issue:

This issue of UPC Connections was made possible by contributions from the Utah Autism Research Program and Utah Registry of Autism and Developmental Disabilities/Utah Department of Health. Thank you for your contributions!!!

Autism Information Resources at the Utah Parent Center

The Utah Parent Center (UPC or the Center) has recently increased its ability to serve families of children with autism. Late in 2003 the board of the Autism Society of Utah (ASU) dissolved the organization, notified their membership that they would no longer be available and referred them to the UPC as a resource. They approached the UPC to see if we were willing to accept the resources that they could pass on to us and use them to serve families who have looked to the ASU for information and support. This was an excellent solution. The award-winning UPC has served parents of children with autism and many professionals in the field of disabilities since 1984. In fact, the Center has received more calls from families of children with autism than any other disability!

As a result of this collaborative effort between the ASU and the UPC, the designation "Autism Information Resources at the Utah Parent Center" was created to make it easy for interested individuals reach the Center when looking in the phone book for autism information. The Center received most of the materials from their library, seed money to plan the Northern Utah Autism Conference, and some additional funding to help us respond to the information, training, and peer support needs of families. Our services are almost entirely free and we are a statewide organization.

Some of the services that we can provide to families are:

- ✓ A resource library of books, videos, etc. on autism
- ✓ An electronic newsletter that includes events, community-based autism support group
- ✓ Announcements, information about autism issues, etc. e-*Connections* is disseminated weekly.
- ✓ Information and referral to agencies, organizations, programs, and groups.
- ✓ Individual peer support and assistance through our statewide toll-free telephone line and in person when arranged.
- ✓ Support to and collaboration with parents and others who run local, community-based support groups for families of children with autism.
- ✓ Training opportunities that address a number of issues and concerns for families including IEPs, communication and teaming with professionals, a special needs child in the family, transition to adult life.
- ✓ The annual Family Links Conferences for parents of children and youth with disabilities. These conferences are scheduled in various locations across the state each year. A wide variety of topics designed to help parents are included on the conference agenda, including those that address the needs of families of children with autism.

We welcome your comments, suggestions and ideas! We encourage you to help us find and help families of children with autism by sharing information about the Utah Parent Center.

Just What <u>Is</u> Autism?

Autism is a complex developmental disability that typically appears during the first three years of life. The results of a neurological disorder that affects the functioning of the brain, autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism typically have difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities.

Autism is one of five disorders coming under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders characterized by "severe and pervasive impairment in several areas of development," including social interaction and communication skills (DSV-IV-TR). The five disorders under PDD are:

- Autistic Disorder
- Aspergers Disorder
- Childhood Disintegrative Disorder (CDD)
- Rett's Disorder
- PDD-NOS (Not Otherwise Specified)

Each of these disorders has specific diagnostic criteria as outlined by the American Psychiatric Association (APA) in its *Diagnostic & Statistical Manual of Mental Disorders* (DSM-IV-TR).

This information was taken from the Autism Society of America's website at www.autism-society.org.

Did you know that parents are welcome to attend autism in-service trainings that are provided by the Utah State Office of Education? To see the many excellent training events that are offered, view the calendar at http://updc.hosted.webevent.com/cgi-bin/webevent.cgi. or contact the Utah Parent Center at (801) 272-1051 for assistance.

How Prevalent is Autism?

Autism is the most common of the Pervasive Developmental Disorders, affecting an estimated 2 to 6 per 1,000 individuals (Centers for Disease Control and Prevention, 2001). This means that as many as 1.5 million Americans today are believed to have some form of Autism.

Autism was thought to be rare 20 years ago, but it is now recognized as more common. Whether the current increased prevalence has resulted only from changes in recognition, referral, diagnosis, and treatment availability is not clear. Controversial claims of an autism "epidemic" in California have lead to recognition of the need for new studies of the epidemiology of autism spectrum disorders.

The overall incidence of autism is consistent around the globe, but is four times more prevalent in boys than girls. Autism knows no racial, ethnic, or social boundaries, and family income, lifestyle and educational levels do not affect the chance of autism's occurrence.

This information was taken from the Autism Society of America's website at www.autism-society.org.

What Causes Autism?

There is no known single cause for autism, but it is generally accepted that it is caused by abnormalities in brain structure or function. Brain scans show differences in the shape and structure of the brain in autistic versus non-autistic children. Researchers are investigating a number of theories, including the link between heredity, genetics and medical problems. In many families, there appears to be a pattern of autism or related disabilities, further supporting a genetic basis to the disorder. While no one gene has been identified as causing autism, researchers are searching for irregular segments of genetic code that autistic children may have inherited. It also appears that some children are born with a susceptibility to autism, but researchers have not yet identified a single "trigger" that causes autism to develop.

Other researchers are investigating the possibility that under certain conditions, a cluster of unstable genes may interfere with brain development resulting in autism. Still other researchers are investigating problems during pregnancy or delivery as well as environmental factors such as viral infections, metabolic imbalances, and exposure to environmental chemicals.

Did you know that the Family Links Conferences feature sessions on autism as well as other topics of interest to all families of children with disabilities?

Sign up for the Utah Parent Center electronic newsletter or mailing list to receive more information.

Autism tends to occur more frequently than expected among individuals who have certain medical conditions, including Fragile X syndrome, tuberous sclerosis, congenital rubella syndrome, and untreated phenylketonuria (PKU).

Some harmful substances ingested during pregnancy also have been associated with an increased risk of autism. Early in 2002, The Agency for Toxic Substances and Disease Registry (ATSDR) prepared a literature review of hazardous chemical exposures and autism and found no compelling evidence for an association; however, there was very limited research and more needs to be done.

The question of a relationship between vaccines and autism continues to be debated. A national panel of the Institute of Medicine found no link between vaccines and Autism. The Autism Society of America does not support the conclusions and continues to call for more research. To read more on this topic, read the report at http://iom.edu/ and search for "Immunization Safety Review: Vaccines and Autism" and visit the Autism Society of America website at www.autism-society.org.

Whatever the cause, it is clear that children with autism and PDD are born with the disorder or born with the potential to develop it. Bad parenting does not cause it. Autism is not a mental illness. Children with autism are not unruly kids who choose not to behave. Furthermore, no known psychological factors in the development of the child have been shown to cause autism.

This information was taken from the Autism Society of America's website at www.autism-society.org.

> *"Doing the best at this moment puts you in the best place for the next moment."*
> *Oprah Winfrey*

Is it Autism?

Diagnosing Autism, PDD, or Aspergers Syndrome

The term "PDD" is widely used by professionals to refer to children with autism and related disorders; however, there is a great deal of disagreement and confusion among professionals concerning the PDD label. Diagnosis of PDD, Autism or any other developmental disability, is based upon the *Diagnostic & Statistical Manual of Mental Disorders – Fourth Edition* (DSM-IV-TR), published by the American Psychiatric Association, Washington D.C., 1994, the main diagnostic reference of Mental Health professionals in the United States of America.

Diagnostic labels are used to indicate commonalities among individuals. The diagnosis of autism indicates that qualitative impairments in communication, social skills, and range of interest and activities exist. As no medical tests can be performed to indicate the presence of autism or any other PDD, the diagnosis is based upon the presence or absence of specific behaviors. For example, a child may be diagnosed as having PDD-NOS if he or she has some behaviors that are in autism, but does not meet the full criteria for having autism. **Most importantly, whether a child is diagnosed with PDD, PDD-NOS, or Autism, his or her treatment will be similar.**

Autism is a spectrum disorder, with symptoms ranging from mild to severe. As a spectrum disorder, the level of developmental delay is unique to the individual. If a diagnosis of PDD-NOS is made, rather than autism, the diagnosticians should clearly specify the behaviors present. Evaluation reports are more useful if they are specific and become more helpful for parents and professionals in later years when reevaluations are conducted.

Ideally, a multidisciplinary team of professionals should evaluate a child suspected of having autism. The team may include, but may not be limited to, a psychologist or psychiatrist, speech pathologist, and other medical professionals including a developmental pediatrician or neurologist. Parents and teachers also have important information to share when determining a child's diagnosis.

In the end, parents should be more concerned that their child finds the appropriate educational treatment rather than spending too much effort to find the perfect diagnostic label. Most often, programs designed for children with autism will benefit children with PDD, and sometimes the use of the PDD label can keep a child from obtaining much needed services.

Common Characteristics of Autism

While understanding of autism has grown tremendously since it was first described by Dr. Leo Kanner in 1943, most of the public, including many professionals in the medical, educational and vocational fields, are still unaware of how autism affects people and how they can effectively work with individuals with autism. Contrary to popular understanding, many children and adults with autism may make eye contact, show affection, smile and laugh, and demonstrate a variety of other emotions, although in varying degrees. Like other children, they respond to their environment in both positive and negative ways.

Autism is a *spectrum disorder*. The symptoms and characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Although autism is defined by a certain set of behaviors, children and adults can exhibit *any combination* of the behaviors in *any degree of severity*. Two children, both with the same diagnosis, can act very differently from one another and have varying skills.

Parents may hear different terms used to describe children within this spectrum, such as autistic-like, autistic tendencies, autism spectrum, high-functioning or low-functioning autism, or more-abled or less-abled. More important than the term used is to understand that, whatever the diagnosis, children with autism can learn and function productively and show gains with appropriate education and treatment.

Every person with autism is an individual, and like all individuals, has a unique personality and combination of characteristics. Some individuals mildly affected may exhibit only slight delays in language and greater challenges with social interactions. The person may have difficulty initiating and/or maintaining a conversation. Communication is often descried as talking at others (for example, a monologue on a favorite subject that continues despite attempts by others to interject comments).

People with autism process and respond to information in unique ways. In some cases, aggressive and /or self-injurious behavior may be present. Persons with autism may also exhibit some of the following traits.

- Insistence on sameness, resistance to change
- Difficulty in expressing needs, using gestures or pointing instead of words
- Repeating words or phrases in place of normal, responsive language
- Laughing, crying, showing distress for reasons not apparent to others
- Preferring to be alone, aloof manner
- Tantrums
- Difficulty in mixing with others
- Not wanting to cuddle or be cuddled
- Little or no eye contact
- Unresponsive to normal teaching methods
- Sustained odd play

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- Spinning objects
- Inappropriate attachment to objects
- Apparent over-sensitivity or under-sensitivity to pain
- No real fears of danger
- Noticeable physical over-activity or extreme under-activity
- Uneven gross/fine motor skills
- Not responsive to verbal cues; acts as if deaf although hearing tests in normal range

For most of us, the integration of our senses helps us to understand what we are experiencing. For example, our sense of touch, smell and taste work together in the experience of eating a ripe peach: the feel of the peach fuzz as we pick it up, its sweet smell as we bring it to our mouth, and the juices running down our face as we take a bite. For children with autism, sensory integration problems are common. Their senses may be over or under-active. The fuzz on the peach may actually be experienced as painful; the smell may make the child gag. Some children with autism are particularly sensitive to sound, finding even the most ordinary daily noises painful. Some professionals feel that some of the typical autism behaviors are actually a result of sensory integration difficulties.

There are many myths and misconceptions about autism. Contrary to popular belief, many autistic children do make eye contact; it just may be less or different from a non-autistic child. Many children with autism can develop good functional language and others can develop some type of communication skills, such as sign language or use of pictures. Children do not "outgrow" autism but symptoms may lessen as the child develops and receives treatment. One of the most devastating myths about autistic children is that they cannot show affection. While sensory stimulation is processed differently in some children with autism, they can and do give affection. But it may require patience on a parent's part to accept and give love in the child's terms.

Aspergers Syndrome

Aspergers Syndrome is one of five Pervasive Development Disorders (PDDs), which also includes Autism, Rett's Syndrome, Childhood Disintegrative Disorder, and PDD-Not Otherwise Specified (PDD-NOS). PDDs are a category of neurologically-based disorders that have a range of delays in different developmental stages.

Aspergers Syndrome as first described in the 1940s by Viennese pediatrician Hans Asperger, who observed autistic-like behaviors and difficulties with social and communication skills in boys who had normal intelligence and language development. Many professionals felt Aspergers Syndrome was simply a milder form of autism and used the term "high-functioning autism" to describe these individuals. Professor Uta Frith, with the Institute of Cognitive Neuroscience of University College London and author of *Autism and Aspergers Syndrome*, describes individuals with Aspergers syndrome as "having a dash of autism." Aspergers Syndrome was added to the American Psychiatric Associations Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) in 1994 as a separate disorder from autism. However, there are still many professionals who consider Aspergers Syndrome a less severe form of autism.

What distinguishes Aspergers Syndrome from autism is the severity of the symptoms and the absence of language delays. Children with Aspergers Syndrome may be only mildly affected and frequently have good language and cognitive skills. To the untrained observer, a child with Aspergers Syndrome may just seem different.

Children with autism are frequently seen as aloof and uninterested in others. This is not the case with Aspergers Syndrome. Individuals with Aspergers Syndrome usually want to fit in and have interaction with others; they simply don't know how to do it. They may be socially awkward, not understanding conventional social rules, or may show a lack of empathy. They may have limited eye contact, seem to be unengaged in a conversation, and not understand the use of gestures.

Interests in a particular subject may border on the obsessive. Children with Aspergers Syndrome frequently like to collect categories of things, such as rocks or bottle caps. They may be proficient in knowing categories of information, such as baseball statistics or Latin names of flowers. While they may have good rote memory skills, they have difficulty with abstract concepts.

One of the major differences between Aspergers Syndrome and autism is that, by definition, there is no speech delay in Aspergers. In fact, children with Aspergers Syndrome frequently have good language skills; they simply use language in different ways. Speech patterns may be unusual, lacking inflection, or having a rhythmic nature. Speech may be formal and too loud or high pitched. Children with Aspergers Syndrome may not understand the subtleties of language, such as irony and humor, or may not understand the give and take nature of a conversation.

Another distinction between Aspergers Syndrome and autism concerns cognitive ability. While some individuals with Autism experience mental retardation, by definition a person with Aspergers Syndrome cannot possess a "clinically significant" cognitive delay. This does not imply that all individuals with autism have mental retardation. Some do and some do not, but a person with Aspergers Syndrome possesses average to above average intelligence.

While motor difficulties are not a specific criteria for Aspergers, children with Aspergers Syndrome frequently have motor skill delays and may appear clumsy or awkward.

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Diagnosis

Diagnosis of Aspergers Syndrome is on the increase although it is unclear whether it is more prevalent or whether more professionals are detecting it. The symptoms for Aspergers Syndrome are the same at those listed for autism in the DSM-IV. However, children with AS do not always have delays in the area of communication and language. In fact, to be diagnosed with Aspergers, a child must have had normal language development as well as normal intelligence. The DSM-IV criteria for AS specifies that the individual must have "severe and sustained impairment in social interaction, and the development of restricted, repetitive patterns of behavior, interests and activities," that must "cause clinically impairment in social occupational or other important areas of functioning."

The first step to diagnosis is an assessment, including a developmental history and observation. This should be done by medical professionals experienced with Autism and PDDs. If Aspergers Syndrome or high functioning autism is suspected, the diagnosis of autism will generally be ruled out first. Early diagnosis is important; children with Aspergers Syndrome who are diagnosed and treated early in life have an increased chance of being successful in school and eventually living independently.

Adults with Aspergers Syndrome

The transition for individuals with Aspergers Syndrome from federally-mandated services through the school system to adult services can be a challenge. While entitlement to public education ends when the student graduates, IDEA requires that transition planning begins at age 14 and becomes a formal part of the student's Individualized Education Plan (IEP). This transition planning should include the student, parents, and members of the IEP team who work together to help the individual make decisions about his or her next steps. An Individualized Transition Plan (ITP) is developed that outlines transition services that may include education or vocational training, employment, adult services, living arrangements and community participation.

The first step in transition planning should be to look at the individual's interests, abilities and needs. For example, what type of educational needs must be met: college, vocational training, or adult education? Where can the young adult find employment and training services. What types of living arrangements are best?

Postsecondary Education

Many individuals with Aspergers Syndrome are able to continue their education by attending college or trade schools. This also provides an opportunity to further social interaction, particularly in areas where the individual has key interests. Be sure that the institution offers training or classes of interest to the individual. Find out from the student services offices what help is available to address his or her special needs. Under Section 504, institutions of higher education are required to make reasonable accommodations. Work with your young adult in selecting classes that take advantage of his or her strengths.

Employment

Employment should take advantage of the individual's strengths and abilities. Temple Grandin, Ph.D. suggests that "jobs should have a well defined goal or endpoint," and that your "boss must recognize your social limitations." In _A Parent's Guide to Asperger Syndrome and High Functioning Autism_ the authors describe three employment possibilities: competitive, supported and secure or sheltered.

Competitive employment is the most independent with no support offered in the work environment. Individuals with AS may be successful in careers that require focus on details but have limited social interaction with colleagues such as computer sciences, research or library sciences. In supported employment, a system of supports allows individuals to have paid employment in the community, sometimes as part of a mobile crew, other times individually in a job developed for the person. In secure or sheltered employment, an individual is guaranteed a job in a facility-based setting. Individuals in secure settings generally receive work skills and behavior training while sheltered employment may not provide training that would allow for more independence.

To look for employment, begin contacting agencies that may be of help such as state employment offices, social services offices, mental health departments, disability-specific organizations. Find out about special projects in your area and determine the eligibility to participate in these programs. It is important to find employers who are willing to work with people with Aspergers Syndrome.

Living Arrangements

Whether an adult with Aspergers Syndrome continues to live at home or moves out into the community will be determined, in large part, by his or her ability to manage every day tasks with little to no supervision. For example, can he handle housework, cooking, shopping and bill paying? Is she able to use public transportation? Many families prefer to start with some supportive living arrangement and move towards increased independence.

Supervised group homes usually serve several individuals with disabilities. They are typically located in residential neighborhoods in an average family home. The homes are staffed by trained professionals who assist residents based

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on the person's level of need. Usually the residents have a job, which takes them away from home during the day. A supervised apartment may be suitable for individuals who prefer to live with fewer people, but still require some supervision and assistance. There is usually no daily supervision, but someone comes by several times a week. The residents are responsible for going to work, preparing meals, personal care and housekeeping needs. A supervised apartment setting is a good transition to independent living.

Independent living means just that – individuals live in their own houses or apartments and require little, if any, support services from outside agencies. Services may be limited to helping with complex problem solving issues rather than day-to-day living skills. For instance, some individuals may need assistance with managing money or handling government bureaucracies. It is also important for those living independently to have a "buddy" who lives nearby that can be contacted for support. Support systems within the community might include bus drivers, waitresses or coworkers.

Many people think of adulthood in terms of getting a job and living in a particular area, but having friends and a sense of belonging in a community are also important. Individuals with Aspergers Syndrome may need assistance in encouraging friendships and structuring time for special interests. Many of the support systems developed in the early years may continue to be useful.

Treatment Overview

Discovering that your child has autism can be an overwhelming experience. For some, the diagnosis may come as a complete surprise; others may have suspected autism and tried for months or years to get an accurate diagnosis. In either case, you probably have many questions about how to proceed. A generation ago, many people with autism were placed in institutions. Professionals were less educated about autism than they are today and specific services and supports were largely non-existent. Today the picture is brighter. With appropriate services, training and information, children with autism will grow and can learn, even if at a different developmental rate than others.

While there is no cure for autism, there are treatment and education approaches that may reduce some of the challenges associated with the disability. Intervention may help to lessen disruptive behaviors, and education can teach self-help skills that allow for greater independence. But just as there is no one symptom or behavior that identifies autistic children, there is no single treatment. Children can learn to function within the confines of their disability, but treatment must be tailored to the child's individual behaviors and needs. ***Please keep in mind that the descriptions of treatment approaches provided here are for informational purposes only. They are meant to give you an overview of an approach. The Utah Parent Center does*** *not* ***endorse any specific treatment or therapy***

Treatment and Education Approaches

During your research, you will hear about many different treatments approaches, such as auditory training, discrete trial training, vitamin therapy, anti-yeast therapy, facilitated communication, music therapy, occupational therapy, physical therapy, and sensory integration.

These approaches can generally be broken down into two categories: Treatment and Education. Treatment approaches include:

- Behavioral modification and communication approaches
- Dietary and biomedical approaches
- Complementary approaches

Some treatment approaches have research studies that support their efficacy; others may not. Some parents will only want to try treatment methods that have undergone research and testing and are generally accepted by the professional community. But keep in mind that scientific studies are often difficult to do since each individual with autism is different.

For others, formal testing might not be a pre-requisite for them to try a treatment with their child. Even for those with "scientific" proof, we recommend that the family or caregiver investigate any options being considered to determine the appropriateness.

Understanding Your Options

As a parent, it's natural to want to do something immediately. However, it is important not to rush in with changes. Your child may have already learned to cope with his or her current environment and changes can be stressful. You should investigate various treatment approaches and have a plan in place before proceeding. Treatment approaches have evolved as more is learned about autism. There are therapeutic programs - both conventional and complementary - that focus on replacing dysfunctional behaviors and developing specific skills. Just as there are various treatment approaches, there are multiple educational programs that provide stimulating learning environments. The Individuals with Disabilities Education Act (IDEA) is a federal mandate that guarantees students with disabilities a free, appropriate public education. The education plan for a student with disabilities can include "related services" that may encompass some of the treatments discussed here.

It is important, however, that you gather information concerning various options before making decisions concerning your child's treatment. You will encounter numerous accounts from parents about successes and failures with many of the treatment approaches mentioned. You will also discover that professionals differ in their theories of what they feel is the most successful treatment for autism. It can be frustrating! But, you can learn to sift through them, and make rational, educated

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decisions on what is appropriate for **your child**. You live with your child day by day. You know his/her needs, and you will come to know his/her autism. Trust your instincts as you explore various options.

Finding Treatment Programs in Your Area

Once you become familiar with the treatments that are available and appropriate for individuals with autism, you may be concerned about where they can receive these services. There are a variety of resources you can use to find qualified professionals or service providers in your area. There are several state agencies established to provide this type of information and support, including Protection and Advocacy(Disability Law Center); Developmental Disabilities Planning Councils; Vocational Rehabilitation Centers; Parent Training Centers (Utah Parent Center); and Educational Resources.

Each Child Has Unique Needs and Abilities

Individuals with autism, like everyone, are individuals first and foremost. They have unique strengths and weaknesses. What people with autism have in common is a developmental disability, a disorder of communication, which manifests itself differently in each person. Some individuals with autism may be of average to above average intelligence, while others may be below average. Academic goals need to be tailored to the individual's intellectual ability and functioning level. Some children may need help in understanding social situations and developing appropriate responses. Others may exhibit aggressive or self-injurious behavior, and need assistance managing their behaviors. No one program will meet the needs of all individuals with the disability, so it is important to find the program or programs that best fit your child's needs. Both treatment approaches and educational programs should be tailored to your child's individual needs, should be flexible and should be re-evaluated on a regular basis.

Treatment Options

The following is an introduction to some of the treatment approaches available for individuals with autism. While typically used for children under 3, these approaches may be included in an educational program for older children. Remember, this is not an exhaustive list; its purpose is to provide a **general overview** of available approaches, not specific treatment recommendations. Keep in mind that the word "treatment" is used in a very limited sense. Meeting the challenges of autism can be better described as education rather than treatment. And the term "education" is used broadly to include life skills, as well as traditional academic learning.

It is important to match your child's needs and potential with treatments or strategies that are likely to be effective in moving him or her closer to normal functioning. We do not want to give the impression that you will select one item from a list of available treatments. Move forward in your search for appropriate treatment knowing that you do not have to exclude other options, and that all treatment approaches are not equal. The basis for choosing any treatment plan should be a thorough evaluation of the strengths and weaknesses observed in the child.

Experts agree that early intervention is important in addressing the symptoms associated with autism. The earlier that treatment is started, the better the chance the child will reach normal functioning levels. Many of the approaches we describe can be used on children as young as age 2 or 3. They may also continue to be used in conjunction with special education programs or traditional elementary school for children who are in general education classes.

Most professionals agree that individuals with autism respond well to highly-structured, specialized education programs, designed to meet the individual's needs. Based on the major characteristics associated with autism, there are areas that are important to look at when creating a plan: social skill development, communication, behavior, and sensory integration. Programs sometimes include several treatment components coordinated to assist a person with autism. For example, one individual's program may consist of speech therapy, social skill development and the use of medication, all within a structured behavior program. Another child's may include social skill development, sensory integration and dietary changes.

Programs for Children Under 3

If your child is younger than 3 years old, he or she is eligible for "early intervention" assistance. This federally-funded program is available in every state, but may be provided by different agencies. In Utah, it is provided by the Health Department; you may contact Baby Watch Early Intervention at the Utah Department of Health at (801) 584-8201 or visit their website at www.utahbabywatch.org. This early education assistance may be available to you in two forms: home-based or school-based. As each name signifies, services are either provided in the home or at school. **Home-based** programs generally assign members of an early intervention team to come to your home to train you and educate your child. **School-based** programs may be in a public school or a private organization. Both types of programs should be staffed by teachers and other professionals with experience working with children with disabilities, specifically autism. Related services should also be offered depending on the needs of each child, such as speech, physical or occupational therapy. The program may be only for children with disabilities or it may also include non-challenged peers.

Programs for School-Aged Children

From the age of 3 through the age of 21, your child is guaranteed a free appropriate public education supplied by your local education agency (local school district). The

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Individuals with Disabilities Education Act (IDEA) is a federal mandated that guarantees this education. Whatever the level of impairment, the educational program for an individual with autism should be based on the unique needs of the student, and thoroughly documented in the IEP (Individualized Education Program). If this is the first attempt by the parents and school system to develop the appropriate curriculum, conducting a comprehensive needs assessment is a good place to start. Consult with professionals well versed in autism disorders about the best possible educational methods that will be effective in assisting the student to learn and benefit from his/her school program. Educational programming for students with autism often addresses a wide range of skill development including academics, language, social skills, self-help skills, behavioral issues, and leisure skills.

As a parent, you can and should be an active and equal participant in deciding on an appropriate educational plan for your child. You know your child best and can provide valuable information to teachers and other professionals who will be educating your child. Collaboration between parents and professionals is essential; open communication can lead to better evaluation of a student's progress. (See *Understand the Special Education Process* and *How the Special Education Process Works* on pages 21-22 of this newsletter.)

Evaluating Approaches

Because no two children with autism have the exact same symptoms and behavioral patterns, a treatment approach that works for one child may not be successful with another. This makes evaluating different approaches difficult. There is little comparative research between treatment approaches primarily because there are too many variables that have to be controlled. So what's a parent to do?
Bryna Siegel, Ph.D., in her article "Behavioral and Educational Treatment for Autistic Spectrum Disorders" (*Advocate*, Volume 33, No. 6) suggests thinking about "each symptom as an autism specific learning disability"...that tells "something about a barrier to understanding." Using this model, you can then evaluate what your child can and cannot do well, "take stock of which autistic learning disabilities are present," and "then select treatments that address that particular child's unique autism learning disability profile." Understanding these learning differences is the first step in assessing whether a specific treatment approach may be helpful to your child. Understanding a child's strengths is equally important. For example, some children are good visual learners. The more advanced child may need written, rather than oral, cues.

ASA Guidelines

The Autism Society of America's Panel of Professional Advisors has developed Guidelines to evaluate theories and practices related to autism. Here are a few things to consider as you evaluate treatment options.

- Will the treatment result in harm to the child?
- How will failure of the treatment affect my child and family?
- Has the treatment been validated scientifically?
- Are there assessment procedures specified?
- How will the treatment be integrated into the child's current program? Do not become so infatuated with a given treatment that functional curriculum, vocational life and social skills are ignored.
- In addition, consider the following questions to ask about specific treatments (compiled by the National Institute of Mental Health).
- How successful has the program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children and adolescents with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

This information was taken from the Autism Society of America's website at www.autism-society.org.

★ *Utah Parent Center Mission Statement* ★

The mission of the Utah Parent Center is to help parents help their children with disabilities to live included, productive lives as members of the community.

Behavioral and Communication Approaches

The behaviors exhibited by children with autism are frequently the most troubling to parents and caregivers. These behaviors may be inappropriate, repetitive, aggressive and/or dangerous, and may include hand-flapping, finger-snapping, rocking, placing objects in one's mouth, and head-banging. Children with autism may engage in self-mutilation, such as eye-gouging or biting their arms; may show little or no sensitivity to burns or bruises; and may physically attack someone without provocation. The reasons for these behaviors are complex, but some professionals think that sensory integration issues contribute to them.

Communication skills - both the spoken and written word - are also an issue for children with autism. They have difficulty understanding how communication works, and may have difficulty with reciprocal conversation. Many also have language difficulties, either being nonverbal throughout their lives or having delayed speech. Some children use language in unusual ways, such as repeating the words or sentences said to them (echolalia) or using only single words to communicate. Language difficulties may contribute to behavioral problems. Unable to use language to communicate his or her needs, a child with autism may resort to screaming.

Many treatment approaches have been developed to address the range of social, language, sensory, and behavioral difficulties. Some treatment approaches are:

Applied Behavior Analysis - ABA

Many of the interventions used to treat children with autism are based on the theory of applied behavior analysis (ABA) - that behavior rewarded is more likely to be repeated than behavior ignored. Although ABA is a theory, many people use the term to describe a specific treatment approach with subsets that include discrete trial training or Lovaas. While the terms discrete trial and Lovaas have been used interchangeably, only practitioners who are affiliated with Lovaas can be said to implement "Lovaas Therapy." Children usually work for 30 to 40 hours a week one-on-one with a trained professional. Tasks are broken down into short simple pieces, or trials. When a task has been successfully completed, a reward is offered, reinforcing the behavior or task. This method is not without controversy. Some practitioners feel it is emotionally too difficult for a child with autism, that the time requirement of 30 to 40 hours a week is too intensive and intrusive on family life; and that while it may change a particular behavior, it does not prepare a child with autism to respond to new situations. However, research has shown that ABA techniques show consistent results in teaching new skills and behaviors to children with autism.

TEACCH

The first statewide program for treatment and services for people with autism, TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) was developed at the School of Medicine at the University of North Carolina in the 1970s. It is a structured teaching approach based on the idea that the environment should be adapted to the child with autism, not the child to the environment. It uses no one specific technique, but rather is a program based around the child's functioning level. The child's learning abilities are assessed through the Psycho Educational Profile (PEP) and teaching strategies are designed to improve communication, social and coping skills. Rather than teach a specific skill or behavior, the TEACCH approach aims to provide the child with the skills to understand his or her world and other people's behaviors. For example, some children with autism scream when they are in pain. The TEACCH approach would search for the cause of the screaming and then teach the child how to signal pain through communication skills.

Picture Exchange Communication Systems

One of the main areas affected by autism is the ability to communicate. Some children with autism will develop verbal language, while others may never talk. An augmented communication program, such as Picture Exchange Communication Systems (PECS), is helpful to get language started as well as to provide a way of communicating for those children who do not talk. PECS was developed at the Delaware Autistic Program to help children and adults with autism to acquire functional communication skills. It uses ABA-based methods to teach children to exchange a picture for something they want - an item or activity. The advantage to PECS is that it is clear, intentional and initiated by the child. The child hands you a picture, and his or her request is immediately understood. It also makes it easy for the child with autism to communicate with anyone - all they have to do is accept the picture.

Floor Time

An educational model developed by child psychiatrist Stanley Greenspan, Floor Time is much like play therapy in that it builds an increasing larger circle of interaction between a child and an adult in a developmentally-based sequence. Greenspan has described six stages of emotional development that children meet to develop a foundation for more advanced learning - a developmental ladder that must be climbed one rung at a time. Children with autism may have trouble with this developmental ladder for a number of reasons, such as over-and under-reacting to senses, difficulty processing information, or difficulty in getting their body to do what they want. Through the use of Floor Time, parents and educators can help the child move up the developmental ladder by following the child's lead and building on what the child does to encourage more interactions. Floor Time does not treat the child with autism in separate pieces for speech development or motor development but rather addresses the emotional development, in contrast to other approaches which tend to focus on cognitive development. It is frequently used for a child's daily playtime in conjunction with other methods such as ABA.

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Social Stories

Social Stories were developed in 1991 by Carol Gray as a tool for teaching social skills to children with autism. They address "Theory of Mind" deficits, that is, the ability to understand or recognize feelings, points of view or plans of others. Through a story developed about a particular situation or event, the child is provided with as much information as possible to help him or her understand the expected or appropriate response. The stories typically have three sentence types: descriptive sentences addressing the where, who, what and why of the situation; perspective sentences that provide some understanding of the thoughts and emotions of others; and directive sentences that suggest a response. The stories can be written by anyone, are specific to the child's needs, and are written in the first person, present tense. They frequently incorporate the use of pictures, photographs or music.

Before developing and using social stories, it is important to identify how the child interacts socially and to determine what situations are difficult and under what circumstances. Situations that are frightening, produce tantrums or crying, or make a child withdraw or want to escape are all appropriate for social stories. However, it is important to address the child's misunderstanding of the situation. A child who cries when his/her teacher leaves the room may be doing so because he/she is frightened or frustrated. A story about crying won't address the reason for the behavior. Rather a story about what scares the child and how he can deal with those feelings will be more effective.

Sensory Integration

Children with autism frequently have sensory difficulties. They may be hypo- or hyper-reactive or lack the ability to integrate the senses. Sensory integration therapy, usually done by occupational, physical or speech therapists, focuses on desensitizing the child and helping him or her reorganize sensory information. For example, if a child has difficulties with the sense of touch, therapy might include handling a variety of materials with different textures.

Auditory integration therapy reduces over-sensitivity to sound. It may involve having the child listen to a variety of different sound frequencies coordinated to the level of impairment. Temple Grandin, Ph.D., who herself has autism, developed a "squeeze machine" to help her learn to tolerate touching through regulated deep pressure stimulation.

Before proceeding with any sensory integration therapy, it is important that the therapist observe the child and have a clear understanding of his/her sensitivities.

Facilitated Communication

Facilitated communication (FC) was developed in the 1970s in Australia by an aide who was trying to help a patient with cerebral palsy to communicate. It is based on the idea that the person is unable to communicate because of a movement disorder, not because of a lack of communication skills. FC involves a facilitator who, by supporting an individual's hand or arm, helps the person communicate through the use of a computer or typewriter. It has not been scientifically validated; critics claim it is actually the ideas or thoughts of the facilitator that are being communicated. FC is very controversial and organizations such as the American Association of Mental Retardation and the American Academy of Child & Adolescent Psychiatry have adopted formal positions opposing the acceptance of FC.

The previous information was taken from the Autism Society of America's website at www.autism-society.org

Relationship Development Intervention

Relationship Development Intervention (RDI) was developed by Dr. Steven Gutstein. RDI is a clinical treatment program that teaches dynamic intelligence skills and motivation to children on the autism spectrum. It uses a developmental and systematic step-by-step program that focuses on building the motivations to interact socially so that skills will be used and generalized. It can be implemented at school and at home using day-to-day activities to enrich the life of the whole family. RDI seeks to strengthen pathways in the brain that may be underdeveloped. Strengthening these pathways may result in an increase in the use of meaningful language and communication as well as social skills. While early intervention is always best, RDI can be tailored to meet the unique needs of individuals of all ages. There is a rigorous program for certification of therapists, and families are encouraged to evaluate the qualifications of therapists if considering this program. More information can be found at the RDI website, www.rdiconnect.com.

Complementary Approaches

While early educational intervention is key to improving the lives of individuals with autism, some parents and professionals believe that other treatment approaches may play an important role in improving communications skills and reducing behavioral symptoms associated with autism. These complementary therapies may include music, art or animal therapy and may be done on an individual basis or integrated into an educational program. All can help by increasing communication skills, by developing social interaction, and by providing a sense of accomplishment. They can provide a non-threatening way for a child with autism to develop a positive relationship with a therapist in a safe environment. Art and music are particularly useful in sensory integration, providing tactile, visual and auditory stimulation. Music therapy is good for speech development and language comprehension. Songs can be used to teach language and increase the ability to put words together. Art therapy can provide a nonverbal, symbolic way for the child with autism to express him or herself. Animal therapy may include horseback riding or swimming with dolphins. Therapeutic riding programs provide both physical and emotional benefits, improving coordination and motor development while creating a sense of well-being and increasing self-confidence. Dolphin therapy was first tried in the 1970s by David Nathanson, a psychologist who believed that interactions with dolphins would increase a child's attention, enhancing cognitive processes. In a number of studies, he found that children with disabilities learned faster and retained information longer when they were with dolphins compared to children who learned in a classroom setting. As with any therapy or treatment approach, it is important to gather information about the treatment and make an informed decision. Keep in mind, however, that with most complementary approaches, there will be little scientific research that has been conducted to support the particular therapy.

Dietary and Biomedical Approaches

Because autism is a spectrum disorder, no one method alone is usually effective in treating autism. However, professionals and families have found that a combination of treatments may be effective in treating symptoms and behaviors that make it hard for individuals with autism to function. These may include psychosocial and pharmacological interventions.

While there are no drugs, vitamins or special diets that can correct the underlying neurological problems that seem to cause autism, parents and professionals have found that some drugs used for other disorders are sometimes effective in treating some aspects of or behaviors associated with autism.

Changes to diet and the addition of certain vitamins or minerals may also help with behavioral issues. Over the past 10 years, there have been claims that adding essential vitamins such as B6 and B12 and removing gluten and casein from a child's diet may improve digestion, allergies and sociability. Not all researchers and experts agree about whether these therapies are effective or scientifically valid.

Medications

There are a number of medications, developed for other conditions that have been found effective in treating some of the symptoms and behaviors frequently found in individuals with autism, such as hyperactivity, impulsivity, attention difficulties, and anxiety. The goal of medications is to reduce these behaviors to allow the individual with autism to take advantage of educational and behavioral treatments.

When medication is being discussed or prescribed, ask about the safety of its use in children with autism. What is the appropriate dosage? How is it administered (pills, liquid)? What are the long-term consequences? Are there possible side effects? How will my child be monitored and by whom? What laboratory tests are required before starting the drug and during treatment? Are there possible interactions with other drugs, vitamins or foods?

Given the complexity of medications, drug interactions, and the unpredictability of how each patient may react to a particular drug, parents should seek out and work with a medical doctor with an expertise in the area of medication management.

What Medications are Available?

There are a number of medications that are frequently used for individuals with autism to address certain behaviors or symptoms. Some have studies to support their use, while others do not.

The Autism Society of America does not endorse any specific medication. The information provided here is meant as an overview of the types of medications sometimes prescribed. Be sure to consult a medical professional for more information.

Serotonin re-uptake inhibitors have been effective in treating depression, obsessive-compulsive behaviors, and anxiety that are sometimes present in autism. Because researchers have consistently found elevated levels of serotonin in the bloodstream of one-third of individuals with autism, these drugs could potentially reverse some of the symptoms of serotonin dysregulation in autism. Three drugs that have been studied are clomipramine (Anafranil), fluvoxamine (Luvox) and fluoxetine (Prozac). Studies have shown that they may reduce the frequency and intensity of repetitive behaviors, and may decrease irritability, tantrums and aggressive behavior. Some children have shown improvements in eye contact and responsiveness.

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Other drugs, such as Elavil, Wellbutrin, Valium, Ativan and Xanax have not been studied as much but may have a role in treating the behavioral symptoms. However, all these drugs have potential side-effects, which should be discussed before treatment is started.

Anti-psychotic medications have been the most widely studied of the psychopharmacologic agents in autism over the past 35 years. Originally developed for treating schizophrenia, these drugs have been found to decrease hyperactivity, stereotypic behaviors, withdrawal and aggression in individuals with autism. Four that have been approved by the FDA are clozapine (Clozaril), risperidone (Risperdal), olanzapine (Zyprexa) and quetiapine (Seroquel). Only risperidone has been investigated in a controlled study of adults with autism. Like the antidepressants, these drugs all have potential side effects, including sedation.

Stimulants, such as Ritalin, Adderall, and Dexedine, used to treat hyperactivity in children with ADHD have also been prescribed for children with autism. Although few studies have been done, they may increase focus, and decrease impulsivity and hyperactivity in autism, particularly in higher-functioning children. Dosages need to be carefully monitored, however, because behavioral side effects are often dose-related.

Vitamins and Minerals

Over the past 10 years or more, claims have been made that vitamin and mineral supplements may improve the symptoms of autism, in a natural way. While not all researchers agree about whether these therapies are scientifically proven, many parents and an increasing number of physicians report improvement in people with autism with the use of individual or combined nutritional supplements.

Malabsorption problems and nutritional deficiencies have been addressed in several as-yet unreplicated studies. A few studies conducted in 2000 suggest that intestinal disorders and chronic gastrointestinal inflammation may reduce the absorption of essential nutrients and cause disruptions in immune and general metabolic functions that are dependent upon these essential vitamins. Other studies have shown that some children with autism may have low levels of vitamins A, B1, B3, B5, as well as biotin, selenium, zinc, and magnesium, while others may have an elevated serum copper to plasma zinc ratio, suggesting that people with autism should avoid copper and take extra zinc to boost their immune system. Other studies have indicated a need for more calcium

Perhaps the most common vitamin supplement used in autism is vitamin B, which plays an important role in creating enzymes needed by the brain. In 18 studies on the use of vitamin B and magnesium (which is needed to make vitamin B effective), almost half of the individuals with autism showed improvement. The benefits include decreased behavioral problems, improved eye contact, better attention, and improvements in learning. Other research studies have shown that other supplements may help symptoms as well. Cod liver oil supplements (rich in vitamins A and D) have resulted in improved eye contact and behavior of children with autism. Vitamin C helps in brain function and deficiency symptoms that include depression and confusion. Increasing vitamin C has been shown in a clinical trial to improve symptom severity in children with autism. And in a small pilot study in Arizona using a multivitamin/mineral complex on 16 children with autism, improvements were observed in sleep and gastrointestinal problems as well as in language, eye contact, and behavior.

Using Vitamins and Minerals

If you are considering the addition of vitamins or minerals to your child's diet, a laboratory and clinical assessment of nutritional status is highly recommended. The most accurate method for measuring vitamin and mineral levels is through a blood test. It is also important to work with someone knowledgeable in nutritional therapy. While large doses of some vitamins and minerals may not be harmful, others can be toxic. Once supplements are chosen, they should be phased in slowly - over several weeks - and then the effects observed for one to two months.

The increase in the use of medications to treat autism has highlighted the need for more studies of these drugs in children. The National Institute of Mental Health has established a network of Research Units on Pediatric Psychopharmacology (RUPPs) that combine expertise in psychopharmacology and psychiatry. Located at several research centers, they are intended to become a national resource that will expedite clinical trials in children. Five groups are specifically funded to evaluate treatments for autism, studying dose range and regimen of medications as well as their mechanisms of action, safety, efficacy, and effects on cognition, behavior, and development. For example, the RUPP at Kennedy Krieger Institute is conducting a study on the efficacy of methylphenidate (Ritalin) in children and adolescents with Pervasive Developmental Disorders (PDD).

If you are considering the use of medications, contact a medical professional experienced in treating autism to learn of possible side effects. People with autism may have very sensitive nervous systems and normally recommended dosages may need to be adjusted. Even the use of large doses of vitamins should be done under the supervision of a medical doctor.

Dietary Interventions

Individuals with autism may exhibit low tolerance of or allergies to certain foods or chemicals. While not a specific cause of autism, these food intolerances or allergies may contribute to behavioral issues. Many parents and professionals have reported significant changes when specific substances are eliminated from the child's diet. Individuals with autism may have trouble digesting proteins such as gluten. Research in the U.S. and England has found elevated levels of certain peptides in the urine of children with autism, suggesting the incomplete breakdown of peptides from foods that contain gluten and casein. Gluten is found in wheat, oats and rye; casein in dairy products. The incomplete breakdown and the excessive absorption of peptides may cause disruption in biochemical and

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neuroregulatory processes in the brain, affecting brain functions. Until there is more information as to why these proteins are not broken down, the removal of the proteins from the diet is the only way to prevent further neurological and gastrointestinal damage.

It is important not to withdraw gluten/casein food products at once from a child's diet as there can be withdrawal symptoms. Parents wishing to pursue a gluten/casein free diet should consult a gastroenterologist, nutritionist, etc., who can help ensure proper nutrition. Some hypothesize that children with autism have what is referred to as a "leaky gut" -- tiny holes in their intestinal tract that may be caused by an overgrowth of yeast. Some believe that this overgrowth may contribute to behavioral and medical problems in individuals with autism, such as confusion, hyperactivity, stomach problems, and fatigue. The use of nutritional supplements, anti-fungal drugs and/or a yeast-free diet may reduce the behavioral problems. However, caution should be paid to the fact that just as antibiotics can lead to bacterial resistance; antifungals can lead to fungal resistance.

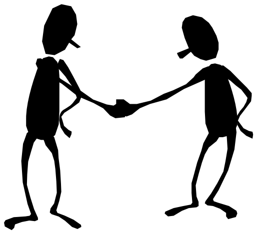
Secretin

Secretin is a hormone produced by the small intestines that helps in digestion. It is currently used as a single dose to diagnose gastrointestinal problems. In 1996, a young boy with autism was given secretin for an endoscopy and showed improvements in some of his symptoms of autism. Other parents and professionals who tried secretin on children with autism reported similar results, including improvements in sleep patterns, eye contact, language skills, and alertness. However, several studies funded by the National Institute of Child Health and Human Development (NICHD) in the past three years have found no statistically significant improvements in the core symptoms when compared to patients who received a placebo. It is also important to remember that secretin is approved by the FDA for a single dose; there are no data on the safety of repeated doses over time.

This information was taken from the Autism Society of America's website at www.autism-society.org.

Help support the Utah Parent Center in their mission to help families by participating in the Albertson's Community Partners program. By using this card, Albertsons donates a percentage of your purchases to the Utah Parent Center at no cost to you. If you are interested in receiving a Community Partners Card from the Utah Parent Center please contact us at (801) 272-1051 or by email at upcinfo@utahparentcenter.org.

Consulting with Professionals



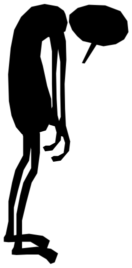
Whether you or your child's pediatrician is the first to suspect autism, your child will need to be referred to someone who specializes in diagnosing autism spectrum disorders. This may be a developmental pediatrician, a psychiatrist or psychologist. Other professionals may be included who are better able to observe and test your child in specific areas.

This multidisciplinary assessment team may include some or all of the following professionals. They may also be involved in treatment programs.

- **Developmental pediatrician-** Treats health problems of children with developmental delays or disabilities.
- **Child psychiatrist-** A medical doctor who may be involved in the initial diagnosis; can prescribe medication and provide help in behavior, emotional adjustment and social relationships.
- **Clinical psychologist-** Specializes in understanding the nature and impact of developmental disabilities including autism spectrum disorders. May perform psychological and assessment tests and may help with behavior modification and social skills training.
- **Occupational therapist-** Focuses on practical, self-help skills that will aid in daily living such as dressing, eating; may work on sensory integration, coordination of movement, and fine motor skills.
- **Physical therapist-** Helps to improve the use of bones, muscles, joints and nerves to develop muscle strength, coordination and motor skills.
- **Speech/language therapist-** Involved in the improvement of communication skills including speech and language.
- **Social Worker-** May provide counseling services or act as a case manager helping to arrange services. It is important that parents and professionals work together for the child's benefit. While professionals will use their experience and training to make recommendations about your child's treatment options, you have unique knowledge about his/her needs and abilities.

Once a treatment program is in place, communication between parents and professionals is essential to monitor the child's progress. Here are some guidelines for working with professionals.

- ★ **Be informed.** Learn as much as you can about your child's disability so you can be an active participant in determining care. If you don't understand terms used by professionals, ask for clarification.
- ★ **Be prepared.** Be prepared for meetings with doctors, therapists, and school personnel. Write down your questions and concerns, and then note the answers.
- ★ **Be organized.** Many parents find it useful to keep a notebook detailing their child's diagnosis and treatment as well as meetings with professionals.
- ★ **Communicate.** It's important to ensure open communication – both good and bad. If you don't agree with a professional's recommendation, for example, say *specifically* why you don't.



Getting Past the Diagnosis

Often, the time immediately after the diagnosis is a difficult one for families, filled with confusion, anger and despair. These are normal feelings. But there is life after a diagnosis of autism. Life can be rewarding for a child with autism and all the people who have the privilege of knowing the child. While it isn't always easy, you can learn to help your child find the world and interesting and loving place.

> *"...Our lives were totally changed without our consent! We felt badly because our new baby won't be able to walk...we talked about this with our other children and our 4 year old said, "Mom, NO babies can walk!"* *Louise Ogden*

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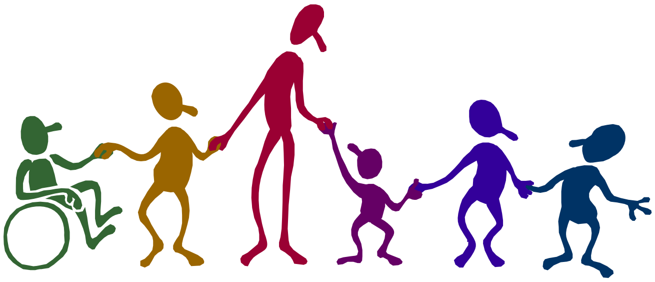
Managing Together as a Family

Managing a family that includes a child with Autism or other disability can be a challenging task. Some general suggestions are that:

- Even though having a child with a serious disability is difficult, it is important to know that there are accomplishments to appreciate, opportunities to grow, and moments to laugh and enjoy.
- Families should try to lead as normal a life as possible. Try not to allow the disability to dominate all phases of family life.
- Your child who has a disability needs to be involved in family activities and to know that he or she has a responsibility for helping with such things as household chores.
- Talking things over regularly with all members of the family helps prevent the build- up of tensions and fears.
- Brothers and sisters want and need to share both the joys and some of the responsibilities of family life when a child has autism.

What are some of the feelings that parents of children with autism experience?
What can help me release some of the tensions that I feel as a parent?
How much should my child know about his or her disability?
How can I help my child express anger or frustration?
Should I discipline the child who has autism?
What are the reactions that siblings may have about the brother or sister who has a disability?
How can I help my other children cope with their feelings?
How can I handle the reactions of my child's grandparents?
Can our marriage survive the stresses of managing this disability?
How can I find a babysitter I can trust and who is comfortable with my child?
How can our family take a vacation?
How can I obtain appropriate schooling for my child?
How can my child receive medications at school?
Can my child participate in a school sports program?
What can my child say to friends about his or her disability?
How can I help my child deal with reactions of other children?
How can I encourage my child's friendships?



Questions to ask yourself if you are a parent of a child with disabilities:

? ***What wakes me up at 2:00 a.m.? (What am I most worried about?)***
? ***What do I want for my child?***
? ***What needs to be different or to be changed?***
? ***What needs to happen?***
? ***What needs to be worked on first? Second? Third?***
? ***What do I need?***

Now what do I do?

√ ***Make a list.***
√ ***Prioritize your concerns.***
√ ***Determine steps to take—first, second, and third.***
√ ***Do something now!***

Answers to these questions can have a tremendous effect on your ability to manage as a family. If you would like this article, "Managing as a Family" in its entirety, please visit our website at www.utahparentcenter.org or contact the Utah Parent Center at (801) 272-1051 or Toll Free in Utah at 1-800-468-1160.

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Stress Management –"Survival Plan"

1. **RECOGNIZE WHEN YOU HAVE TOO MUCH STRESS.** Learn to recognize your unique cues that tell you about your level of stress. Everyone has some stress in their lives. Remember, significant stress over a long period of time can lead to illness, accidents, or lowered self-esteem.
2. **TALK OUR YOUR TROUBLES.** Find a friend, member of the clergy, counselor or psychotherapist you can be open with. Expressing your bottled-up tension to a sympathetic ear can be incredibily helpful. Be sure the person you talk to can keep confidences and accept you for who you are. Avoid people who give a lot of advice.
3. **LEARN A SYSTEMATIC, DRUG-FREE METHOD OF RELAXING.** Meditation, yoga, autogenic training or progressive relaxation can be learned from various accredited teachers, licensed psychotherapists, and even books. The only way it will work for you is if you practice relaxation on a regular basis. Practicing relaxation during crisis will probably not work.
4. **GET REGULAR PHYSICAL EXERCISE.** Check with your phsycian before beginning any exercise program. You will be more likely to stay with an exercise program ifyou choose one that you really enjoy, rather than one that is hard work and drudgery.
5. **PROPER NUTRITION.** Eat well balanced meals, if you can, and on a regular basis. You may want to consider moderate use of viatmins, especially if you are under a great deal of stress.
6. **SLEEP.** Although each person has different needs, getting sever hours of sleep per night on a routine basis will help more moderate stress.
7. **LEARN TO PLAY.** Disorganization can breed stress. Having too many projects going simultaneously often leads to confusion, forgetfulness, and the sense that uncompleted projects are hanging over your head. When possible, take on projects one at a time and work on them until completed. Schedule yourself. Prioritize. Delegate. Long range and short range planning. Quiet time.
8. **RECOGNIZE & ACCEPT LIMITS.** Most of us set unreasonable and perfectionistic goals for ourselves. We can never be perfect, so we often have a sense of failure or inadequacy no matter how well we perform. Set achieveable goals for yourself. Learning to say "no" to others may be helpful here. You may want to take a class in or read about assertiveness training.
9. **HAVE FUN!!!** You need occasionally to escape from the pressures of life and have fun. Find pastimes which are absorbing and enjoyable to you no matterwhat your level of ability. Remember, you are not being LAZY. Having fun is OK!
10. **BE A POSTIVE PERSON.** Avoid criticizing others. Learn to praise the things you like in others. Focus upon the good qualities those around you possess.
11. **LEARN TO TOLERATE & FORGIVE.** Intolerance of others leads to frustration and anger. An attempt to really understand the way other people feel can make you more accepting.
12. **AVOID UNNECESSARY COMPETITION.** There are many competitive situations in life we cannot avoid. Too much concern with winning in too many areas of life can create excessive tension and anxiety and make one unnecessarily aggressive.

More Tips:

- ➜ Dress comfortably. When you feel comfortable in your clothes and look nice, you can meet the day with greater confidence. Pinchy shoes, creepy pantyhose, too-tight pants, etc. can ruin the best of moods.
- ➜ Make duplicates of all keys. Put them where you can get to them when they are needed (e.g. when you've locked yourself out of the car, etc.)
- ➜ Avoid rush hour traffic by changing your driving time 30 minutes earlier or later.
- ➜ Take leisurely baths. Showers are more efficient, but a long soak in a hot fragrant bath is more relaxing and don't forget to unplug the phone!
- ➜ See the humor in life. Every situation has something funny about it if you look for it. Laughter is one of the best tension reducers!
- ➜ Take a break from the children. Babysitters are not just for emergencies or special occasions. You are a legitimate person...exchange services with another mother so there is no cost involved. Take time for self renewal.
- ➜ Work off tensions. The body prepares for fight or flight when under stress. Since we ususally can do neither, having a "cleaning fit" is very beneficial. You can get a lot accomplished if you covert the "mad" into muscle. Working in the yard is very therapeutic for some.

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Sibling Tips for Families

What do parents of children with disabilities need to know about their brother or sister? What can you, as a parent, do to help? Often, parents ask what they can be doing to make sure their other child or children won't get "shortchanged" in the hustle and bustle that frequently happens when on e of the family members has a disability.

As with other suggestions about what it takes to do a good job as a parent, it's important to remember that there is no magic formula that works for all families or in all situations. Every family will approach the situation differently.

You, too, will need to take time to think about your own circumstances and the kinds of things that are important for your family. You will need to be ready to try different things, often more than once, because there aren't any quick or easy "answers" to the questions you and your children will inevitably have.

What follows are some tips that can be used as a guide to help you thing about what will work best for you. They take into account one of the most important facts about living with a child with a disability; that is, he or she has the same wants and needs as any other child.

To the extent possible, you will need to come to think of the disability as just another characteristic that makes one child different from another, much the way eye color, physical size, or specific talents and abilities distinguish children as individuals.

The most important thing to keep in mind is that growing up with a brother or sister who has a disability can be a loving and happy experience; it is not necessarily or automatically "bad" or painful or difficult. Like everything else in life, much of it is what you make of it.

There are certainly aspects of living with a disability that could be a lot more convenient, and a lot less frustrating, confusing, or expensive. There are, however, ways to make it easier — for parents and for brothers and sisters.

If there is one thing that make living and learning with a child who has a disability more manageable, it is remembering that all children, regardless of whether or not there's a disability in the family, need the security and comfort that comes from feeling the unconditional love and acceptance of their parents. As much as anything else, this will go a long way toward making sure that the experience of living with a brother or sister who has a disability will be a positive one for everyone.

There are six basic tips to keep in mind as you think about your family, your children, your spouse, the other important people in your children's lives, and especially, yourself. They are:

1. Children need to have at least basic information in order to understand.
2. Parents need to treat all their children equitably and fairly.
3. Children need to learn how to express their feelings.
4. Each child needs his/her own individual identity.
5. Siblings do not automatically get along with each other.
6. Siblings, like parents and others, need to be involved with the "goings-on" that accompany living with a disability in the family.

Questions Parents Can Ask Siblings of Children with Disabilities

Our children often have many concerns about their sister (or brother) with a disability. It is important that we address their questions with answers they can understand. Consider using the following questions as you communicate with your children.

- **?** Do you wonder why (Sally) has Autism?
- **?** Are you afraid that you will be like (Sally)? Can you tell me why?
- **?** Do you want/need more information? Do you want/need to know more?
- **?** How do you think your friends feel about (Sally)? What do they say? How do you feel about that?
- **?** What do you tell your friends about (Sally)? What do they do/say when you tell them that?
- **?** Would it help if you could explain about (Sally)? Let me tell you...
- **?** Do you feel that we give (Sally) too much attention? How does that make you feel?
- **?** Do you do things to get attention from us?
- **?** Do you feel that we expect too much from you because of (Sally)? Tell me more...
- **?** Do you sometimes feel you hate or are angry with (Sally)? Do you feel guilty for hating or being angry at (Sally)?
- **?** Where do you go to get support when you feel this way?
- **?** What would help you the most to deal with (Sally)?
- **?** What do you like about (Sally)?
- **?** What do you like to do with/for (Sally)?

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Equal Treatment of Sibs

Most children resent it when one of their brothers or sisters is treated “more special” that they are. Sometimes, the sibling will complain that Mom or Dad spends “all their time with the child with a disability or that “one child always gets more than the other.” Take a step or two back and think through your day to find a little bit of sacred time for your other child.

Some feel like they have to do chores around the house and their brother or sister doesn’t have any. It’s important that you require your child who has autism to do as much for himself as possible. If, in your family, children have chores, explain how everybody in the family has different ones, and talk about the things that (Sally) has to do. The point is that you have the same standards of behavior; that (Sally) has to help out in whatever ways she can, even if they may not be exactly the same; that she’s expected to behave properly; and that spending lots of time with her doesn’t mean you don’t love your other children).

In some families, there are lots of “special” people (teachers, therapists, or doctors) that come to visit their sibling. “No on ever comes to visit: your other children and they may have to leave the room, as well, causing them to literally feel “pushed out” of the situation. Talk to the “special people” and make arrangements for the other child to meet them. Occasionally try having your other child sit quietly in on the session, so they can see what goes, on or to be part of whatever is happening when appropriate.

Admittedly, there are times when there just isn’t enough time to go around. These are the times that make you feel pulled in a thousand directions. Rather than trying to clone yourself, or create more hours in the day, it’s easier on everybody to accept the fact that there are some inequities, and to talk about them with your child. Remember, that fairness means that each person receives what he or she needs!

Sibling Reaction to Disability

There are at least two things that differ in the ways adults and siblings react to a child with a disability:

The first is that children often lack information about the child’s disability, possibly because they are too young and inexperienced to understand the problem. They may have many unrealistic fears, like it’s catching or that maybe even they (the sibling) caused it, or that surely their brother or sister with a disabilties could change if he/she really wanted to.

Secondly when they are experiencing negative feelings, they’ll often “act out” or behave badly to get attention. They have to learn more socially acceptable ways to deal with negative feelings.

You can help children cope in a number of ways:

- Talk to them honestly when they act out. Reassure them of special love you have for them. Model how to talk about feelings and better ways to express them.
- Give them room to be “normal” kids. Sometimes you won’t like to hear the feelings they express and sometimes we forget that all kids go through periods of “hating” each other.
- Try to minimize embarrassing situations for your children.
- Look at things from their point of view. Remember how “normal” you wanted to be when you were their age.
- Try to balance the special things the child with a disability gets with special things for siblings, for example: special time alone with mom and dad or times when the family goes out without the child with a disability.
- Give the other children specific tasks to do to help their sibling with a disability as a way to defuse resentment and help them feel a part of the helping team.

Some of the pluses of having a brother or sister with a disability are:

- Studies show that siblings tend to have a greater tolerance for human differences and a greater level of acceptance of others.
- Siblings have a greater sense of a family bond.

Finally, help the whole family to look at the child with a disability as just another, important member of the family not a disabled child, but a child with a disability (a child first).

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Jack Stanley – An Autistic 5 year old boy.

Written by Joy Stanley, mother of Jack

Jack was born the youngest of 3 boys. If ever there is a good family sequence for a child with ASD, this is it. He has 2 older models from which to learn by example. We didn't suspect anything different about Jack until he turned 2; the pediatrician seemed uneasy about his lack of language. Jack was the cutest, easy-going toddler I'd ever had.

He was content to sit in his stroller as we carried on with the older boys. I thanked God for giving me such an easy child as my third.

Jack was diagnosed as "probably autistic" at 2 and a half years of age. At times I thought how cute Jack was as he sifted sand, dirt, and even toilet paper that he would first shred and then sift. What a great way to live life, enjoying the basics and not worrying about the outside world. Oh, I thought, he'll snap out of it. He was little and good looking and so gentle with people. He'll be fine.

After 2 years of thinking everything's okay and then bursting into tears every day, I faced the fact that Jack needed help. He was late to start the ABA program at age 4. I kept hearing about the dreaded 'window of opportunity' for these kids. Was it too late? We hired a consultant and a staff of 5 instructors and started the training process. Jack currently receives 25-30 hours per week of individual instruction on a curriculum provided by the Redwood Learning Center. Biweekly staff meetings keep everyone operating as a tight team so that Jack gets consistency throughout.

These children have huge capacities to learn, they just have to be taught differently and in greater detail. There is very little intuition, so even pushing a toy truck must be taught. Once parents understand this part, it's easy to reach out for help.

It has been almost 2 years since then and Jack is indeed a changed child. He knows his alphabet and numbers; he just doesn't understand what they represent. Jack 'appears' to be in line with typical children his age. One thing I've learned about autism is that in many cases it can be masked in society. Jack's brothers will have no part of that, though. They usually delight in Jack's quirkiness and use his autism to weed out their true friends from those less tolerant.

Jack is still the cutest, fun-loving, happiest child in the world. He is very socialable, often using facial expressions to make others smile. His sense of balance is incredible; we think he may be an athlete one day.

He is the only child in our house allowed to free fall off the arm of the sofa onto the cushions. Only Jack can dribble a basketball in the kitchen. Trampolines make him so excited. It's fascinating to watch his sensory system.

Jack's biggest gift is his ability to teach people tolerance, patience and unconditional love. Strangers immediately take to Jack as he is so happy and gentle. He loves babies but never touches. His autism comes up when these strangers speak to Jack and he doesn't respond. When I tell people he's autistic, a few people walk away, some people step forward and ask about the disorder, but many volunteer that they know other children with the disorder. It typically turns into an opportunity to speak of the wonders of ASD. This seems to relax the stranger and a friendship is made. If Jack's place on this earth is to educate others in this way, he will accomplish far more than the typical 'normal' human being. This is God's work.

Leesa's Story

By Melonie Curtis, Leesa's Mom

Leesa is a twin born 8 weeks premature. We knew we had to face the challenges of having a child that was delayed. We were told the first eighteen months would be catch up time. From early on, we could tell Leesa was different. She didn't cuddle into your arms like her twin sister did. Holding her was like holding a board. Her body was always stretched out in a rigid position. When she stood or walked, she would be on her tippy toes, her calves were like rocks. She never really looked at you; it was more like she was looking through you. Her eyes lacked expression. She didn't come to you with open arms; instead she backed into your lap.

Leesa failed many hearing tests. She failed her first hearing test when she was just days old. She was tested again several times later. Always the same result, "your daughter failed the hearing test". This would become a common occurrence. She didn't talk. Complete and total silence. You could walk into a room where she was and she would never turn and acknowledge your presence. We couldn't keep clothes on her. She was always taking her clothes and diaper off. She preferred to be in the buff. We tried putting her clothes on backwards. That didn't work.

There were times when life with Leesa was exasperating. She would rock back and forth, and bang her head on what ever was near by. It could be the wall, floor, or even the furniture. She would hit her head so hard that her eyes would roll in the back of her head and she would pass out. She would sit on the floor for hours on end and

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spin the red ball on her Disney toy over and over a hundred times. When she would spin the ball, the wheel would turn round and round. Her eyes would focus on the wheel spinning. She would get extreme pleasure watching the wheel spin. Leesa loves anything that spins. The faster the better. Leesa liked to pick at things. She would pick the wallpaper off the walls. I would put it back up and she would tear it down again. We would tell her no over and over again. The urge to pick and pull was just too great. We did this several times before we figured out that this was not the answer. We eventually took off all the wallpaper and just painted the walls in her room. When our friend moved into a home, it had layers and layers of wallpaper. She called and asked if Leesa could come over and peel the wallpaper off. We agreed to let her go. Leesa was in her height of glory. She picked and pulled to her hearts content. It was something that she could do and not get in trouble for it. Life with Leesa was certainly a challenge. Around the age of two, our friend and neighbor referred us to DDI. She worked with Special Needs people and knew we needed help. DDI came out and assessed the situation. From there we made a plan of action. We would figure out what was the most crucial area that needed to be worked on. We couldn’t conquer everything at once. We picked out three or four areas in which we would work on. The important thing is to work together as a team. Everyone needed to be on the same page working together on one common goal. One of our goals was to get Leesa to communicate her wants and needs. Another was to have her sit in a chair without moving for one minute. The final goal was to get her to be calm even if it was just for a moment. Leesa was like the energizer bunny. She just kept on going and going and going. Naps were not the “in” thing for her. The School for the Deaf came to our home and we started working on ways to get Leesa to communicate. We started with signing words and then moved on to picture books. In order to make progress, we had to work with her during the day when she was the least agitated. Leesa had horrible temper tantrums and would scream a high pitched shrill for hours on end. She would be in a complete and total rage. It is important to be consistent. We figured when the best time was to work with Leesa and how long we could work with her. We would work for awhile and then give her a break. We started to take her to DDI for group and snack. Leesa did not interact with other children. We would cheer and celebrate anytime she did anything that we wanted her to do. We offered her praise and more praise. There was a game called “Where O where is my friend.....” Leesa loved this game. She loved to hide under the blanket and pop out when they said her name. She loved to do this over and over again. We would let her do it several times. It took months for us to get her to sit for one minute. We would sit her down and she would get up. Patience and persistence. It took along time but eventually we got her to do it.

When Leesa was four years old, we learned that she could hear. Leesa had a hearing test in which she was sleep deprived (that was tough because she was always on the go). The test was performed at the hospital where she was sedated. They measured the activity in her brain while she slept as they administered different sounds. Shortly after, Leesa was diagnosed with Autism. We weren’t surprised. Deep in our heart, we knew Leesa was more than just Developmentally Delayed. Fortunately for us, the things that we were already doing were the right things to do. A lot was instinct on our part. We tried different thing over and over again.

One day, Leesa was lying on the floor looking at a bug. Her dad lay down beside her and asked her what she was doing. Silence as usual. She was repeatedly manipulating her elastic back and forth. Her dad started to stretch her elastic. An amazing thing happened. She let him do it. She stretched her elastic with him. That was our turning point. From that moment on, we invaded Leesa’s world. We knew she could hear. We started to sign and make her sign for what she wanted. We made her picture books from magazines and pictures of things around the house (ex. Glass of juice, milk, the refrigerator, bed etc.) .We had her find in the picture books what she wanted and point to it. We then proceeded to have her use words to ask for what she was pointing to, saying the word with her. Leesa started to speak. By the time she was six years old, she could put together short sentences.

Leesa is making progress. She is now in the sixth grade, mainstreamed in a regular classroom with pull outs for resource and speech. She is still about three years behind academically. Socially, she is still working hard. There are times when she is more like a toddler. She still needs a lot of help with social skills. Talking to strangers is a problem. Knowing what to say and what not to say is yet another area. Leesa did not toilet train until she was about eight years old. She wore pull-ups to school. We sent a package to the school and had an extra set of clothes there. It was put in a bag with Leesa’s name on it. It was all very discreet. We have to figure out when Leesa is ready to move on or learn a new task and be patient. Leesa can learn a new task and then forget it as quickly as she has learned it. We believe her brain is like a computer. The information is there, she just doesn’t know how to retrieve it. Keeping a journal proved to be extremely helpful. Prior to going to bed, we would write in a journal about the day. You can learn a lot about your child from what you write in your journal. You can learn when different behaviors happen and maybe what was the trigger that caused those behaviors. It can give you patterns, it can tell you what distresses your child or makes your child happy. It can provide you with so much data. It is a helpful tool when going to the doctors or a specialist, even when they go to school.

Having a child with Autism is not the end of the world. It is just different. You do things differently. Each child is different. Educate yourself. Learn about Autism. Read. I would recommend reading Temple Grandin’s book, “Thinking in Pictures”. It is an excellent book written by someone with Autism. Put yourself in your child’s world. Visualize life as they do. Get down to their level. When they feel the soil, you feel the soil. Try and figure out what they are thinking. When they get into something, usually it is for a reason. An example would be, if your child gets into the flour and sugar and plays in it, they probably have a need to feel textures. They could have tactile, sensory issues. Get a container and fill it with play sand. Give them tools that

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they can play in the sand with like a cup or a strainer. Watch them as they pour the sand over their hands. Children with Autism are not bad nor are they children with manipulating and intentional behaviors. They are children whose brains are wired differently and they just need a little extra time or to be taught differently. These are amazing children that have so much to offer and so much to give. Don't think you have to do it by yourself. Let people help you. It took an army of people to get Leesa where she is today and it will take an army of people to get where she needs to go. Leesa has a lot of challenges and even more bumps in the road. When you solve one issue, you have another to take its place. Our hope for Leesa is to be independent and with the progress that she has made, it can happen.

To be most effective for your child, you must take care of yourself. I know this is easier said than done. Take one night for yourself and spouse or significant other. Even if it is only an hour or two. It can make all the difference in the world in how you handle your child. Choose your battles wisely. Celebrate the positives, ignore the negatives. Find something to laugh about each day, it helps. Praise, praise, praise -- it makes a difference for the right reason. Celebrate their strengths; enjoy your child for who they are right now at this moment.

The Success Story of a Man with Autism

By Wendy Rammell, his mother

Matt is pictured at the left, me in the middle, and one of his sisters Kristen, to the right.

My son Matt, was born as what seemed to be a normal, healthy, beautiful baby boy. He had dark thick hair that framed his angelic face and big china blue eyes that sparkled. He drew you in with his melodic infectious laugh that could bring you to tears. Strangers would stop me on the street and say what a beautiful, striking child he was.

He seemed precocious for his age, repeating big words, the alphabet while I changed his diaper at six months, taking light switch plates apart with a screwdriver and lining the screws up neatly in a row at age three. He was very mechanical yet Matt could not seem to understand the big words he said. (He had echolalia as we found out later). He could repeat commercials verbatim and he was very entertaining. He was also a little Houdini, escaping out the door when I had turned my head for only 5 seconds, wandering the neighborhood into peoples' basements where he had toys to play with. He darted out in front of cars and was pulled out of their paths just in time by concerned neighbor children who would help me search for him when I lost him, on many occasions. Matt got to know the neighbors well. Unfortunately my son did not understand how to communicate and interact with the neighborhood children and soon after they had come into the yard to play, they left. You could see the sadness and frustration in Matt's eyes watching them leave, not being able to call them back and relate to them. This brought tears to my eyes, so I sought out the medical doctors to find out what we were dealing with, since he wasn't developing like the other children. He is my firstborn and so I was accused of being an over-protective mother and told to relax. I suspected he was Autistic and made my suspicions known.

One doctor said it was impossible he was autistic, because he was too social and his father and I seemed too loving and caring for it to be Autism. At that time, Autism was thought to be caused by "refrigerator parents" cold and unfeeling, causing the child to withdraw. So we were sent to a couple of special pre-schools, one for emotionally disturbed children where he did not fit in at all, and CBTU Children's Behavioral Therapy Unit, where it seemed to fit him like a glove and was for autistic children. He was four years old at the time.

By the time we got him going to CBTU, he was playing in closets and our shower stall, seeming very withdrawn from the world, and I thought we were losing him. I was sure he would need to be institutionalized further down the road when he got older. Things looked pretty bleak for my baby boy. Luckily after a few short months at CBTU, Matt was pulling out of it. It was a miracle. At four and a half years old he finally looked me in the eye and called me Mom. Tears were streaming down my face and I was so overjoyed to hear the word Mom, and to this day I do not take it for granted. He was also taught American Sign Language to bridge the gap to his brain to help him understand the words he was repeating. It was a miracle it worked and at the time they had no idea why it worked, it just did. That was fine with me.

My son loved to watch the weather channel and knew the weather anywhere in the world. He would impress the adults with his knowledge. There was a young autistic girl who didn't speak but understood what you said. Matt was quite a tease and had her convinced there was a hurricane off the coast of Florida coming her way and it would get her. One of the teachers found her under the desk and Matt grinning from ear to ear. They called me and told me what he had done. He was always teasing his sisters.

As my son went through his special classes and tried to integrate into the classrooms, it was difficult at best for him, but his rote memory and ability with math seemed to pull him through to where he only needed resource and was mainstreamed into 4 of his classes by the time he reached Jr. High School. When he was in grade school

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and Jr. High School, he switched from weather to love of sports. This was acceptable since sports are almost a religion in this country and his knowledge impressed even the most avid sports fan of any age with his ability to remember the statistics.

In the neighborhood of about a mile radius, Matt started the, "little basketball league," and the "little baseball league," of which he was the commissioner. He set up the rules, refereed, and played in the games. Each yard became a stadium, such as Rammell stadium. If anyone used profanity or got violent, he would make them do pushups and they always obeyed him without question. One other autistic boy had to do 100 pushups quite regularly.

Matt was so brilliant in some things, yet difficulties in areas that we take for granted and learn almost by osmosis. His robotic speech also set him apart. When he got to High School, he impressed the boys who played on the school sports teams with his knowledge of their games as well as the professionals, and he became very popular with them. His younger sister liked to hang out with him because he knew all the cute boys. He barely passed High School Academically, but had a very strong ability in math and reading skills that seemed to be his saving grace. He could times three place numbers in his head. He did have a couple of dates to the proms, one of which he was asked by a young lady. He was in seventh heaven feeling he was a part of everything.

The day he graduated from High School helped us to see just how popular Matt was. It wasn't like him to come home and tell you how his day went; you had to pry it out of him, because verbalizing his feelings was difficult. When they called Matt to receive his diploma he got a standing ovation and the loudest cheering of anyone. I was so choked up and tears streaming down my face because it was such a nice surprise! I still tear up when I think about that day. We do not take for granted each step it took him to reach this point and I honestly had no clue what he was capable of doing. I had always encouraged my children to work hard and not give up, and Matt had such focus to do all of these things.

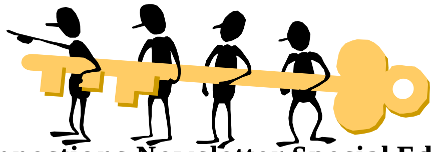
Matt is going to the Salt Lake Community College, and he had it difficult for the first couple of years but refused to give up, taking classes over when necessary. He finally took a break from them and served a service mission for the LDS church at the Bishops Storehouse. There he helped people fill their orders and do data entry. The first day he was there they gave him 120 orders to enter and he felt bad because he only got 100 orders entered. When the Bishop found out he laughed and said he had only expected about 30 from him and he did excellent for his first day. He would have contests with himself to break his personal best scores and he did regularly. He got them so caught up that they would send him around to the other storehouses to get them caught up also, as well as down to the Church Office buildings downtown. He served well for a year and they were very sad to see him go because of his dedication and ability.

Now he is back at the Salt Lake Community College where he will graduate in June and get his associate degree in accounting. He came in the other day and told me he had the highest score on his test in the class, so he is doing well. He has taken tax preparation classes and helped at the mall at Christmas time last year with H & R Block doing taxes for people as part of his homework for class. He has done our taxes around our house for the last few years and we wouldn't trust anyone else to do them!

Matt would like to go to the University of Utah and finish a Bachelors degree in Accounting and possibly Business. Unfortunately he will have to pay his own way, because the federal government has come out with a new policy to discourage perpetual students, so that after so many credit hours that add up to a Bachelor's degree then they cut off the funding. Unfortunately they do not take into account someone with disabilities who needs some extra time to finish up, Matt falls between the cracks because he functions so well. Luckily his Dad gives him money each month to help out and he lives at home with me. (We are divorced).

Matt did work at Arby's for about six years part time and is healthy as a horse, so he only had a few times where he called in sick. He got employee of the month once and he's dedicated and focused in whatever he chooses to do. His disabilities of being perseverative have actually served as ability when doing any kind of a job because it focuses him into getting the job done. His perseverative abilities in rote memory helped him fit in when he could talk sports on an advanced level with his peers. Matt's rote memory has also helped him memorize bus and TRAX schedules and he gets anywhere in the city he wants to go. He is very independent. He does have a friend who picks him up and takes him to school since he does not drive. He went through two learners permits trying to learn, but he decided driving wasn't for him because it was too crazy out on the road; I have to agree with him on that one!

I have no doubt that when he finishes school he will be able to move away from home and live on his own. It will take him longer than most, but considering what his outlook was as a child, I think he is my little miracle child and has done exceptionally well with what he has had to overcome to get this far! He will be turning 27 in November and he has become a successful, witty, intelligent, and charming young man and I am proud to call him my son.



"Alone we can do so little; together we can do so much!"
Helen Keller

Becoming an Advocate for your Child

What does it mean to be an advocate? When you are a parent (guardian or responsible family member), it means doing whatever is necessary to make sure your child gets what he or she needs....and what you need as a family to support and care for your child.

When you have a child with autism, advocacy is very important. Children with autism have varying needs, and it is often up to the parents to help health care providers and school personnel understand the child's particular needs. Families need to develop skills to become the best advocates they can for their children.

Advocacy Tips

- Prepare yourself with information. Ask questions. Know your rights.
- Keep records. Be organized.
- Don't go it alone. Seek out other families and supportive people.
- Advocate with confidence! You are the expert on your child.
- Trust your instincts: You may be right, even if professionals disagree with you. However, be open to learning new things.

The sooner we parents become knowledgeable and strong advocates for our children, the smoother life becomes for our entire family. Here are some ideas about how to start:

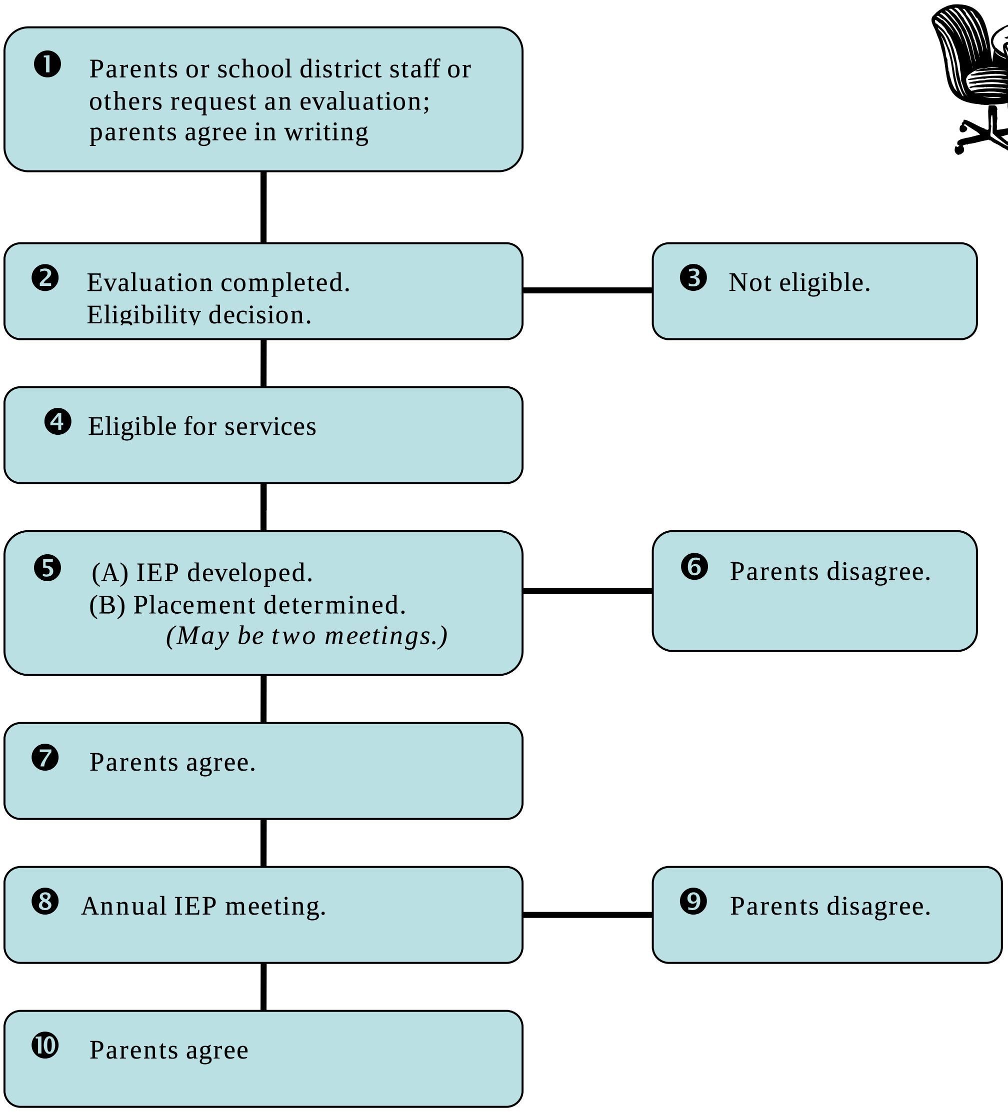
> **"Families need to develop skills and knowledge to become the best advocates they can for their children."**

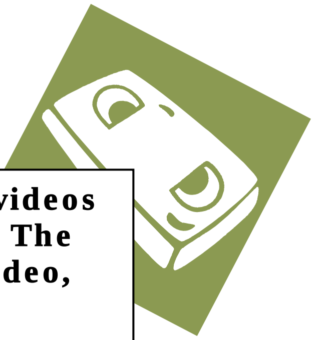
- **Tell the world about this precious gift!** Your child, like all children, is wonderful - even when he or she gobbles up so much of your time and energy. Remember, though, that your child with autism is not the heart of your family, but part of your family.
- **Make contact with another family who also has a child with autism or other disability.** Hearing from another parent who never sleeps, feels inadequate at times, and is also frightened about the future will change your life. We know it's not easy to talk with a stranger, but it's worth it.
- **Find out everything you can about your child's disability.** Ask your pediatrician psychologist , parent support groups, disability organizations, children's hospital, the Internet, libraries, etc.
- **Learn about all the resources, services, and providers your child may need and use.** Ask other parent advocates about local resources they have used. Call disability organizations for information and referrals.
- **Keep records** of all phone calls, doctor's visits, insurance bills, Medicaid notices, and forms related to your child. Take notes. Request copies of everything.
- **Become an expert on your child's health insurance plan.** Make sure to ask lots of questions about how it works.
- **Develop a strong partnership with your medical and other professionals.** You can work together and use the expertise and skills each brings in caring for your child to effectively advocate for what your child needs.
- **Know that YOU are your child's best advocate.** No one else will do the job as well. Use all the information, contacts, friends, and skills that you have gathered to practice your advocacy firmly, but with kindness and humor. As your child grows up, teach him/her to be their best advocate if possible, or prepare a family member or friend to do so.
- **Take care of yourself too.** To be an effective caretaker and advocate for your child, you need to advocate for your needs also. Please believe above all - *You Are Not Alone.*

The Utah Parent Center offers afree workshop on "Parents as Partners in the IEP Process" on the second Thursday of everymonth from 7:00 to 9:00 p.m. at the Utah Parent Center offices located at 2290 East 4500 South, Suite 110 in Salt Lake City. Please call to pre-register at (801) 272-1051 or Toll Free in Utah at 1-800-468-1160. We reserve the right to cancel classes if no one has pre-registered.

Understanding the Special Education Process
An Overview for Parents

The chart below is of the special education process. It is not designed to show all steps or the specific details. It shows what happens for the time a child is referred for evaluation and is identified as having a disability through the development of an individualized education plan (IEP). The process begins when someone (school staff, parents, etc.) makes a referral for an initial evaluatin. An explanation of each numbered area follows the chart.





The Utah Parent Center has "Parents as Partners in the IEP Process" videos available for purchase. The video also includes the parent handbook. The cost for the video is $10.00. If you are interested in purchasing this video, please contact the Utah Parent Center at (801) 272-1051 or by email at upcinfo@utahparentcenter.org.

How the Special Education Process Works

❶ Parents, school personnel, students, or others may make a request for evaluation. If you request an evaluation to determine whether your child has a disability and needs special education, the school district must complete a full and individual evaluation. If it refuses to conduct the evaluation, it must give you appropriate notice and let you know your rights.

★ *You must give permission in writing for an initial (first-time) evaluation and for any tests that are completed as a part of a reevaluation.*

❷ A team of qualified professionals and you will review the results of the evaluation, and determine if your child is eligible for special education services.

❸ If your child is not eligible, you will be appropriately notified and the process stops. However, you have a right to disagree with the results of the evaluation or the eligibility decision.

★ *If you disagree with the results of an evaluation, you have a right to an Independent Educational Evaluation (IEE). Someone who does not work for the school district completes the IEE. The school district must pay for the IEE or show at an impartial due process hearing (see box below) that its evaluation is appropriate.*

❹ If you and the school district agree that your child is eligible for services, you and the school staff will plan your child's Individualized Education Program (IEP) at an IEP team meeting. You are an equal member of the team.

❺ The IEP lists any special services your child needs, including goals your child is expected to achieve in one year, and objectives or benchmarks to note progress. The team determines what services are in the IEP, as well as the location where those services and modifications will be provided. At times the IEP and placement decisions will take place at one meeting. At other times, placement may be made at a separate meeting (usually called a *placement meeting*).

❻ **If you disagree** with the IEP and/or the proposed placement, you should first try to work out an agreement with your child's IEP team. If you still disagree, you can use your due process rights. (See box below.)

❼ **If you agree** with the IEP and placement, your child will receive the services that are written into the IEP. You will receive reports on your child's progress at least as often as parents are given reports on their children who do not have disabilities. You can request that the IEP team meet if reports show that changes need to be made to the IEP.

❽ The IEP team meets at least once per year to discuss progress and write any new goals or services into the IEP. As a parent, you can agree or disagree with the proposed changes. If you disagree, you should do so in writing.

❾ If you disagree with any changes in the IEP, your child will continue to receive the services listed in the previous IEP until you and school staff reach agreement. You should discuss your concerns with the other members of the IEP team. If you continue to disagree with the IEP, you have several options, including asking for additional testing or an Independent Educational Evaluation (IEE), or resolving the disagreement using due process. (See box below.)

❿ Your child will continue to receive special education services if the team agrees that the services are needed. A reevaluation is completed at least once every three years to see if your child continues to be eligible for special education services and to decide what services he or she needs.

Due process protects the right of parents to have input into their child's educational program and to take steps to resolve disagreements. When parents and school districts disagree with one another, they may ask for an impartial hearing to resolve issues. Mediation must also be available.

Mediation is a meeting between parents and the school district with an impartial person, called a mediator, who helps both sides come to an agreement that each finds acceptable.

An impartial due process hearing is a meeting between parents and the school district. Each side presents the position, and a hearing officer decides what the appropriate educational program is, based on requirements in the law.

School districts must give parents a written copy of special education procedural safeguards. This document outlines the steps for due process hearings and mediation. Parents must be given a copy when their child is first referred for an evaluation and each time they are notified of an IEP meeting for their child.

For more information, please contact the Utah Parent Center at (801) 272-1051!

School Based Accommodations and Modifications for Students with Autism

Students with ASD have a need for routine and consistency. A change in routine or transitions are time when students with ASD may have significant difficulty.

- Provide notification of teacher's pre-planned absences.
- Provide pre-warning of changes in daily routines, such as assemblies, shortened days, or invited guests.
- Visual supports for changes in routine may be beneficial. This could be a picture schedule or written schedule.
- Time management requires an ability to predict, prepare or anticipate the duration of an activity. Provide visual clues that represent small time increments (i.e. three blocks each representing 5 minutes to help child understand 15 minutes. Remove one block every 5 minutes.)
- Post daily schedule on child's desk.
- Provide one consistent location/box for student to turn in all papers, daily assignments as well as homework. Students with ASD are not typiclly good "junk mail" sorters. This allows the teacher to sort allpapers at the end of th day and determine those that need to go home, be thrown away or returned to the student to complete.
- Use written lists or picture cues in student locker to help student manage materials between classes.

Communication difficulties may include difficulties in "reading" facial expressions, body language, the use of sarcasm and idioms, and processing multiple step oral directions.

- Pause between instructions and probe for understanding. Probing for understanding needs to go beyond asking the questions, "Do you understand?".
- Avoid the use of abstract language such as metaphors, idioms and puns in daily instruction.
- Keep statements short and to the point.
- Slow the rate of presentation.

Modify the presentation of materials.

- Break assignments into shorter tasks.
- Reduce the number of concepts presented at one time.
- Allow students to obtain and report informaiton utilizing, cassette recorders, dictation, computers, interviews, calculators, fact sheets.
- Provide clear, concise direction and concrete examples for homework assignments.
- Allow for the oral administration of tests.
- Avoid having the student copye from the board.
- Avoid crowded, cluttered worksheets by utilizing techniques such as blocking (blocking assignments into smaller segments), cutting (cut worksheets into sections), folding (fold worksheets in to sections), and highlighting, color coding or underlining.

Modify the environment.

- Use study carrels.
- Use preferential seating.
- Set student in an area free of distractions.

Caution!

Be reasonable about classroom expections. No student with an Autism/Aspergers diagnosis will need every accomodation/modification based soley on the diagnosis. Accommodations/modifications should be based on the students need, not the diagnosis. The diagnosis should however, trigger some thought as to the underlying cause of difficulties manifesting themselves in the school setting.

Determine the end. Where is it that you want your student to be in 5 years, 10 years or even 1 year? Will a particular accommodation/modification help the student achieve the desired outcome or will it create a need for even more accommodation down the road?

Although a paraeducator or aide may at times appear to be most beneficial for a student in terms of accessing the general currriculum, it can create one of the most restrictive enviornments for the child. Caution should aways be taken that an aide never becomes the voice of the child, the mind of the child, or the social partner for that child.

Aides often unknowingly create a prompt dependent environment that can inhibit the independence of the child and also can become a social barrier for peer interactions.

> *"Just because something hasn't been done in the past doesn't mean that it can't be done."*
>
> *Unknown*

When the Going Gets Tough, It's Time for Partnerships between Parents and Educators

If teaching children with disabilities were easy, there would be very few conflicts between parents and schools. Teachers would be proud of their work and their students' progress and parents would be thankful that their children were becoming more successful learners and achievers. There would be joy, respect and gratitude that children were getting the help they need.

But, teaching children with disabilities to be successful is a challenging job. Multiple demands make it difficult to devote the time and effort teachers need to so a child can succeed. Sometimes limited resources or lack of help makes it difficult to support learning and development. Teachers who are feeling worried, ineffective or unsupported may feel *personally* attacked when a parent questions why the child isn't making progress.

Parents also may feel it never seems possible to do everything needed to help a child succeed. Parents and children have power struggles over homework, with parents sometimes giving up in frustration and resignation. Uncertainty about why a child is not progressing or what it will take to succeed drains energy and hope. It is heart breaking to see a child failing and fearing that he or she may not be able to realize a high quality of life, as an adult.

Students with disabilities can feel trapped between high expectations and negative emotions from parents and teachers. They do well, but despite all their efforts, they don't succeed. Even when they do well, they are still far behind their peers. Other children may tease them, or worse, feel pity for them. students worry that they will not succeed and sometimes wonder if they should even try.

This is when disagreements among parents, teachers, and students begin. Feelings of frustration and powerlessness could be an opportunity to seek help, but instead, some people become oppositional, deny responsibility or assign blame. This signals the start of a frustrating pattern of guilt and anger over what isn't being accomplished. For example, consider a boy who is not yet reading. His mother learns of a new computerized curriculum she believes can work. She is frustrated by her son's reading difficulties and the behavior problems starting at school. This curriculum is expensive, but the school gives in to the mother's requests after several IEP meetings. Getting the program on the child's IEP may be a success for the parent and meet the school's desire to prevent further conflict. Unfortunately, the program may go unused because of limited technical support and lack of free time in the student's life. The student still struggles and the battles between parent, student and school continue. Too often conflict is settled the easy way. One person gives in because it is more difficult to disagree or resolve the real conflict. Parents believe the child can't learn and so don't expect much from the child or the school. An administrator may listen politely as a parent complains about a teacher and then respond by adding new services to the IEP, while allowing the child's learning failures to continue. Students may misbehave to get out of uncomfortable situations when they can't participate in the "read-aloud" activity. Sometimes this apparent lack of conflict even looks like partnerships.

Students in special education don't learn easily. Things don't often go well for them. Partnerships are not what happen only during eligibility or IEP season. They are what happen on an ongoing basis.

Sometimes what is **not** said is much more powerful than what is said. Schools are not supposed to tell parents that lack of resources is the reason that they don't provide a service because students are entitled to appropriate services. Parents may demand services be described in great detail on the IEP because of negative experiences with their child's special education services. A student may not ask for a class she would like because she doesn't think that she has a say in her education.

What are some things that can help, when it looks like the family, student and/or school may be headed for a conflict? For many, the first instincts are fight or flight: either build up "ammunition" and defend the strongest position possible or run away and ignore the problem. However, there is a third option: listen and respond to each other's perspectives, experiences and priorities so that you can work toward a mutually agreeable and respectful solution. While this option may be more difficult, it is usually the most successful. For even if a person wins a fight, he or she is still dependent on his or her opponents to carry it through.

Here are some things to consider when worried about potential conflict:

Reflect upon your own assumptions about the conflict. How does what has happened in the past color how you perceive this situation? Do you have negative experiences that make you less willing to accept the other's perspective? What are some of your unwritten and unspoken rules? How can you check these assumptions with others in this situation?

Share your assumptions and perspectives. Communicate with your head and your heart. What principles guide your actions? What do you dream about? What worries you? How are you feeling about this situation? Do you share any assumptions and perspectives? What do you question?

Try to think and feel about the situation from other points of view. Listen very carefully and try to think and feel about the situation from the other's perspectives. Don't interrupt! Be sure you understand what they are saying and give them the experience of being understood. What may be causing the other person to take this position? How would you feel if you were in his or her shoes? What is getting in the way of resolution? What might make it easier for that person feel more comfortable with the situation?

Find agreement. Where do you agree? How can you build on these agreements to address your disagreements?

Continued on Page 29

Reframe the issues. How can you restate the problem in a way that doesn't place blame? How can this issue become more manageable? How can everyone share responsibility and credit for success?

Identify options and opportunities. How can constraints, negative experiences, and concerns be acknowledged and addressed? Are there assumptions that do not seem appropriate in this situation? How can you build upon each other's dreams and priorities? What are the expanded opportunities if you work in partnership? Who else needs to be involved in finding solutions?

Partnerships are not easy. Parents and professionals are partners, not necessarily by choice, but because of what the child needs. Since many placements are for one year, the partners are just getting comfortable with each other when it is time to change. With so many professionals involved in a child's life, and so many children on those professionals' workloads, it can be difficult to take the time that partnerships require to work well.

Ultimately, it is the child with disabilities that benefits from the hard work of partnerships. When partnerships do not go well, the child is often caught in the crossfire. However, when parents and professionals work well together, they model skills that will be useful in the future as students take more responsibility for their own lives. The child will learn how when the going gets tough, it is time to bring in the partners.

NOTES: Marshall Peter generously collaborated on this article. Marshall is the Director of CADRE (http://www.directionservice.org/cadre), which is funded by the U.S. Department of Education to serve as The National Center on Dispute Resolution in Special Education. He has written an article on this subject that can be accessed on his website, http://www.directionservice.org/Working_Effectively.pdf. *Collaborative Problem Solving and Dispute Resolution in Special Education* is a helpful manual by Ron Windle and Susan Warren from Hood River School District in Oregon. It can be found on the CADRE site at http://www.directionservice.org/cadre/contents.cfm. *Article was originally printed in the PEATCpress, the March 2002 newsletter published by the Parent Educational Advocacy Training Center in Springfield, VA.*

Materials to Choose & Use

The Utah Parent Center library is a good place to start if you want to learn more about the autism spectrum.

The Autism Society of Utah donated this collection to us when they decided to discontinue the Society. It has been a wonderful addition to our Center and has provided so much information to the staff and to parents who contact us. We hope over the years to see it expand with the latest print and audio/visual materials available. We encourage parents (and others) to visit the Center and the library where they can check out materials for two weeks and renew them another two weeks if needed. We are open 9:00 a.m. to 5:00 p.m. but we close promptly at 5:00 p.m. so you might want to come no later than 4:30 p.m. to have time to look over the collection. A refundable deposit is required for checkout.

Audio Cassette- There are numerous tapes from the Autism Society Conferences of 1997, 2000, 2001, and 2002. These can be checked out for two weeks with a two week renewal.

Video Section- This section is relatively small but there are some very good titles, 3 of which need to be mentioned.

- "Aspergers Syndrome – A guide for Parents and Professionals", with Dr. Tony Atwood (3 hours)
- "The Autism Continuum", with Dr. Temple Grandin
- "Writing Social Stories", with Carol Gray

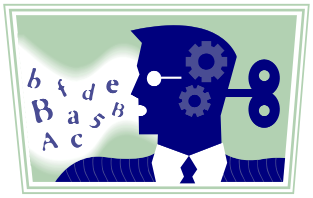
Book Collection- This now includes one hundred twenty-eight (128) volumes. A brief sample follows:

- *Pervasive Developmental Disorders – Finding a Diagnosis and Getting Help,* Mike Waltz (parent of a child with PDD – NOS)
- *The World of the Autistic Child – Understanding and Treating Autism Spectrum Disorders,* Dr. Bryna Siegel
- *Children with Autism, A Parent's Guide,* editor Dr. Michael Powers
- *Behavioral Intervention for Young Children with Autism,* editor Catherine Maurice
- *Creating a "Win – Win IEP" for Students with Autism,* Beth Fause, Ph.D.
- *Pervasive Developmental Disorders – Finding a Diagnosis and Getting Help,* Mitzi Waltz (parent of child with PDD – NOS)
- *Facing Autism – Giving Parents Reasons for Hope and Guidance for Help,* Lynn Hamilton (parent of a son with autism)
- *Autism Aspergers: Solving the Relationship Puzzle,* Steven Gutstein, Ph.D.
- *Thinking In Pictures – My Life with Autism,*Dr. Temple Grandin
- *A Parent's Guide to Aspergers Syndrome and High Functioning Autism – How to Meet the Challenges and Help Your Child Thrive,* Dr. Sally Ozonoff, Geraldine Dawson, Ph.D. and James McPartland
- *Parent Survival Manual – A Guide to Crisis Resolution in Autism and Related Developmental Disorders,* editor Dr. Eric Schopler
- *I Need Help with School! A Guide for Parents of Children with Autism and Aspergers Syndrome,* Rebecca Moyes

Please call the Utah Parent Center at (801) 272-1051 or 1-800-468-1160 for more information.

Acronyms & Abbreviations Related to Autism

Have you ever wondered what all those acronyms and abbreviations were?
This list may help you as you move your way through the world of disabilities.



ABA	Applied Behavior Analysis (Lovass)
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ADA	Americans with Disabilities Act
ASA	Autism Society of America
AIRS	Autism Information and Resources at the Utah Parent Center
AT	Assistive Technology
BIP	Behavior Intervention Plan
CD	Communication Disorder (Speech, Language)
CPD	Center for Persons with Disabilities, Utah State University
CSHCN	Children with Special Health Care Needs Bureau, Utah State Department of Health
DD	Developmental Delay
DDS	Division of Disability Determination Services
DFS	Division of Family Services, Utah State Department of Human Services
DLC	Disability Law Center
DMH	Division of Mental Health, Utah State Department of Human Services
DRS	Division of Rehabilitation Services
DSDHH	Division of Services for the Deaf and Hard of Hearing, Utah State Office of Rehabilitation
DSPD	Division of Services for Persons with Disabilities, Utah State Department of Human Services
DSBVI	Division of Services for the Blind and Visually Impaired, Utah State Office of Rehabilitation
ED	Emotionally Disturbed (Category that under law also includes Behavior Disorders)
FACT	Families, Agencies and Co0mmunities Together
FAPE	Free Appropriate Public Education
FERPA	Family Education Rights and Privacy Act
FBA	Functional Behavioral Assessment
GCPD	Governor's Council for People with Disabilities
IAES	Interim Alternative Education Setting
ICC	Interagency Coordinating Council
ID	Intellectual Disability
IDEA	Individuals with Disabilities Education Act
IEP	Individualized Education Plan
SLD	Specific Learning Disability
LEA	Local Education Agency (School District)
LCPD	Legislative Coalition for People with Disabilities
LRBI	Least Restrictive Behavioral Intervention
LRE	Least Restrictive Environment
MD	Manifestation Determination or Multiple Disabilities
OI	Orthopedic Impairment
OHI	Other Health Impaired
OSEP	Office of Special Education Programs, U.S. Department of Education
OSERS	Office of Special Education and Rehabilitative Services, U.S. Department of Education
OT	Occupational Therapy
PDD-NOS	Pervasive Developmental Disorder- Not Otherwise Specified
PLEP	Present Level Of Educational Performance
PT	Physical Therapy, Physical Therapist
PTI	Parent Training and Information Project of the Utah Parent Center
RDI	Relationship Development Intervention
SLP	Speech Language Therapist
SPED	Special Education
SSA	Social Security Administration
SSI	Supplemental Security Income
STO	Short Term Objective
TBI	Traumatic Brain Injury
UPC	Utah Parent Center
USEAP	Utah State Office of Education Special Education Advisory Panel
USOE	Utah State Office of Education
VR	Vocational Rehabilitation

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Connect to the World Wide Web & Collect Great Information

This list was updated in February 2008.

Utah Parent Center
ww w.utahparentcenter.org

Utah Personnel Development Center
www.updc.org

Utah Autism Registry
http://health.utah.gov/autism/

Utah Autism Research Project
http://uuhsc.utah.edu/childpsych/autism.html

Utah Autism Research Program
http://utahautismresearchprogram.genetics.utah.edu/

Autism Society of America
www.autism-society.org

Aspergers/Autism
www. aspergersautism.com

Unlocking Autism
www.unlockingautism.org

Autism Resources
www.autism-resources.com

Autism Information
www.autisminfo.com

Autism & Asperger Information
www.asperger.org

Autism & Asperger Syndrome
www.aspergerssyndrome.org

Center for the Study of Autism
www.autism.org

Autism/PDD Resource Network
www.autism-pdd.net

Federación Autismo España
www.autismo.com

Autism Online
www.autismonline.org

Autism Society of North Carolina
www.autismsociety-nc.org

Utah Autism Foundation
www.xmission.com/~uaf/

Access Utah
www.accessut.org

Disability Law Center
www.disabilitylawcenter.org

Legislative Coalition for People with Disabilities (Utah)
www.gcpd.stat.us/legcoal.htm

NAMI Utah
www.namiut.org

Utah Family Center
www.utahfamilycenter.org

Utah Governor's Council for People with Disabilities
www.gcpd.org

Utah Information & Referral
www.informationandreferral.org

Utah State Office of Education – Special Education
www.usoe.k12.ut.us/sars

Utah State PTA
www.utahpta.org

Office of Special Education & Rehabilitative Services
www.ed.gov/offices/OSERS

National Coalition on Disabilities
www.ncd.gov

Reed Martin
www.reedmartin.com

ADA Information – US Department of Justice
www.usdoj.gov

Homework Help
www.homeworkhelp.com

Special Families
www.specialfamilies.com

Alliance for Parent Involvement (ALLPIE)
www.croton.com/allpie/

Family Education Network
www.familyeducation.com

Family Fun
www.family.go.com

US Department of Education Publications for Parents
www.ed.gov/pubs/parents.html

National Coalition for Parent Involement in Education
www.ncpie.org

IDEA News
www.ideapractices.org

Utah Families for Effective Autism Treatment (FEAT)
www.utahfeat.org

Autism Council of Utah (ACU)
www.autismcouncilofutah.org

OASIS - Asperger Syndrome Information & Support
www.udel.edu/bkirby/asperger/

Association for Science in Autism Treatment
http://www.asatonline.org

Autism National Committee (AUTCOM)
http://www.autcom.org

Autism Network International (ANI)
http://ani.autistics.org/

Autism/PDD Information
http://www.autism-pdd.net/

Autism Resource Links
http://www.autism-resources.com/

Autism Research Institute (ARI)

http://www.autismresearchinstitute.com

Autism Speaks - Biomedical
http://www.autismspeaks.org/index2.php?intro=1

Autism Society of America (ASA)
http://www.autism-society.org

Centers for Disease Control and Prevention
http://www.cdc.gov/search.do?action=search&queryText=Autism

Center for the Study of Autism
http://www.autism.org/contents.html

Cure Autism Now (CAN) – Biomedical Treatments
http://www.cureautismnow.org

First Signs – Early Intervention & Identification
www.firstsigns.org

First Words Project – Early Identification & Intervention
www.firstwords.fsu.edu

Global Autism Project
http://www.globalautismproject.org

Interdisciplinary Council on Developmental and Learning Disorders (ICDL)
www.icdl.com

International Pre-Autistic Network – Early Identification & Intervention
preautistic@aol.com

Kids Health
http://www.kidshealth.org

MAAP Services for Autism, Aspergers, and PDD
http://www.maapservices.org

Marbles for Miracles
www.marblesformiracles.org

Mayo Clinic.Com
http://www.mayoclinic.com/health/autism/DS00348/DSECTION=5

Medline Plus – Autism
http://www.nlm.nih.gov/medlineplus/autism.html

National Alliance for Autism Research (NAAR)
http://www.naar.org

National Center on Birth Defects and Developmental Disabilities
http://www.cdc.gov/ncbddd/autism/

National Dissemination Center for Children with Disabilities
http://www.nichcy.org

National Institute of Child Health and Human Development (NICHD)
http://www.nichd.nih.gov/autism/

National Institute on Deafness and Other Communication Disorders Information Clearinghouse (NIDCD)
http://www.nidcd.nih.gov

National Institute of Mental Health (NIMH)
http://www.nimh.nih.gov

Relationship Development Intervention (RDI)
www.rdiconnect.com

The P.L.A.Y. Project
http://www.playproject.org/

TalkAutism
www.talkautism.org

Unlocking Autism
http://www.unlockingautism.org

USAAA Autism and Asperger Association
www.usautism.com

The Utah Parent Center website has a list of additional website links. Please visit us at: www.utahparentcenter.org

Autism & Aspergers Support Group Information

This list was updated in February 2008.

Brigham City

Options for Independence
Contact: Deanne Crockett; Phone: (435) 723-2171
Email: dcrockett@brigham.com
Location: Box Elder Family Center;
276 North 200 East; Brigham City
Day: 4th Wednesday
Other: Respite care provided for FREE for children under 11 years old

Carbon County

Price Family to Family Network
(Mom's Lunch Bunch)
Contact: Darrelyn Davis; Phone: (435) 637-3654
Website: www.utahfamilytofamilynetwork.org/
Location: Castle Valley Center; 755 North Cedar Hills Drive; Price
Day: Second Tuesday of each month; Time: 11:30 a.m.

Davis County

UPASK –
(Utah Parents of Asperger Syndrome)
Contact: Natalie Longson; Phone: (801) 593-8652
Email: ASnproudofit@msn.com
Hotmail: UPASK@hotmail.com
Website/Chat line:
http://groups.msn.com/UtahParentsofAspergerSyndromekids

Family to Family Network – North Davis
Contact: Vickie Radl; Phone: (801) 628-6023
Website: www.utahfamilytofamilynetwork.org/
Location: Division of Services for People with Disabilities; 1290 East 1450 South; Layton
Day: Third Wednesday of each month; Time: 6:30 - 8:30 p.m.

MAKS Group – (Mothers of Autistic Kids)
Davis School District
Contact: Laura Anderson; Phone: (801) 936-1810
Email: launderson@comcast.net

Iron County

Iron/Parowan Family to Family Network
Contact: LuWenn Jones; Phone: (435) 586-8745
Website: www.utahfamilytofamilynetwork.org/

Cedar City
Contact Bob Wasden at the
Southwestern Educational Development Center
Phone: (435) 586-2865
Email: bob.wasden@m.sedc.k12.ut.us

Logan

Family to Family Network
Contact: Ryan Rigby; Phone: (435) 453-6846
Website: www.utahfamilytofamilynetwork.org/
Location: 115 West Golf Course Road; Logan
Day: Third Wednesday of each month; Time: 7:00 p.m.

Park City & Summit County

Autism Information
Contact: Joy Stanley; Phone: (435) 640-6427
Email: jofs@comcast.net

Summit Family to Family Network
Website: www.utahfamilytofamilynetwork.org/
Location: Park City
Day: No regularly scheduled meetings at this time

South Davis

Family to Family Network
Website: www.utahfamilytofamilynetwork.org/
Location: South Davis Hospital
500 South 400 East; Bountiful
Day: Third Thursday of each month; Time: 7:00 p.m.

Salt Lake County

UPASK –
(Utah Parents of Asperger Syndrome)
Contact: Jana Gold
Hotmail: UPASK@hotmail.com
Website/Chat line:
http://groups.msn.com/UtahParentsofAspergerSyndromekids
Location: Sandy Library; 10100 Petunia Way; Sandy
Day: Fourth Tuesday of every month; Time: 7:00 p.m.

Utah FEAT
Families for Effective Autism Treatment
Website: www.utahfeat.org
Excellent referrals for autism resources
Location: Changes
Day: 2nd Monday of each month

Big MAKS (Mother's of Autism Kids)
Contact: Cheryl Smith Smithfam29@msn.com
Day: Social activities in summer

U of U Neuropsychiatry Institute - Autism Project
Contact: U of U Neuropsychiatric Institute
Phone: (801) 585-1212
Cost: $35 per session

San Juan County

Montezuma Creek Family to Family Network
Contact: Elsie Dee; Phone: (435) 459-9186
Website: www.utahfamilytofamilynetwork.org/
City: Montezuma Creek
Day: No regularly scheduled meetings at this time

Sanpete

Sanpete Family to Family Network
Website: www.utahfamilytofamilynetwork.org/
Location: Manti
Day: No regularly scheduled meetings at this time

Tooele

Action 4 Autism
Contact: Misty; Phone: (435) 843-8562
Day: 1st Tuesday of each month; Time: 6:30 P.M.

Utah County

UPASK – *Utah Parents of Asperger Syndrome*
Contact: Toni Sly; Phone: (801) 592-6409
Email: Tttiger200@msn.com
Hotmail: UPASK@hotmail.com
Website/Chat line:
http://groups.msn.com/UtahParentsofAspergerSyndromekids
Location: Timpanogos Hospital Women's Center
(North Entrance)
Day: 2nd Wednesday of each month; Time: 7:00 P.M.
Hotmail: UPASK@hotmail.com
Website/Chat line:
http://groups.msn.com/UtahParentsofAspergerSyndromekids

Utah County Family to Family
Website: www.utahfamilytofamilynetwork.org/
Location: Orem Community Hospital
331 North 400 West; Orem
Day: Third Thursday of each month; Time: 7:00 p.m.

Washington County

Washington Family to Family Network
Contact: Marcee; Phone: (435) 627-0433
Website: www.utahfamilytofamilynetwork.org/
Location: DSPD, St. George
Day: Second Wednesday of each month; Time: 7:00 p.m.

Online Autism Support Groups

OASIS - Asperger Syndrome Information & Support
http://www.udel.edu/bkirby/asperger/
Includes chat line for teenagers and adults with Asperger Syndrome

Unlocking Autism.Org – National On-line Support Network
http://www.unlockingautism.org

UPASK
http://groups.msn.com/UtahParentsofAspergerSyndromekids

Utah Autism Spectrum Support Group
www.msnusers.com/autismcommunitydedicatedtomakingadifference

For more information Autism and Autism Spectrum Disorders, please contact the Utah Parent Center.

Utah Parent Center Information Disclaimer

Utah Parent Center
Celebrating more than 24 years of service!!!
Utah Family Voices - Family to Family Health Information and Education Center
Family to Family Network – A Program of DHS/DSPD
Phone: (801) 272.1051 • Toll Free Utah: (800) 468.1160 • Fax: (801) 272.8907
Email: autisminfo@utahparentcenter.org • Website: www.utahparentcenter.org

Our mission is to help parents help their children with disabilities to live included, productive lives as members of the community. We accomplish this through the provision of information, training, and peer support. The Utah Parent Center is a private, non-profit organization that receives federal funding to be Utah's Parent Training and Information Center by the Office of Special Education Programs under grant #H328M020032. The Center also receives funding from other federal, state, and private agencies, organizations, and individual donors. The Utah Parent Center (UPC or Center) does not represent or endorse any particular point of view, program, organization, business or professional unless expressly stated and no endorsement may be inferred by the UPC or any of its funding sources. Every effort is made to provide accurate and complete information. Information provided to the UPC by other individuals, agencies, or organizations is solely the responsibility of the source and readers are encouraged to contact them with questions or concerns. Only approved items are included herein. The UPC is not responsible for information or services provided by agencies, organizations, or individuals listed. Readers are responsible to investigate resources to determine if appropriate when making informed decisions. Permission to reprint the information herein is granted with complete attribution.