



PARENT INFORMATION BOOKLET

*A Message of Hope
For You and Your Child*

About ASD HOPE

Mission Statement

- **Encourage** parents of children diagnosed with an Autism Spectrum Disorder (ASD) by offering a message of **HOPE!** Autism **IS** treatable.
- **Empower** parents by educating them about the options and resources available for their child who has been diagnosed with an Autism Spectrum Disorder.
- **Motivate** parents to take charge of their child's treatment—let them know that they will be the key to their child's success!
- **Serve** as a source for information about Autism Spectrum Disorder programs and services available in south central Pennsylvania.

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Note: Funding for this publication has been provided through the Greater Harrisburg Area Chapter of the Autism Society of America. This booklet is also available on our website in a .pdf format and can be downloaded or printed out.

Disclaimer: This information booklet includes information ASD HOPE parents “wish we had known when our children were first diagnosed.” It comes from a variety of sources and, while ASD HOPE believes the information to be accurate, we cannot independently verify any of it. Nothing in this information booklet should be construed as medical or legal advice. Always consult with your child's doctor regarding his or her individual needs.



*A Message of HOPE
For You and Your Child!*

Dear Parent:

This Parent Information Booklet has been compiled by ASD HOPE, a group of local parents, caregivers and professionals whose lives have been impacted by a diagnosis of Autism Spectrum Disorder (ASD), and is meant to serve as a resource of HOPE—Help, Options and Parent Empowerment—for you and your family. Inside, you will find information ASD HOPE parents “wish we had known when our children were first diagnosed.” In addition to the booklet, we also offer:

- **A Helpline with voice mail and email that are checked regularly.**
ASD HOPE believes that parent and caregiver contacts are one of the most valuable resources for other parents. You can reach us by calling (717)732-8400 ext. 8120 or by emailing ASDHOPE1@yahoo.com. A local parent will call you back to offer support, share experiences with you and provide more detailed information.
- **Parent Chat Seminars offered on a quarterly basis.**
This informal setting provides parents of newly diagnosed children the opportunity to hear more about treatment options and interventions, find out about local resources and talk to other parents to gain support.
- **Empowerment Workshops offered on a regular basis.**
Each workshop will generally cover 2-3 topics relevant to autism treatment. Subjects may include areas such as Medical Assistance and Behavioral Health Rehabilitation Services, biomedical and diet information, supplemental therapies, etc.

Please call or email us with any questions you may have or if you would like to get in touch with a local parent or caregiver for support and additional information. You can also visit us online at www.asdhope.org for information about upcoming events or to download this booklet in .pdf format.

Sincerely,

ASD HOPE

The Members of ASD HOPE

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Welcome and Introduction

Welcome

This information booklet has been created by a group of local parents and caregivers whose lives have been impacted by a diagnosis of Autism Spectrum Disorder (ASD). Diagnoses can include Autism, High-Functioning Autism, Asperger's Syndrome, Non-Verbal Learning Disability, Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS), Rett's Disorder, or Fragile X Syndrome.

The booklet is meant to serve as a resource of HOPE for you and your family. **Autism IS treatable.** And, while it can be tricky to navigate all the options available to you, ASD HOPE has parents and caregivers available to talk with you, support you, and share their experiences with you as you begin this journey.

You will find some information about therapy and other local resources in this booklet. It is by no means an exhaustive list. Much of the information contained within is what ASD HOPE parents and caregivers have learned through experience.

ASD HOPE believes that parent and caregiver contacts are one of the most valuable resources for other parents. You can access these local contacts by calling the ASD HOPE Helpline at (717)732-8400 ext. 8120 or by emailing us at ASDHOPE1@yahoo.com. Both voicemail and email are checked on a regular basis, and a local parent will contact you. These parent and caregiver contacts can provide support, share information and experiences with you, and provide more detailed information.

A diagnosis of ASD does not change who your child is...he or she is still the same incredible, exasperating, terrific, frustrating, wonderful, beautiful child he or she has always been. An ASD diagnosis is not an ending but a beginning—the beginning of a new journey. It's a journey that will bring you happiness and sorrow, joy and pain, smiles and tears, elation and frustration. Please know that you are not alone!

Icon Description



When you see this icon, it means that ASD HOPE can provide additional information and/or local parent contacts for that particular subject. Please call the ASD HOPE Helpline at (717)732-8400 ext. 8120 or email ASDHOPE1@yahoo.com for more information. You can also visit us online at www.asdhope.org.

A Mother's Story

The following is the story of an ASD HOPE parent:

That “little voice” told me something was wrong. But, everyone would tell me to give it time...that my son was just a toddler and that kids all develop differently. But, I couldn't get the nagging suspicion out of my mind that something was wrong. Then, one day, I watched him on the playground with other children. While the others interacted at some level, he was off in the corner of the playground, spinning in a circle and muttering to himself about computers. That's when I decided I had to find out more.

I asked his pre-school teacher if she thought his behavior was markedly different from the other children. Even though I suspected something was “wrong,” I was still shocked and even a little angry when she told me I should consider having him evaluated.

That led to an initial evaluation with the Intermediate Unit's Early Intervention Program. In turn, we were scheduled for a full evaluation. And, once again, even though I knew my son was “different,” it was very difficult, very painful, to go through the diagnostic process and finally hear the word autism associated with my child. I cried on and off for days after hearing the words “Autistic Spectrum Disorder.” I spent a great deal of time researching, but I also spent just as much time denying that there was a problem and refusing to associate the word “autism” with my child.

After the diagnosis, I wanted someone to tell me that with a little time and help, he'd be “normal.” I was frustrated that no one would tell me that. So, I began to mourn the loss of “normal.” I became depressed and angry that my son was going to be different. I asked “Why me?” a lot. But, then I began to ask, “What IS normal?” “Who is without idiosyncrasies?” And, it was at that point, I realized none of us knows how ANY child will turn out. It is simply our role as parents to do the best we can with what we have available to us.

Your circumstances are probably different, yet similar. You may have accepted the diagnosis much more easily. Or, you may still be struggling with what you've heard and wonder if the label of “autism” really fits your child. Your child may have very noticeable symptoms. Or, he or she may have symptoms that seem to be just a little out of the ordinary. You may be feeling strong and confident in your ability to deal with this latest issue in your life. Or, you may feel scared, angry and hopeless and not even know where to turn. No matter what your circumstances, it is our hope that through this booklet, you will discover that there ARE resources to help you.

Autism IS treatable. The circumstances you are living with today do not have to be the circumstances you experience tomorrow. And, most importantly, you are not alone.

A Father's Perspective

My son was two years old when I left for a one-year deployment to Kosovo with the Army National Guard. He had met all the normal milestones of development. He sat up. He crawled. He walked. He talked. Heck, he started reading by the time he was two. Yes, he was moody some times and he threw a lot of tantrums – but don't most kids? My wife was concerned about autism and other disorders almost from the time he was born. We were both older than average when he was born and we knew the possibilities of some kind of problem were much greater with the parents' age. But, I always discounted those concerns.

A year away from your family is a very long time. The Army prepares deployed soldiers to be ready for family changes upon returning home. But no military training could have prepared me for what I was about to face. In addition to changes, I anticipated a lot of other things too. I looked forward to doing "guy things" with my son. I think I am like most fathers in this respect. I anticipated the challenge of teaching my son to play sports. We were going to play catch, and kick the soccer ball around, and maybe, when my wife wasn't looking, learn some wrestling moves. I also looked forward to teaching him how to ride a bicycle. I remembered my father teaching me those things and I couldn't wait to experience that part of being a dad.

When I got home, I didn't really notice anything. My wife's concerns had increased because she believed our son had noticeable social and emotional delays. "You're overreacting," I said. "He just isn't interested in playing yet. Give him time". Our pediatrician agreed. We just needed to give him time. But, slowly, I began to realize that my wife was not overreacting. There were other things that weren't right. He showed some interest in sports. But, he didn't have the motor skills to play. Not only that, he really didn't seem to understand the object of any game.

We started soccer once a week. Our son was very excited about going. But, when he was supposed to be kicking the ball from one end of the field to the other, he held conversations with himself. We had to spend most of the time there on the field keeping him focused and diverting the coach's attention away from him. Maybe if we tried hard enough, he'd "get it." All this still was not enough to convince me. (Yes, "denial" is not just a river in Egypt.) One day I went to his school when the kids were out on the playground. All the other children in his class, and even the younger kids, were playing together in some fashion - all except our son. He was off in a corner by himself spinning around in circles and talking to himself. I finally had to admit there was something wrong.

We had already agreed that we would have him assessed by the Intermediate Unit's Early Intervention services. Unfortunately, as is all too common for dads – especially those in the military, I couldn't be there when the assessment was conducted. I was going to Germany for a week. When I returned, the report waited for me. Although I knew that something was wrong, I still was not prepared for the diagnosis. Our son has high-functioning autism. I didn't really know what the high-functioning part was all about. But, I sure knew what autism meant. It meant a child who couldn't really communicate. It meant a child who didn't know how to make friends. It meant no sports. It meant no hope for any improvement. (At least that's what I thought.)

My wife and I both took time to grieve. We realized we had lost something and needed to go through the process. That something we had lost was normalcy. We weren't going to be like other families. We weren't going to be like all our other friends. Even though we expected the diagnosis, we weren't really prepared for it. Maybe there is no way to really prepare for it.

There were some other things that I wasn't prepared for. One thing that took me totally by surprise, and angered me, was how medical and service providers treat fathers. I learned that, as a father, the best that you can hope for is an occasional acknowledgement that you are present. In many cases, you are simply ignored. The most ego-damaging incident occurred when the doctor we were seeing for a secondary evaluation sat my wife and son in front of his desk and put me in a corner out of the way. Apparently, it was OK if I listened to the proceedings, but I was certainly not expected to offer any input. He even said something like he'd ask me a question if he needed to hear what I had to say.

On more than one occasion, I felt like some sort of oddity - as though most practitioners had never seen a father before. However, I was determined not to fit the father mold that they expected. I encourage every father of a child with ASD to go to every appointment possible. Although as a stay-at-home mom, my wife spends the majority of the time with our son, I have some different perspectives based upon the activities that I do with him. I'd like to think that my input has been valuable in his assessments and treatment.

The treatment that we have chosen for our son, the biomedical approach espoused by DAN!, [Defeat Autism Now!—See later references in information booklet] resulted from a great deal of research. The majority of that research my wife conducted. I couldn't possibly have put the time and effort into the research that she has. But, my job was to listen to what she had discovered and to read as much as I could to understand. It is very important for both parents to be on board for any treatment to be successful. I am convinced that autism is treatable and am totally committed to following through with the diet and treatments that we believe are significantly helping our son.

I no longer grieve for what we have lost. In fact, I have great hope that some day soon my son and I will be playing catch. Regardless, I know that God has given us a very special child to care for. I cherish every moment that I spend with him. Although there is some sadness now and then, there is much more joy, and hope.

“A study released ... by the Centers for Disease Control & Prevention (CDC) found that Autism Spectrum Disorders (ASD) affect an average of 1 child in every 150 children.”

www.pathfindersforautism.org

Welcome to Holland

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I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills.... and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, *ever* go away... because the loss of that dream is a very, very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

What Should I Do Now? ASD HOPE's Top 10 List

Now, that your child has received an ASD diagnosis, what should you do next? You can choose a number of different options, and every child (and every family) is different and has different needs. Here is a suggested list of the “Top 10” things to do based on the experiences of ASD HOPE members.

1. Don't wait one more day to start helping your child.

It is natural to feel paralyzed by the ASD diagnosis. The sadness, grief and denial all stem from a place of fear--fear of the unknown, fear of the present and future as well as fear of no hope. ASD HOPE can “walk the first mile” of this journey with you, helping you to see that your best defense against this diagnosis is taking action – now.

Learning that your child has an ASD can be and often is an overwhelming experience. Please know that feeling this way is completely normal. It will take time to adjust and it may take some time to fully accept the diagnosis. Meanwhile, you can also start some interventions that could significantly help your child. **The single biggest regret for most parents is that they did not start certain interventions sooner.** Seek the support you need while you are learning about and accepting this change in your life. Often, talking with other families and parents about their experiences can be helpful, supportive and encouraging.

ASD HOPE encourages you to accept and use the term autism. Many times, professionals will avoid using the word “autism” because of the emotions it can bring. Also, parents who have children with milder autism symptoms will often question a diagnosis of autism because their child doesn't have “classic” autism symptoms such as head-banging or complete lack of social interaction. Many more children are being diagnosed (latest statistics indicate 1 out of every 150 children or 1 out of every 75 families will receive an ASD diagnosis.) Each child is different and has many different symptoms. Many children with autism appear “normal” and do not have defining physical characteristics.

Professionals even disagree about how to classify children within the various categories of autism. Many times, a child with ASD will be diagnosed with a different “type” of autism depending on the professional who was seen. This does not necessarily mean the professionals are wrong—it simply indicates how much about autism is not known.

Acceptance of the word autism will allow you to access greater services and treatment options. And, most professionals agree, the earlier you start an intervention for your child, the better your chances of success will be. As you read our Top Ten list, keep in mind that you may be dealing with most of these things simultaneously.

2. Arrange for your child to receive Early Intervention or School Services.

If you have not already done so, you can contact the appropriate agency (per the list below) for an evaluation to determine what services are suitable for your child. These services may include speech therapy, occupational therapy, physical therapy, and special instruction. Request this evaluation as soon as possible because there is often a wait of several weeks. These services are provided through the Individuals with Disabilities Education Improvement Act.

❖ If your child is under age 3, contact the following for Birth-3 Early Intervention:

- In Cumberland County or Perry County, call (717)240-6325 or (717)697-0371.
- In Dauphin County, call (717)441-7034.
- In Lancaster County, call (717)399-7323.
- In York County or Adams County, call (717)771-9618.

❖ If your child is age 3 or older, contact the following for Preschool Early Intervention:

- In Cumberland, Perry, Dauphin, or Northern York counties, call the Capital Area Intermediate Unit (CAIU) at (717)732-8400 or 1-800-244-2425.
- In Lancaster County, call the Lancaster-Lebanon Intermediate Unit at (717)606-1601.
- In York or Adams County, call the Lincoln Intermediate Unit at (717)624-4616.

❖ If your child is of school age, contact your local school district.

❖ If you live outside one of these counties, contact CONNECT Early Intervention at 1-800-692-7288 to locate the appropriate office.

3. Educate yourself about autism and available treatments.

There is a lot to learn about autism—including possible causes, differences among diagnoses, common co-occurring conditions, medical testing, medical treatments, state and local services, etc. This information booklet lists many helpful starting places.

Start with the doctor who gave you the diagnosis. Ask the doctor as many questions as necessary for you to understand why he or she feels this diagnosis “fits” your child. Also, talk with other parents who have a child with ASD and therapists working with your child. Often their experiences and knowledge can be very useful.

There are many wonderful organizations working to support, educate, and help caregivers who have a loved one diagnosed with an ASD. See the “Internet and Book Resources” section of this booklet for a listing of helpful publications and web sites. Listed below are five organizations ASD HOPE believes may be the most help to you as you are getting started on your journey.

- ❖ **Autism Research Institute (ARI)** – Founded in 1967, this organization conducts scientific research to improve the methods for treating, diagnosing, and preventing autism. They also provide information to parents seeking help. Dr. Bernard Rimland, the founder of ARI, was very well known and respected in the field of autism. He was also the father of a child with autism. ARI has a quarterly newsletter called the *Autism Research Review International* (ARRI) that provides up-to-date information. Dr. Rimland also started the Defeat Autism Now (DAN!) project. You can reach ARI at (619)281-7165 (8am-12pm Monday-Friday PST). Their web address is www.autism.com.
- ❖ **Talk About Curing Autism** – Talk About Curing Autism (TACA) provides information, resources, and support to families affected by autism. For families who have just received the autism diagnosis, TACA aims to speed up the cycle time from the autism diagnosis to effective treatments. Their web address is www.tacanow.com.
- ❖ **Autism Speaks** – This organization is a merger of Autism Speaks and the National Alliance for Autism Research (NAAR). Their commitment is to accelerate and fund biomedical research into the causes, prevention, treatments and cure for autism spectrum disorders; to increase awareness of the nation’s fastest growing developmental disorder; and to advocate for the needs of affected families. Autism Speaks can be reached by calling (212)252-8584 or by visiting www.autismspeaks.org. NAAR can be reached by calling 1-888-777-NAAR, and their web address is www.naar.org.
- ❖ **National Autism Association (NAA)** – www.nationalautismassociation.org
The mission of the National Autism Association is to educate and empower families affected by autism and other neurological disorders, while advocating on behalf of those who cannot fight for their own rights. One of their goals is to encourage those in the autism community to never give up in their search to help their loved ones reach their full potential, funding efforts toward this end through appropriate research for finding a cure for the neurological damage from which so many affected by autism suffer.
- ❖ **Autism Society of America (ASA)** – This is the largest and oldest national organization advocating on behalf of Americans with autism. The Greater Harrisburg Area chapter of the ASA has monthly support meetings as well as other family events throughout the year. Please call 1-800-244-2425 ext. 8408 for more information or visit their website at www.autismharrisburg.org. The National ASA website is www.autism-society.org.



4. Start the Gluten and Casein Free Diet.

Many parents are unaware of the significant link between gastrointestinal, immune system problems and autism spectrum disorders. The digestive system is considered the "second brain" of the body and relates directly to neurological functioning. Eliminating certain foods from your child's diet can often result in dramatic improvements! The gluten and casein free diet is usually considered the first biomedical intervention to be tried with a child (casein is the protein found in cow's milk and gluten is the protein found in many grains such as wheat, barley, and rye). This is a highly specialized area of medicine and therefore most family doctors, pediatricians and nutritionists will not be familiar with how and why this diet works for children on the autism spectrum.

- ❖ **If done correctly, the GF/CF diet helps 85%** of ASD children by improving their ability to learn and their overall well being. Many parents, including local ASD HOPE members, report dramatic improvements in areas such as speech, bowel movements, sleep patterns, behaviors, mood, eye contact, stimming, focus, and awareness.

- ❖ **Doing the diet properly and 100% are the keys to its success!** The first step is to read the book, Unraveling the Mystery of Autism and PDD by Karyn Seroussi. ASD HOPE sells this book at cost for \$10. If you have read the book and want help getting started and/or maintaining the diet, contact ASD HOPE to be put in touch with a local parent with years of experience.

- ❖ **The following symptoms* in an ASD child are serious indicators that the diet approach will help:**
 - Very picky eaters/Self limiting to OR craving certain foods (esp. those containing dairy or gluten, e.g. milk, pasta, yogurt, crackers, bread)
 - Asthma, allergies or eczema
 - Recurrent ear infections
 - Chronic diarrhea or constipation or both

***Even children without any of the symptoms listed above have benefited greatly from the diet.**

The www.tacanow.com web site previously mentioned offers helpful advice and a 10 week program for implementing the diet. More information can also be found in the "Dietary Intervention" section of this booklet.



5. Make an appointment with a doctor who specializes in biomedical treatments of ASD.

The latest scientific research indicates that there are underlying medical conditions in many ASD kids that contribute to and/or cause their autistic symptoms. Safe and effective treatments are

available to address problems with biochemical imbalances, immune system regulation, digestive functioning and heavy metal toxicity. **Autism is not just in the head—it is a condition that affects many systems of the body and can, in many cases, be successfully treated, producing dramatic improvements.**

After learning about and starting the GF/CF diet, investigate other biomedical treatments which could significantly help your child. The Biomedical Treatment Section of this booklet gives more information and several helpful websites. There are also a number of good books listed in the Internet and Book Resources section.

This is a highly specialized area of medicine and therefore most family doctors and pediatricians will not be familiar with the treatment protocols. To find a doctor who can help you determine a treatment plan based on biomedical interventions, the two main choices are:

- **“DAN! Doctors”** are physicians who utilize the DAN! (Defeat Autism Now!) protocol. The DAN! Approach started in 1995 when a group of 30 professionals in autism research and treatment (representing specialties in psychiatry, neurology, immunology, allergy, biochemistry, genetics and gastroenterology) joined together to determine an alternative approach to treating autism. They continue to hold bi-annual conferences and have trained a number of physicians who are working together toward the goal of finding effective treatments for ASD. DAN! doctors use natural treatments such as diet, vitamins, minerals and amino acid therapies, not drugs. For more information, visit <http://www.autism.com/dan/index.htm>.
- **The Pfeiffer Treatment Center** is a not-for-profit medical research and treatment facility in Warrenville, Illinois which focuses on research and treatment of biochemical imbalances. PTC is staffed by a team of physicians, practitioners, chemists and other professionals who specialize in the effects of biochemistry on behavior, thought and mood. Recent research has identified underlying medical (biochemical) conditions that can cause the ‘symptoms’ associated with autism. Natural treatments such as diet, vitamins, minerals and amino acid therapies are producing many reports of striking improvements and in some cases elimination of the autistic symptoms. The Pfeiffer Treatment Center is a leader in these treatments and current research in this field. One of the few centers in the world with this biochemical focus, PTC has grown into a thriving clinic with patients from 70 countries. In addition, the center evaluates patients in other states during its outreach clinics, one of which is held in Annapolis, MD. PTC can be reached by calling (630)505-0300 or by visiting www.hriptc.org.



6. *Apply for a Medical Assistance Card (ACCESS) for your child.*

In Pennsylvania, children with disabilities are currently eligible for medical assistance (also known as Medicaid) regardless of their parent’s income. It also DOES NOT matter if the parents already have health insurance. Many parents do not apply for medical assistance for their child with ASD because they believe they make too much money or because they already have health insurance for the child. Unfortunately, many private health insurance plans currently DO NOT cover a lot of the therapies and treatments available for ASD. However, medical assistance does

often help to cover many of these types of services. Please see “Resources for Obtaining a Medical Assistance (ACCESS) Card” in this information booklet for more information.



7. *Apply for Behavioral Health Rehabilitation Services, if appropriate.*

Behavioral Health Rehabilitation Services (also called “Wraparound Services”) provide the opportunity for specialists to work with your child in the home, school or other community settings. Children **MUST FIRST BE ELIGIBLE** for Medical Assistance (see number 5 above) before you can apply for Behavioral Health Rehabilitation Services.

Once your child is eligible for Medical Assistance you can contact your county’s mental health/mental retardation office (MH/MR). A case manager may then be assigned to help you begin accessing services for your child and/or family. They can also supply a list of agencies to call for an “intake.” At that “intake,” a psychologist will evaluate your child and decide if your child has a need for Behavioral Health Rehabilitation Services.

The Behavioral Health Plan (BHP) in your area provides this service. In this area (Cumberland, Dauphin, Lancaster, Lebanon, and Perry counties), this insurance company is Community Behavioral HealthCare Network of Pennsylvania (CBHNP). In York County, the insurance company is Community Care Behavioral Health (CCBH). This service is covered under the Medical Assistance plan. For additional information, including covered therapies and contact information, please see the page in this booklet entitled, “How to Apply for Behavioral Health Rehabilitation Services.”



8. *Network and talk with other parents of children on the spectrum.*

One of the goals of ASD HOPE is to connect parents and caregivers that are just beginning their journey with ASD with other parents who may be at the same place or a little farther ahead in their journey. Many parents and caregivers who have a loved one on the spectrum often believe that other parents and caregivers have been their best source of information, support, encouragement, inspiration and hope. If you would like to contact other parents, please call the ASD HOPE Helpline at (717)732-8400 ext. 8120 or email at ASDHOPE1@yahoo.com to be put in contact with local parents.

Parent to Parent is another organization that will put you in contact with other parents. You can reach them by calling toll free to 1-800-986-4550. The local number for this region of Parent to Parent is (717)531-4842.

You can also network informally with other parents whose children have a similar diagnosis. Many times, you can meet other parents by asking friends and family members if they know of anyone else who has a child “on the spectrum.” You will also often meet others when taking your child to various therapy and intervention programs. Also, consider attending the local Autism Society of America’s monthly meeting. Details on this group can be found in item number 3 of this top 10 list.

9. Understand that YOU are your child's BEST advocate.

You may be surprised to learn that you will need to play many roles for your child in addition to being the parent. You will need to be his or her case manager, therapist, and advocate, not to mention chauffeur and secretary. There is no one else who will have the comprehensive view of your child—understanding his or her current therapy schedule, doctor's appointments, recent successes and current challenges. The good news is that no one else knows your child better than you, so you are uniquely qualified for these roles.

Parents play an extremely important role in the treatment team; they have a say in everything that happens. In order to be your child's best advocate, take the time to educate yourself on the therapies he or she is receiving as well as other options out there. Take an active role in determining what services will best help your child. Familiarize yourself with the information in your child's Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP) so you can get the most and best services for your child. Become involved with your child's therapies so you can reinforce what he or she is being taught. Use every opportunity you have to teach something or reinforce a concept.

Accepting this role as your child's advocate will also bring additional stress. But, the rewards of doing it will pay off in the end. The time you invest working with your child is a crucial factor in his or her success.

10. Know there is HOPE for your child to flourish and grow.

ASD HOPE is here to provide you with just that—HOPE! Our organization wants to give you Hope: Help make you aware of the treatment Options for your child and encourage Parent Empowerment. While there are no guarantees of where any child will end up, the current perspective (and our belief) is that autism IS treatable. The circumstances you are living with today do not have to be the same challenges you have tomorrow. There is a lot that can be done for your child and your family. You are not alone.

“I promise that in the future, to your surprise, your dreams will have changed, and changed you.

I know that is not what you want.

What you want is a real talisman, a magic something you think I conjured up to coax Temple into joining life as you hope your child will.

There was no magic, there was just doing the best I could. That's the point, that's the talisman.

And never letting go of hope.

*A Thorn in My Pocket by Eustacia Cutler
(Temple Grandin's mother)*

 **Resources for obtaining a Medical Assistance (ACCESS) Card**

Medical Assistance (also known as Medicaid) can help you pay for services that regular insurance may deny. In Pennsylvania, there is no family income limit. Having a medical assistance card can be a great help to offset the costs that come with some treatment options. The factors in getting approved for an ACCESS card include the child's income and his/her diagnosed disability.

Contact your County Assistance Office to receive an application or complete one that was given to you through Early Intervention (EI) or the Intermediate Unit (IU). The County Assistance Office is a state agency that is overseen by the Department of Public Welfare. Local offices include:

- ❖ **Dauphin County Assistance Office**
2432 N 7th Street
Harrisburg, PA 17110-0959
Phone: (717)787-2324
Fax: (717)787-3040
- ❖ **Cumberland County Assistance Office**
PO Box 599
33 Westminister Drive
Carlisle, PA 17013-0599
Phone: (717)240-2700
Fax: (717)249-8141
- ❖ **Lancaster County Assistance Office**
PO Box 4967
832 Manor Street
Lancaster, PA 17604
Phone: (717)299-7421
Fax: (717)299-7565
- ❖ **Perry County Assistance Office**
100 Center St
New Bloomfield, PA 17068
Toll Free: 1-800-991-1929
Phone: (717)582-2127
Fax: (717)582-4187
- ❖ **York County Assistance Office**
PO Box 15041
130 N Duke Street
York, PA 17405-7041
Phone: (717)771-1100
Fax: (717)771-1261

You can also apply on-line by going to www.compass.state.pa.us. Click on "Enter the Compass Site" and then click on "Apply Online for Social Services."

Complete the following steps:

1. Complete the application entitled Health Care Coverage for Children with Disabilities (PA600CH-L) and submit to the previously listed addresses. It is suggested that you write the following at the top of each page in red ink “*Category PS-95 Youth Handbook 355.4*”. The more information you provide, the better the chances your child will be granted the Medical Assistance card without delay. Include any evaluations or medical reports you have that document your child’s disability. Mail the application via the US Postal Service marked “Return Receipt” or hand deliver to the appropriate assistance office (based on where you live.)

2. Once your child qualifies for medical assistance, you will be sent literature regarding your choice for health insurance. You can also visit www.enrollnow.net/paenrollnow/ to compare the three plans. Currently there are three insurance plans to choose from. These insurance companies are:
 - AmeriHealth Mercy 1-888-991-7200
www.amerihealthmercyhp.com
 - Gateway Health Plan 1-800-392-1147
www.gatewayhealthplan.com
 - Unison Health Plan 1-800-414-9025
www.unisonhealthplan.com

Just surviving isn't good enough for anyone and it certainly isn't good enough for special children. These children are like starfish. Each day that we bring them a step forward, they are further away from being lost on the beach. And although a little step isn't a big thing today, or tomorrow or the next day, if you keep taking little steps, you will see one day that you have walked a great distance with your child.

One Small Starfish: A Mother's Everyday Advice, Survival Tactics and Wisdom for Raising a Special Needs Child by Anne Addison.

How to Apply for Behavioral Health Rehabilitation Services

Behavioral Health Rehabilitation Services (also known as Wraparound Services) can provide your child with important services. The following excerpted article provides an excellent description of the services you might receive, and information regarding the application process appears directly after the article.

This excerpt is reprinted with permission from:

Making the Best Choice: Service Selection in Children’s Mental Health

by Gordon R. Hodas, M.D.

a CASSP discussion paper

Behavioral Health Rehabilitation Services for Children and Adolescents

Description:

In 1994, DPW issued a Bulletin (see Appendix C) identifying three specific BHRS services [Behavioral Health Rehabilitation Services]: Mobile Therapy (MT) and Behavioral Specialist Consultant (BSC), staffed by mental health professionals with at least a Master’s degree and specified experience, and Therapeutic Staff Support (TSS), now staffed by a mental health paraprofessional with a Bachelor’s degree or at least 60 college credits and specified experience and training. (The Summer Therapeutic Activities Program, or STAP, another specific BHRS, was developed later and is discussed elsewhere). By definition, these services are offered in the home and community, including the child’s school setting, when medically necessary, to support the continued community tenure of the child with SED [severe emotional disturbance], and are not offered in a clinic setting. A summary of each of the three BHRS services listed on the MA fee schedule follows:

1) Mobile Therapist

A Mobile Therapist (MT) is a therapist, similar to an outpatient therapist in many respects, who meets with the child in the home, school, and other community sites as appropriate and as identified in the child’s treatment plan. When BHRS is used, the MT typically serves as the “primary clinician”—the individual with primary clinical leadership responsibilities—although this role may also be assumed by an outpatient or community therapist, when MT is not used. The MT can help the child with individual goals (such as controlling temper or dealing with depression), family goals (such as getting along better with parents or siblings), and community goals (such as developing and maintaining peer relationships and community attachments). The MT can work with the child individually, the family as a whole, and various family subsystems, as long as the interventions are related to the needs of the child in question. The MT can also work with community resource persons as part of the therapy for the child. Such individuals may be seen with the child, parents, and/or the entire family. The MT, like the traditional outpatient therapist, can develop a treatment plan for the child, and can include behavioral approaches as part of the interventions used. The use of Mobile Therapy does not necessitate concurrent use of

BSC (see below), nor is the MT restricted from using behavioral approaches or developing a treatment plan.

Regardless of the specific roles of the MT identified in the treatment plan, the MT is expected to link all intervention efforts back to the child's parents or guardians. There is thus need to clarify the nature and limitations of confidentiality with the child, and also to ensure that the child and family understand that the goal of treatment involves both helping the child individually and also supporting parental leadership. Such explanations are best introduced as part of the service orientation, and can then be reinforced as treatment proceeds.

2) Behavioral Specialist Consultant

According to the 1994 Bulletin, the Behavior Specialist Consultant (BSC) is a consultant resource for a child in need of specialized behavioral interventions. The BSC is to be used under exceptional circumstances.

The role of a BSC, when involved, is different than that of a therapist. By focusing on the specific behaviors of the child, the BSC—unlike the primary clinician—is not responsible for addressing the “whole picture” of the child, which includes more than just a child's behaviors. The BSC, when involved, is expected to gather information related to the child's problematic behaviors, develop a plan of behavioral intervention, and assist others in implementing it. The BSC also monitors the child's response to the plan, and makes modifications based on needs and outcomes, in consultation with the child's parents, other caregivers, and the primary clinician. The BSC may need to observe a child in multiple settings and talk to those working with the child, including but not limited to the child's parents. A major goal of BSC consultation with the child's parents involves the transfer of information and skills. When TSS is also being used, the BSC obtains information from the TSS worker that can guide future interventions. The BSC is expected to work closely with the primary clinician, and is properly viewed as a consultant to this individual. While the BSC has direct contact with the child, this is to gather information, ensure that the child “buys into” the behavior plan, explain proposed techniques, and monitor progress. This kind of contact is quite different from the provision of psychotherapy, which is not a BSC function.

Under most circumstances, it is not appropriate for the BSC to be the sole mental health professional within the child's team. This is because the BSC, by design, focuses on discrete behaviors rather than the whole child, and is a consultant rather than a therapist.

3) Therapeutic Staff Support

The Therapeutic Staff Support (TSS) worker is a mental health paraprofessional, not a mental health professional. Until June 2001, a TSS worker was required to have a Bachelor's degree. Currently, an individual with an Associate's degree or 60 college credits can also serve as a TSS worker, so long as specific experience and training requirements are also met.

TSS provides a one-to-one service to a single child and family. The TSS worker, with oversight by an involved mental health professional and with regular professional supervision, serves a “hands-on” function, working closely with the child, family, and other adults to help implement specific behavioral health interventions in the written treatment plan. The functions of a TSS

How to Apply for Behavioral Health Rehabilitation Services

worker are individualized according to the specific needs of a child at that time, with the TSS worker's tasks clearly identified within the child's treatment plan. Data and other information from the TSS worker, shared with the team, can serve as the basis for modifications of the child's treatment plan and overall treatment strategy.

TSS, provided in varying degrees of intensity as appropriate, can be used to promote a range of goals. TSS roles may include any of the following: supporting the child's adaptation in the home with the family, promoting the child's behavioral functioning in a school setting, promoting the child's community integration, and at times supporting the child in acute settings, as part of an intensive and integrated response. In general, TSS should be used only when it is clear that the efforts of mental health professionals, in combination with the family and community, cannot meet the child's mental health needs satisfactorily. Efforts should be made to follow the least restrictive/least intrusive service principle, in terms of both intensity of service and duration of use.

The need to link intervention efforts to the parents and other caregivers is especially important with the use of TSS. This occurs both through the sharing of information and through direct interventions in the home, consistent with the child's treatment plan. When an identified TSS role involves helping the child integrate more effectively in the community (for example, by participating effectively on a community sports team), outcomes from these efforts should consistently be reviewed with the child's parents. One way for the TSS worker to maintain a family-centered approach is by beginning and ending each contact with the child by discussing interventions and talking, at least briefly, with the child's parent(s). Such contact benefits both the parent and TSS worker, as information is exchanged and a spirit of collaboration reinforced.

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It is never too late to provide every ASD person the benefits of the new diagnostics and therapies now available.

Children with Starving Brains
by Jacquelyn McCandless, MD

Stepping Stones

Another option includes Stepping Stones. Stepping Stones helps to provide a continuum of care that is therapeutically based, bridging the gap between traditional Behavioral Health Rehabilitation Services (BHRS) and inclusion in the classroom. It is a program for children with ASD ages 3-7 and 8-14. Students work in both large and small groups with a 1:2 staff to child ratio being maintained at all times. During your child's intake, you can ask for more information about the Stepping Stones program, which is run by Northwestern Human Services. For more information, contact Diane Dayton at (717)608-5571.

Mental Health/Mental Retardation (MH/MR) Offices

Contact your county's Mental Health/Mental Retardation (MH/MR) Agency. They can help you apply for the medical assistance card and give you a list of agencies you can call for an "intake" (see number 1 below). They can also provide you with a support coordinator to help navigate community resources.

- ❖ **Cumberland-Perry County Mental Health/Mental Retardation (MH/MR)**
Phone (717)240-6320
- ❖ **Dauphin County Mental Health/Mental Retardation (MH/MR)**
Phone (717)232-8761
- ❖ **Lancaster County Mental Health/Mental Retardation (MH/MR)**
Phone (717)299-8021
- ❖ **York-Adams County Mental Health/Mental Retardation (MH/MR)**
Phone (717)771-9618

The following outlines the process that will occur after you request Behavioral Health Rehabilitation Services:

1. A psychological or psychiatric evaluation will occur to recommend services for your child, and the evaluation and recommendations will be sent to your Behavioral Health Plan (BHP) for review. (Be sure to request that a copy be sent to you as well.) You may contact your Behavioral Health Plan directly to locate an evaluator or arrange the evaluation with the help of your child's MH/MR caseworker. The BHP for Cumberland, Dauphin, Lancaster, Lebanon and Perry Counties is Community Behavioral HealthCare Network of Pennsylvania (CBHNP). Their phone number is 1-888-722-8646. The BHP in York County is Community Care Behavioral Health Inc., and their phone number is 1-866-542-0299.
2. Your BHP will schedule an Interagency Service Planning Team meeting (ISPT). This meeting is for you, your child, and all people working with your child. At this meeting, you will discuss the child's specific behavioral needs and also be asked to select a service provider. You can request "first available" to minimize time on the waiting list.

How to Apply for Behavioral Health Rehabilitation Services

3. All the information collected up to this point will go back to your BHP for review. Any additional information needed can be requested by your BHP and a decision will then be made about which services will be authorized.
4. Your BHP will then notify you (the parent) of the approval or denial of service.

Note: In Pennsylvania, these services can be authorized for up to twelve months for individuals with an Autism Spectrum Disorder. The evaluator at the intake must include this request in the final evaluation, or the parents/caregivers will need to have services re-approved every four months.

“You, your spouse or other relatives may share some of the same characteristics your child has. If your child counts among her relatives a grandfather who is emotionally distant but a brilliant mechanic, a cousin whose single-minded interest in dinosaurs landed him a scholarship and a plum job at a major museum, or an uncle with an odd, yet refreshing ‘Monty Python’-esque take on the world, you may be less likely to be alarmed by similar behaviors in your child...”

The OASIS Guide to Asperger Syndrome

Internet and Book Resources

This section identifies resources that are available in books and on the Internet. In the “Books and Websites” list, books and websites are listed together under each topic.

Web Pages for the Newly Diagnosed

There is so much information available on the Internet. While much of it is good information, parents should be careful about the source of information (as with any internet research.) The pages below are ones that specifically address issues for parents of newly diagnosed children (although parents who are “not so new” to the autistic spectrum will probably also find them helpful.) Each of these sites also has a lot of other very good information on it, although you should be forewarned—scouring the internet for information can be very overwhelming, especially for parents of children who are newly diagnosed. This list is provided as a “jumping off point.” It is not an exhaustive list by any means.

- ❖ http://www.tacanow.com/autism_intro.htm
- ❖ <http://www.autism-resources.com/advice-to-parents.html>
- ❖ <http://www.autism.com/autism/first/adviceforparents.htm>
- ❖ <http://www.autisminfo.com/action.htm>
- ❖ <http://www.udel.edu/bkirby/asperger/family.html> (*The letter to grandparents is especially good and is also helpful for parents.*)
- ❖ <http://www.tonyattwood.com.au/> (*Click on “Books to Explain the Diagnosis”*)
- ❖ <http://www.autismone.com> (*Click on “Download 2005 Presentations”*)

*If God did not have at least some autistic moments,
why did he make all of the planets spin? Jerry Newport*

Books and Websites – Listed Together by Topic

General - Autism

Autism Spectrum Disorders: The Complete Guide to Understanding Autism, Asperger's Syndrome, Pervasive Developmental Disorder, and Other ASDs by Chantal Sicile-Kira
The Autism Encyclopedia edited by John T. Neisworth and Pamela S. Wolfe
The Everything Parent's Guide to Children with Autism by Adelle Jameson Tilton

General - Asperger's

Asperger's Syndrome: A Guide for Parents and Professionals by Tony Attwood
Aspergers...What Does It Mean to Me? by Catherine Faherty
The OASIS Guide to Asperger Syndrome: Completely Revised and Updated: Advice, Support, Insight and Inspiration by Patricia Romanowski Bashe, Barbara L. Kirby, Simon Baron-Cohen and Tony Attwood - www.udel.edu/bkirby/asperger
The Curious Incident of the Dog in the Night-Time by Mark Haddon (a novel written from the perspective of a person with Asperger's – gives a good picture of how they process their thoughts)

Family Experiences

The Boy Who Loved Windows: Opening the Heart and Mind of a Child Threatened with Autism by Patricia Stacey
The Dragons of Autism by Olga Holland
Facing Autism by Lynn M. Hamilton
Let Me Hear Your Voice by Catherine Maurice
Louder Than Words: A Mother's Journey in Healing Autism by Jenny McCarthy
One Small Starfish by Anne Addison

Personal Experiences

Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome, 2nd ed by Stephen Shore
Emergence: Labeled Autistic by Temple Grandin
Freaks, Geeks and Asperger Syndrome by Luke Jackson
Thinking in Pictures: And Other Reports from My Life with Autism by Temple Grandin

Advocacy

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum, edited by Stephen M. Shore - www.autismasperger.net
The Complete IEP Guide: How to Advocate for Your Special Ed Child by Lawrence M. Siegel
The Right to Special Education in Pennsylvania: A Guide for Parents by Ellen Mancuso, Janet F. Stotland, Esq. and Len Rieser, Esq. (Single copies available FREE to parents and advocates by calling (215)338-6970.)
Wrightslaw: From Emotions to Advocacy - The Special Education Survival Guide by Peter W. D. Wright and Pamela Darr Wright - www.wrightslaw.com

Applied Behavior Analysis (ABA)

Behavioral Interventions for Young Children with Autism edited by Catherine Maurice, co edited by Gina Green and Stephen C. Luce

Teaching Individuals with Developmental Delays: Basic Intervention Techniques by O. Ivar Lovaas - www.lovaas.com

Augmentative and Alternative Communication

International Society for Augmentative and Alternative Communication - www.isaac-online.org/select_language.html

Auditory Integration Training (AIT)

Awakening Ashley: Mozart Knocks Autism on its Ear by Sharon Ruben

The Sound of a Miracle by Annabelle Stahli

Society for Auditory Intervention Techniques - www.sait.org

Biomedical Interventions

Autism: Effective Biomedical Treatments by Drs. Jon Pangborn and Sidney Baker

Biological Treatments for Autism and PDD by William Shaw

Children with Starving Brains by Jacquelyn McCandless, M.D.

Enzymes for Autism and Other Neurological Conditions by Karen DeFelice

The Puzzle of Autism: Putting It All Together by Garry F. Gordon and Amy Yasko

Daily Life Therapy - www.bostonhigashi.org

Developmental, Individual-Difference, Relationship-Based (DIR)/Floortime

Engaging Autism: Using the Floortime Approach to Help Children Relate, Communicate and Think by Stanley I. Greenspan, M.D. and Serena Wieder, Ph.D.

Floortime Foundation - www.floortime.org

Dietary Interventions – GFCF & Others

Breaking the Vicious Cycle by Elaine Gottschall – www.breakingtheviciouscycle.info

www.pecanbread.com (Book and websites refer to Specific Carbohydrate Diet)

Is This Your Child?: Discovering and Treating Unrecognized Allergies in Children and Adults by Doris Rapp, MD

Special Diets for Special Kids by Lisa S. Lewis

Unraveling the Mystery of Autism and Pervasive Developmental Disorders by Karyn Seroussi www.autismNDI.com (Website started by Lisa S. Lewis and Karyn Seroussi)

Facilitated Communication (FC)

Facilitated Communication Institute - www.soeweb.syr.edu/thefci/fcfacts

Feeding Issues

Just Take a Bite: Easy, Effective Answers to Food Aversions and Eating Challenges by Lori Ernsperger, Ph.D. and Tania Stegen-Hanson, OTR/L

Home Schooling

Home Educating Our Autistic Spectrum Children: Paths Are Made By Walking edited by Terri Dowty and Kitt Cowlshaw

Home Schooling Children with Special Needs: Turning Challenges into Opportunities by Sharon Hensley

Inspirational

Angel Behind the Rocking Chair: Stories of Hope in Unexpected Places by Pam Vredevelt

Finding God in Autism: A 40 Day Devotional for Parents of Autistic Spectrum Children by Kathy Medina

His Name is Joel: Searching for God in a Son's Disability by Kathleen Deyer Bolduc

Parenting

Asperger Syndrome and Difficult Moments: Practical Solutions for Tantrums, Rage, and Meltdowns by Brenda Smith Myles and Jack Southwick

The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children by Ross W. Greene

Picture Exchange Communication System (PECS)

A Picture's Worth: PECS and Other Visual Communication Strategies in Autism by Andy Bondy and Lori Frost - www.pecs.com

Pivotal Response Treatment

Overcoming Autism: Finding the Answers, Strategies, and Hope That Can Transform a Child's Life by Lynn Kern Koegel, Ph.D. and Claire LaZebnik

Pivotal Response Treatments for Autism: Communication, Social & Academic Development by Robert L. Koegel, Ph.D. and Lynn Kern Koegel, Ph.D.

Rapid Prompting Method (RPM)

Helping Autism through Learning and Outreach (HALO) - www.halo-soma.org

Relationship Development Intervention (RDI)

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

Relationship Development Intervention with Young Children by Steven E. Gutstein and Rachelle K. Sheely

Connections Center - www.connectionscenter.com

Sensory Integration

The Out-of-Sync Child by Carol Stock Kranowitz, M.A.

The Out-of-Sync Child Has Fun by Carol Stock Kranowitz, M.A.

Raising a Sensory Smart Child by Lindsey Biel, M.A., OTR/L and Nancy Peske

Sensational Kids: Hope and Help for Children with Sensory Processing Disorder by Lucy Jane Miller, Ph.D., OTR and Doris A. Fuller

Take Five! Staying Alert at Home and School by M. Williams and S. Shellenberger

Henry Occupational Therapy Services - www.ateachabout.com

Sensory Integration International - www.home.earthlink.net/~sensoryint/

Social Skills Training & Social Stories

My Social Stories Book and The New Social Story Book, edited by Carol Gray and Abbie Leigh White – The Gray Center for Social Learning and Understanding - www.thegraycenter.com

Social Skills Training for Children and Adolescents with Asperger Syndrome and Social-Communication Problems by Jed E. Baker, Ph.D.

The Social Skills Picture Book by Jed E. Baker, Ph.D.

Son-Rise Program

Autism Treatment Center of America (The Option Institute) - www.son-rise.org

Treatment and Education of Autistic and related Communication-Handicapped Children (TEACCH) - www.teacch.com

Vaccines

Evidence of Harm: Mercury in Vaccines and the Autism Epidemic: A Medical Controversy by David Kirby

What Your Doctor May Not Tell You about Children's Vaccinations by Stephanie Cave, MD, with Deborah Mitchell

Generation Rescue – www.generationrescue.org

National Vaccine Information Center (NVIC) - www.909shot.com

Put Children First – www.putchildrenfirst.org

Safe Minds – www.safeminds.org

Verbal Behavior

The Assessment of Basic Language and Learning Skills (The ABLLS) by James W. Partington and Mark L. Sundberg

Teaching Language to Children with Autism and Other Developmental Disabilities by Mark L. Sundberg and James W. Partington

Behavior Analysts, Inc - www.behavioranalysts.com

Vision Therapy

Irlen Lenses - www.irlen.com

Parents Active for Vision Education - www.pavevision.org

Visual/Teaching Strategies

Teaching Children With Autism: Strategies to Enhance Communication and Socialization by Kathleen Quill

Visual Strategies for Improving Communication by Linda Hodgdon, M.Ed, CCC-SLP

Magazines

The Autism Perspective - www.theautismperspective.org

Spectrum Magazine - www.spectrumpublications.com

As with Internet sites, there are many other publications out there. Choose carefully to avoid becoming overwhelmed and spending a lot of money. Local libraries sometimes have these titles available. Two other lending libraries are the Capital Area Children's Center at UCP - (717)975-0611, and the Greater Harrisburg Area ASA chapter - (717)732-8400 ext. 8408.

Books may be available through special purchase at area bookstores. Other times, they are only available through specialty web site locations, including the following: www.Amazon.com (search "autism"), www.autism-resources.com/books.html, www.jkp.com, www.futurehorizons-autism.com and www.asperger.net.

As time goes on, you will find that everything related to autism tends to be a process—the process of finding the label and understanding it, the process of accepting the journey once you have begun, and the process of treating the autism. Explore what you can when you are ready. Taking each process one step at a time, you may discover, as we have, the anxiety about the unknown transforming into new hope for your child's future.

Facing Autism
by Lynn M. Hamilton

Therapy Resources

ASD HOPE has additional information on all the therapies listed below. In many cases, we can also put you in touch with a parent who has done or is currently doing these therapies. Call the Helpline at (717)732-8400 ext. 8120 or email ASDHOPE1@yahoo.com for more information or parent contact information.

Core Therapies

This includes treatments such as Speech Therapy, Occupational Therapy, Physical Therapy and Developmental Therapy. These core therapies are **routinely offered through Early Intervention**, and there are many providers who can be accessed through that program. To obtain the list of contracted providers in your county, please contact the appropriate location as listed under #2 of our Top 10 List (page 13).

Biomedical and Dietary Interventions

❖ **DAN! Doctors**

For a list of DAN! doctors, please see the following list:

<http://www.autismwebsite.com/ari-lists/danus.html>

❖ **The Pfeiffer Treatment Center**

The Pfeiffer Treatment Center (PTC) is a non-profit outpatient facility for children and adults specializing in the evaluation and management of biochemical imbalances. PTC deals with casein/gluten free diets, yeast overgrowths, nutrient therapies and individualized treatment plans. Although PTC is located in Warrenville, IL, they do hold “outreach clinics” in Maryland at least twice a year. You may contact them for more information at (630)505-0300 or visit their web site at www.hriptc.org.

❖ **Homeopathic Therapy**

➤ Eric Doerfler, CRNP

Nightingale Health Center

2801 North Front Street, Harrisburg

(717)920-9579

➤ Dr. Dan Duryea, N.D.

Savemart

241 W Roseville Rd, Lancaster

(717)508-9189

DoctorDan@gmx.net

Life Coaching, Diet & Nutrition, Homeopathy & Herbology, Natural Health Education – consultation by appointment.

Educational

❖ Schools for Children with an Autism Spectrum Disorder

- Janus School
205 Lefever Rd
Mount Joy, PA 17552
(717)653-0025
www.thejanusschool.org
- Milestones Achievement Center (MAC)
2700 Commerce Dr
Harrisburg, PA 17110
(717)651-0017
156 Donnerville Rd
Mountville, PA 17554
(717)285-7373
- NHS Autism Schools
898 Waggoners Gap Rd
Carlisle, PA 17013
(717)249-4525
3151 W Market St
York, PA 17404
www.nhsonline.org/AutismSchools.htm
- The Vista School
1249 Cocoa Ave
Hershey, PA 17033
(717)835-0310
www.thevistaschool.org

❖ Tutoring

- Attain Learning Center
608 Market Street
New Cumberland, PA 17070
(717)730-7070
Computer assisted help in math and reading

Supplemental Therapies

❖ Aquatherapy

- HealthSouth of Mechanicsburg
Esther Strader (717)790-8689

❖ Aromatherapy and Massage Therapy

- Capital Area Therapeutics
Monica Pageler (717)303-1776

❖ **Chiropractic**

- Becker Chiropractic
501 Market St, Lemoyne
(717)763-7711
Gentle adjustments on children, if necessary, focusing on restoring proper blood flow to the brain and optimum functioning of the central nervous system.

❖ **CranioSacral Therapy**

- Massage Therapy Associates
2507 Gettysburg Rd
Camp Hill, PA 17011
(717)920-9355
www.massagetherapyexperts.com
Delicate balancing of the central nervous system through the analysis of the cerebral spinal fluid. Gentle palpations release blockages throughout the body encouraging the natural healing mechanisms to engage.

❖ **Cognitive Therapy**

- William Thomas, psychologist
10 Curtis Drive, Carlisle
Therapy can also be done at Trindle Rehab on Trindle Road in Mechanicsburg
(717)249-1419

❖ **Hippotherapy and Therapeutic Horseback Riding**

- Capital Area Therapeutic Riding Association (CATRA), New Day Equestrian Center, Grantville (717)469-7517 or www.catra.net
- Easter Seals with Camp Hebron, Halifax (717)718-3510 or 1-888-273-7351.
- Franklin County Therapeutic Riding Center, Chambersburg (717)263-0443 or (717)263-9226
- Kidz 'n Motion – a program of the S. June Smith Center, Lancaster (717)299-4829 or contact Mary Beth Marzulli at (717)368-2656
- Lancaster County Therapeutic Riding (717)615-9222
- Quest Therapeutic Services, 461 Cann Rd, West Chester (610)692-6362 or www.questtherapeutic.com
- Rocking Horse Ridge Farm, Carlisle (717)243-1321
- Therapeutic Riding Association of Cumberland County (TRACC), Carlisle (717)245-2341 or www.helptracc.org

❖ **Hyperbaric Oxygen Therapy**

- Hyperbaric Oxygen Medical Center
255 N 6th St
Columbia, PA 17512

(717)684-3228 or 1-877-426-9943
www.hboxygen.freeyellow.com

❖ **Leg Up Farm**

Leg Up Farm is a proposed developmental and therapeutic center being built in York County for children with special needs and their families. (717)843-8341 or www.legupfarm.org.

❖ **Listening Therapies**

- The Davis Center
One Mannino Dr
Rockaway, NJ
1-888-257-5119 or (973)400-0010
www.thedaviscenter.com/
- HealthSouth of Mechanicsburg
(717)790-8689
They offer both Therapeutic Listening and Interactive Metronome Therapy.
- MyndWorks, Inc.
207 House Ave, Ste 105B
Camp Hill, PA 17011
(717)909-3773
Programs offered include Therapeutic Listening, SAMONAS, auditory training based on the Tomatis method, Earobics, Fast ForWord, and Interactive Metronome.
- The Spectrum Center of Maryland, Bethesda
(301)657-0988
www.spectrumcenter.net/
- Therabilities
4210 Linglestown Road, Harrisburg
(717)540-9218
www.therabilities.com
Therabilities offers Therapeutic Listening, Tomatis, The Listening Program, and Interactive Metronome Therapy.

❖ **Music Therapy**

- Living Unlimited Program (717)526-2111
- Elizabethtown College's Music Therapy Clinic
Dr. Gene Ann Behrens (717)361-1991 or behrenga@etown.edu

❖ **Social Skills Groups**

- Therabilities
4210 Linglestown Road, Harrisburg
www.therabilities.com
(717)540-9218

Offers social skills groups for ages 4-15.

- Prompt and Play
330 Kennet Pike Ste 207
Chadds Ford, PA
www.promptandplay.com
(610)388-7878

Offers various groups designed to promote social and developmental growth in children ages 3-18.

❖ **Vision Therapy**

When locating a Developmental Optometrist, ask them if they are an Associate Member or Fellow of either the College of Optometrist and Vision Development (C.O.V.D.) or Optometric Extension Program (O.E.P.)

- Joseph Bytof, OD
Dillsburg, PA – (717)432-4911
- Mitchell Davis, OD
Dillsburg, PA – (717)732-2423
- AJ Grieneisen, OD & Wayne Yorkgitis, OD
Carlisle, PA – (717)249-4948
- Christa Roser, OD
Dallastown, PA – (717)741-5531
- William Sisson, OD
Newport, PA – (717)567-3103
- Vision Learning Center of Greater Harrisburg
5012 Carlisle Pike, Mechanicsburg
(717)901-5917
- Vision Development Center
152 E. Main Street, Leola
(717)656-0534

Some of our families have been told to put their child in an institution. We're hoping for Harvard.

www.tacanow.com

 **Other Local Resources**

❖ **Access Program**

A new program was introduced in 2005 to help families in Lancaster County build accommodations to their homes to assist a family member with a disability. The program currently has funds available for families living in Lancaster City which allows the family to make their apartment or home more accessible for their child with a disability. Accommodations must be built into the existing structure and must be used for disability accommodations only. For more information, contact Kirk Hummel of United Disability Services at (717)391-6925.

❖ **Adventure and Special Days Together (ASD Together)**

ASD Together is committed to providing families living with autism spectrum disorder the opportunity to come together for special events and adventures. For more information regarding their upcoming projects, please visit their website at www.asdtogether.org or contact:

- 118 S Locust St
Shiremanstown, PA 17011
(717)763-7590

❖ **Advocacy and Resources for Citizens with cognitive, intellectual and developmental disabilities (ARC).**

For more information visit their website at www.thearcpa.org/ or contact:

- **Arc, Cumberland/Perry Counties**
PO Box 386
117 N Hanover St
Carlisle, PA 17013
Telephone: (717)249-2611
- **Arc, Dauphin County**
2569 Walnut St
Harrisburg, PA 17112
Telephone: (717) 920-2727
- **Arc, Lancaster County**
630 Janet Ave
Lancaster, PA 17601
Telephone: (717) 394-5251
- **Arc, Lebanon County**
VA Medical Center Bldg #27, 1st Fl
17005 Lincoln Ave
Lebanon, PA 17042
Telephone: (717) 270-5307
- **Arc, York County**
497 Hill St
York, PA 17403
Telephone: (717) 846-6589

❖ **A.H.E.D.D.**

Assisting people with disabilities and students in transition in obtaining competitive employment through pre-employment, job development, job coaching and follow-along services.

- 1834 Oregon Pk., Lancaster, PA 17601
(717)560-1000
www.ahedd.org

❖ **Angel Flight Mid-Atlantic**

A non-profit organization that provides air transport to specialized medical facilities for evaluation, diagnosis, treatment and rehabilitation. Patients needing help, call 1-800-296-3797 or go to www.angelflightmidatlantic.org.

❖ **Autism Insurance Info Group**

http://health.groups.yahoo.com/group/autism_insurance_information/

A new Yahoo! group has been established to discuss insurance issues. This group is open to all members of the Autism community, professionals and service providers. The purpose of the board is to share information and ideas on working with the system of insurance provisions, along with discussion on ways of ensuring that coverage is provided according to the laws that govern insurance, Medicaid and Tricare.

❖ **Autism Living and Working (ALAW)**

ALAW's goals are to secure the services and supports necessary to sustain the participation of adults with autism in the normal round of adult life and to enable adults with autism to form households apart from their parents. For more information, visit their website at www.autismlivingworking.org or contact:

- 11 S Forge Manor Dr
Phoenixville, PA 19460-2701
Telephone: (610) 935-9499
Fax: (610) 935-4320

❖ **Autism Society of America (ASA)—The Greater Harrisburg Area Chapter**

Meetings are held the second Thursday of every month at the Capital Area Intermediate Unit in Summerdale. A potluck dinner is held from 6:30pm-7:30pm with a topic or presentation from 7:30-8:30. Onsite childcare is available upon reservation. For more information, call (717)732-8400 ext.8408 or visit www.autismharrisburg.org.

❖ **Autism York**

This is a non-profit group comprised of parents, educators, therapists and friends, based in York, PA, which has come together to help make life easier for children and parents coping with autism and other pervasive developmental disorders. Meetings are generally held on the second Wednesday of every month at the York Learning Center from 12:30pm-2:00pm. They also offer a Yahoo group for ongoing support and exchange of information. For more information, visit their website at www.autismyork.org.

❖ **AutismLink Mentor Program**

AutismLink wants to help parents of newly diagnosed children with their mentor program. If you're the parent of a child with an autism spectrum disorder, you can go to www.autismlink.com/mentor and sign up to either find or become a mentor. AutismLink will pair you with someone in your area.

❖ **Baseball**

Challenger Little League is a program developed by Williamsport Little League and sponsored by Camp Hill Baseball to provide boys and girls with disabilities the opportunity to experience the fun of playing Little League Baseball. The game is designed to give all school-age children a chance to play, regardless of limitations. Games are played on Sunday afternoons at the Camp Hill Little League Facilities on 21st Street in Camp Hill. The season runs from mid-April to mid-June. For information, contact Ted Pauley at (717)944-2766.

❖ **Blue Hound Farm in Lewisberry, PA**

Children with disabilities can visit the farm and their animals. To set up an appointment or find out more information about their services, call (717)938-8159 or visit www.bluehoundfarm.com.

❖ **Canine Companions for Independence**

Non-profit organization that enhances the lives of people with disabilities by providing highly trained assistance dogs and ongoing support to ensure quality partnerships. For general inquiries regarding the Philadelphia Area Chapter, call 1-800-572-BARK (2275) or visit www.ccphiladelphia.com.

❖ **CARES (Children with Autism Resource Education and Support) Foundation**

The mission of this group is to provide education, support and resources for children with autism, their siblings, parents, caregivers, educators, and therapists. They currently sponsor a monthly support group. Contact them at (717)944-2277 or at <http://hometown.aol.com/caresfndtn>.

❖ **CCPP – Concerned Cumberland Perry Parents**

This organization is a group of Cumberland and Perry County families with children or adults who are mentally disabled. They have established a website at www.ccpparents.org to “enlarge our support system, share pertinent information, become advocates for our families locally and statewide, and have more fun times together.”

❖ **Center for Autism and Developmental Disabilities**

This is an outpatient program based in Lancaster that provides multidisciplinary evaluation and ongoing care addressing the emotional and behavioral needs of children adolescents and adults with autism spectrum and other developmental disorders. For more information, contact Dr. Michael Fueyo at (717)735-1920.

❖ **Classroom Plus Program**

This program from the PA Dept of Education offers grants for tutoring students struggling in reading and math. Grants are up to \$500 with approved tutors throughout the state. For more information, visit www.classroomplus.k12.pa.us/.

❖ **CONNECT**

Referral hotline for info about services for children with disabilities from birth to 21. They also provide lists of free literature. Call them at 1-800-692-7288.

❖ **Community Links**

The goal of Community Links is to “link” caregivers with everyday community learning opportunities...those places in which all children can grow, learn and have positive experiences. Community Links staff locates and compiles information about everyday community resources and learning opportunities, and activities for young children in Dauphin, Cumberland and Perry counties. The information is contained in a searchable database and allows a map to be generated, if available. You can visit their website at www.community-links.net.

❖ **Daniel’s Den**

A new fully accessible playground is coming to Lancaster County. In the Spring of 2008, “Daniel’s Den” will be introduced to the community and, more importantly, to children with disabilities. If you have any ideas or would like to help, please contact Lisa Seaman (Schreiber Center Parent) at lisaseaman@yahoo.com. For more information or to join a sub-committee for “Daniel’s Den”, please contact Denise Haldeman at dlhddh@verizon.net.

❖ **Dentists**

ASD HOPE has a list of local dentists who work with children on the autism spectrum. Please call the Helpline for more information at (717)732-8400 ext. 8120.

❖ **Disability Rights Network of Pennsylvania (DRN)**

DRN provides the full range of legal, policy and advocacy services necessary to protect and advance the rights of persons with disabilities. They can be reached at:

- 1414 N Cameron St, 2nd Fl
Harrisburg, PA 17103
1-800-682-7443
www.dlp-pa.org

❖ **Easter Seals**

For more than 70 years, Easter Seals has provided for and has been dedicated to meeting the needs of children and adults with disabilities. The Easter Seals mission is, "To help people live with equality, dignity, and independence." The Easter Seals South Central PA chapter serves the six counties of Cumberland, Dauphin, Lancaster, Lebanon, Perry, and York. Visit their website at www.visiteasterseals.org/ or contact them at: Easter Seals South Central PA 2201 South Queen Street, York, PA 17402 or by phone at 1-888-273-7351 or (717)741-3891.

❖ **Education Law Center**

Provides free telephone consultation, technical assistance and limited representation. Call (412)391-5225 in Pittsburgh or (215)238-6970 Philadelphia. Or, visit their website at www.elc-pa.org.

❖ **The GF Bake Shop**

719 New Holland Ave, Lancaster
Contact Arnold Angelillo at (717)490-6676 or visit gfbakeshop@comcast.net.

❖ **Gluten-Free Casein-Free Bakery**

Baking business dedicated to gluten-free baking, including some items that are also casein-free. Located just outside of Reading. Contact Cathy Caron or Rick Allebach at (610)670-4885 or visit their website at www.goodeatz.org.

❖ **Gluten-Free Source, LLC**

20 S Baltimore St
Dillsburg, PA 17019
(717)432-5100 or 1-800-514-5212
www.glutenfreesource.com

In this store, everything is gluten-free. They carry over 800 products from a variety of vendors, including two Pennsylvania gluten-free bakers. Internet orders and shipping is available.

❖ **Gymboree**

Gymboree offers developmental play programs (including music and art) for children from birth up to age 5. Many children with developmental disabilities will benefit from Gymboree's structured programs. Additionally, the site is available for parents to use as a place to conduct personal playgroups; one group of parents used the site to hold a weekly sensory integration playgroup based on the book The Out of Sync Child Has Fun. If you are interested in Gymboree's programs and/or if you would like to sponsor a sensory integration play group, please call them at (717)540-9335.

❖ **Haircuts**

Individuals with Autism Spectrum Disorder are often extremely sensitive around the head and scalp area. This, along with other sensitivities the child may have, can make getting a haircut a very difficult and uncomfortable task. However the mom listed below is not only a licensed beautician, but also has talent and first hand experience when it comes to cutting the hair of children with ASD. Contact Sue Brenner, Mechanicsburg (717)766-1413.

Another great location is Kids Kutters at (717)612-0312. They are located at 5010 Carlisle Pike in Mechanicsburg and offer a kid-friendly environment with toys in the waiting area and videos to watch during the haircut. The staff welcomes children with special needs.

❖ **Joni and Friends**

Working with churches for disability ministry, family retreats for families with disabled

family members, used wheelchair collection, support groups for people affected by disabilities.

- 5307 Main St
East Petersburg, PA 17520
(717)509-6170
www.joniandfriends.org

❖ **Keystone Children & Family Services (KC&FS):**

KC&FS offers a continuum of integrated services to children with ASD and their families. KC&FS employees have training in a variety of methods & interventions.

3700 Vartan Way
Harrisburg, PA 17110
(717) 541-9620
www.keystonehumanservices.org

- **Early Intervention Services** (Speech, Occupational, Physical and Developmental Therapy as well as Behavior Intervention).
- **Behavioral Health and Rehabilitation Services** (BHRS) including TSS, BSC, MT and Summer Therapeutic Activities Program (STAP).
- **Day Care** is offered at several locations in the Harrisburg area. Children are served in an integrated setting and staff members are able to provide support to children with disabilities.
- **Host Home** services provide temporary residential placement for children with emotional, behavioral or mental issues in licensed family settings.
- **Outpatient Behavioral Health Services** including psychological and psychiatric evaluations, multi-disciplinary Autism evaluations and outpatient counseling for both individuals and families.
- **Resource Library** provides a variety of books, DVD's and periodicals about a variety of topics including Autism, inclusion, IEP's, Behavior and other disabilities. The resource library also has a computer, Boardmaker® and PECS software available for families to use. A complete list of library resources can be found on the website.
- **Respite Care** services are offered to families with children receiving mental health case management services when a family or child needs some time apart for everyone's well being.
- **Susquehanna Service Dogs** raises, trains and provides service dogs to individuals with disabilities.

❖ **Lending Libraries**

- The Access Pennsylvania Database provides a way to search for resources across the state, which you can then request from your local library via an interlibrary loan. Their website is www.accesspa.state.pa.us/.
- Keystone Children & Family Services has a Resource Center with a variety of books, magazines, and DVDs that can be borrowed free of charge. Contact them at (717)541-9620 or visit www.keystonehumanservices.org/kcfs/kcfs_resourceLibrary.php.

- The lending library at UCP has more than 1,100 books, videos, and cassettes. The library is open to anyone and is free of charge. Categories include, but are not limited to, disability specific information, sibling issues, parenting, self-help, and special education. Contact them at (717)975-0611.

❖ **Martial Arts**

Jose Johnson Chinese Martial Arts & Wellness Center
2233 Paxton Church Road
Harrisburg, PA 17110
(717)540-5345
www.dowellness.com

This facility offers various classes, and the instructors have received training on Autism Spectrum Disorders. Programs include Little Heroes, designed especially for younger children ages 4-6, and Contemporary Wushu for people 7 through adult. Families are encouraged to train together. For more information, call and ask for Coach Jose or Coach Juli.

❖ **The National Autism Conference**

This conference is held annually in Pennsylvania (usually in August). The mission of the conference is to provide comprehensive, evidence-based information to assist educators and families in developing effective educational programming for all students with autism spectrum disorders. Currently it is held in State College and is available at a small charge to parents who live in Pennsylvania. For more information visit www.pattan.k12.pa.us or at www.outreach.psu.edu/c&i/autism/.

❖ **New Life Assistance Dogs**

Training service dogs to enable persons with physical disabilities to live more independent and meaningful lives, helping overcome architectural, service, and cultural barriers of society.

- 1901 Olde Homestead Ln., Lancaster, PA 17605
(717)397-1841
www.udservices.org/new_life_dogs.htm

❖ **Nutritional Counseling**

Kelly Dorfman, M.S., L.N.D., is a health program planner and nutritionist specializing in developing nutrition and lifestyle strategies to address autism. Contact her at (301)340-2239 or at kelly@kellydorfman.com.

❖ **PA Elks Home Service Program**

This program provides services by a registered nurse and/or medical care coordinator to Pennsylvania residents with a developmental disability at no charge. Their mission is to “support and promote the independence of individuals with developmental disabilities, by providing advocacy services in their home environment.” For more information, visit <http://www.paelks.com/files/homeserv.htm> or contact Theresa Crimmel at (717)436-8151.

❖ **PA Families Inc**

This is a statewide network of support groups for parents who have children with behavioral, learning, emotional, autistic, mental health, drug, alcohol, suicidal and other problems. They also support organizations and provide information important to the raising of special children. They can be reached by calling 1-800-947-4941 or by emailing pafamilies@alltel.net.

❖ **PA Health Law Project**

PHLP provides free legal services and advocacy to Pennsylvanians having trouble accessing publicly funded health care coverage or services. For assistance, call their helpline at 1-800-274-3258 or 1-866-236-6310 TTY; you can also e-mail them at staff@phlp.org.

❖ **Parent Education Network (PEN)**

PEN is Pennsylvania's statewide Parent Training and Information Center. Their goal is to support Pennsylvania parents of children with special needs. They can be reached by calling 1-800-522-5827. Their website is www.parentednet.org.

❖ **Parent to Parent of Pennsylvania**

Parent to Parent of Pennsylvania is a network created by families for families of children and adults with special needs. They connect families in similar situations with one another so that they may share experiences, offer practical information and/or support. You can reach them by calling the same number as the Special Kids Network 1-800-986-4550 and asking for Parent to Parent. Their website address is www.parenttoparent.org.

❖ **PaTTAN (Pennsylvania Training and Technical Assistance Network)**

This organization supports the efforts of the Bureau of Special Education and its initiatives and builds the capacity of local educational agencies to provide appropriate services to students who receive special education services. Visit their web site at www.pattan.k12.pa.us or call 1-800-446-5607.

❖ **Religious Services**

Daybreak Church in Mechanicsburg offers a “Special Stars” ministry where volunteers sit with children who have special needs in their Sunday School Classes. Many Special Education teachers from the Cumberland Valley School District attend this church and work as 1:1 volunteers in the classrooms. This offer is open to anyone. Their number is (717)791-1200 x112, and their website is www.daybreakweb.com, or you may email Alison Kubiak at allie@daybreakweb.com.

There are several other churches in the area who have or are planning to start a special needs ministry:

- Allison United Methodist Church, Carlisle. Contact Janet Borden at 243-5962 or jborden@allisonumc.org.
- CrossPoint United Methodist Church, Harrisburg. Contact them at 545-1911.
- Living Water Community Church, Harrisburg. Contact them at 564-5003.

❖ **Research Studies**

- The Kennedy Krieger Institute in Baltimore, MD and Dr. Rebecca Landa are currently conducting numerous research studies about autism, infant and toddler development, and siblings of children with autism. You can contact Kennedy Krieger toll free at 1-877-850-3372 to get more information about what research studies they are currently conducting.
 - You can also check the following website for listings of current research studies and clinical trials that are being offered: <http://www.clinicaltrials.gov>.
 - The University of Pittsburgh is also conducting studies. Contact Dr. Nancy Minshew at minshewnj@msx.upmc.edu.
- ❖ **Shared Support Inc.**
This group provides consultation and support for families and people living with autism. Their mission is to support people with autism and create a meaningful life. They focus on one person, one family at a time through the development of person-centered support services. (717)738-3175 or www.sharedsupports.us.
- ❖ **Sibling Support Group**
Offers opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context.
➤ 630 Janet Ave., Lancaster, PA 17601
(717)394-5251
www.TheArcofLancasterCo.org
- ❖ **Sibshops**
Sibshops provide opportunities for peer support to children between the ages of 6 and 12 who have a brother or sister with a disability. This is done within a lively, recreational context that emphasizes a kids'-eye-view. The program is provided by the Capital Area Children's Center (CACC) in Camp Hill. Contact them at (717)975-0611.
- ❖ **Soccer**
The National TOPSoccer (The Outreach Program for Soccer) is a community-based soccer program for young athletes with disabilities, organized in our area by the Lower Dauphin Soccer Association. Children ages 6 to 19 with disabilities are welcome to play; registration fee and scholarships available. For more information, call the Soccerline at (717)566-6950 or see <http://www.ldsoccer.com/lds/TopSoccer/index.htm>.
- ❖ **Spanish Language Resources**
➤ "Programas para Infantes y Ninos Pre-escolares con Discapacidades." NICHCY publication on Early Intervention – what it is and how to find it. Access it online at: www.nichcy.org/pubs/spanish/pa2stxt.htm
➤ A website created by families for families that provides information and support to Spanish-speaking families with children on the autism spectrum: www.manitasporautismo.com.

❖ **Special Education ConsultLine**

This service is part of the PA Dept of Education and provides help to families and advocates for children with special needs about school-related concerns, special education regulations and the complaint system. Call 1-800-879-2301 to leave a message for a specialist to call you back.

❖ **Special Kids Network**

Database that includes over 9,000 providers of specialized services for children and youth is linked on the Special Kids Network webpage. For a search over the phone, call them at 1-800-986-4550 or visit their webpage at www.health.state.pa.us/skn.

❖ **Special Olympics**

Special Olympics provides year-round sports training and competition opportunities for individuals from age 6 and up with intellectual disabilities. There is no cost to families. (Area M includes Cumberland, Perry, Dauphin and Northern York Counties.) Contact:

Special Olympics: *Area M*
PO Box 382
Summerdale, PA 17193
(717)732-6756
www.sopam.org

Special Olympics: *Lancaster County*
PO Box 7442
Lancaster, PA 17604-7442
(717)299-2930
www.specialolympicslancastercounty.com

❖ **Summer Programs**

- Aaron's Acres provides ongoing supportive, educational and recreational services to individuals with special needs ages 5-21 and their families. It was founded in 1998 in the Lancaster area and became available in Harrisburg in 2006. For more information, contact Risa Paskoff at (717)397-1841 or visit their website at www.udservices.org.
- Adams Hanover Counseling Services offers a program for high functioning children with autism. For more information call (717)657-2080.
- Carlisle Parks and Recreation has a summer "Playground Program" for children with special needs. It is open to children who live in Cumberland and Perry counties and also children enrolled in the Carlisle School District. Call (717)243-3318 for more information.
- Keystone Children & Family Services offers a Summer Therapeutic Activities Program (STAP) that is integrated with the YWCA's Camp Riley. It serves children within the CBHNP service area ages 6-12 with a DSM-IV behavior diagnosis. Contact Denise Romary at (717)541-9620.
- Milestones offers an 8, 9, or 10 week Summer Therapeutic Activities Program (STAP) from June to August. Participants must be ages 5-15 with a diagnosis on the Autism Spectrum. Contact Milestones Community Healthcare Inc. at (717)651-0016.
- Mynd Works has 2 week Buddy Camps in the summer for children ages preschool to early teens. Camp experiences will promote self-regulation, social-emotional growth, individual and group problem solving, and sustained interaction with others through

natural and developmental playful interactions. Contact them at (717)909-3773 or www.myndworks.org for more information; new clients will require an intake appointment to determine readiness.

- Schreiber Pediatric Rehabilitation Center offers a number of summer programs including Camp Schreiber which is filled with creative, fun activities for children with disabilities. There are multiple mini-camps including golf, volleyball, dance, bumper bowling, etc. There is a program called Waterworks which provides physical therapy-based activities in a recreational way. Swimming lessons are also available. Contact (717)393-0425 for more information.
- United Support Group offers Summer Enrichment which is summer day camp for school-age children ages 5-21. Recreational experience that reinforces skills that are learned in school. Call (717)392-5670 for more information.
- You may also wish to contact CBHNP or CCBH directly to discuss other Summer Therapeutic Activities Programs (STAP's) that may be available in your area, as they can vary from year to year.

❖ **Support Groups**

➤ **A Child's Heart**

Support, encouragement and prayer for parents raising children with emotional and behavioral challenges (ADD, ADHD, Autism, Etc.). Childcare provided. Meets on the 2nd & 4th Wednesdays from 7 - 9 pm at The Worship Center, 2384 New Holland Pk., Lancaster, PA 17601. Call (717)656-4271 or visit www.worshipcenter.org.

- **God's R.O.P.E. – Reaching Out to Parents of Extra Special Children** meets the third Saturday of each month, normally at Caring Community Church of God in Hummelstown. For more information, contact Teresa Zimmerman at (717)944-1522 or Godsrope@yahoo.com. The church phone number is (717)566-7970.

- **Managing Autism Together** is a support group for parents of children on the autism spectrum, formed to share ideas and information. Child care is not provided. The group meets from 6:30-8:30 pm on the second Monday of each month at the YWCA Carlisle on 301 G Street. Jody Eckenrode is the group leader. Call (717)243-3818 for more information.

- **Parents of Special Needs Kids (POSNK)** meets monthly on a Tuesday or Wednesday evening at the Grace United Methodist Church located on 433 East Main Street in Hummelstown. The parents meet together and the children go to another room where they are supervised by volunteers from the church. You do not need to be a member of the church or even attend there to take part in the support group. Call Sandy Grimes at (717)566-2897 for more information.

➤ **Lancaster County Asperger Syndrome Support Group**

This AS support group meets monthly to share support and information to families from Lancaster and Lebanon counties. Plans include new meeting formats, planning for

community services and group activities. Second Wednesday of the month at 7:00 PM.
Contact Tim and Alison Mekeel at (717)560-4095.

❖ **Swimming**

➤ **West Shore Branch YMCA**

410 Fallowfield Road

Camp Hill 17011

(717) 737-0511

email: wsymca@ymcaharrisburg.org

Offers individual/special needs swimming lessons and a Special Olympics swimming program.

➤ **Schreiber Pediatric Rehabilitation Center**

(717)393-0425

Offers 1/2 hour private lessons with certified Water Safety instructor – 6 week sessions.

❖ **UCP Central Pennsylvania**

➤ **Family Support Services** is a family driven program for parents, siblings, and extended families of children with disabilities. The goal of this program is to help families feel less overwhelmed and alone by acquiring the skills and knowledge they need to be better advocates for their child and reduce family stress.

➤ **Advocacy and Support**

Family Service staff is available to come to your home, school, or community site to provide support throughout the educational planning process for your child. An essential component of support includes the explanation of parental rights and special education regulations.

➤ **Information and Referral**

Information and Referral services are available for assistance with locating a variety of information, including but not limited to: community resources, disability specific information, and special education related information.

➤ **Lending Library**

The lending library has more than 1,100 books, videos, and cassettes. The library is open to anyone and is free of charge.

➤ **Parent Connections**

Volunteer parents are parents of children with disabilities who have expressed interest in supporting other parents that are experiencing similar circumstances.

For more information on **Family Services**, please contact: Roxanne or Terry at the Capital Area Children's Center, (717) 975-0611.

❖ **United Disabilities Services**

In-home personal care, service coordination, day programming, personal assistance dog training, information/referral service, summer day camp & respite, job training/placement, support services.

- 1901 Olde Homestead Ln., Lancaster, PA 17605
717-397-1841
www.udservices.org

❖ **United Support Group**

Social and recreational programs for children and adults with developmental and intellectual disabilities in Lancaster County.

- 935 E. Walnut Street, Lancaster, PA 17602
717-392-5670
www.unitedsupportgroup.org

❖ **United Way LINC**

Free and confidential information and referral service that quickly guides you to the agencies and programs in the Lancaster community that can help. For more information: (717)291-5462 or www.uwlanc.org

❖ **Vista Outreach Services**

Vista Outreach Services offer a range of services to support students with autism spectrum disorders and the professionals who serve them in central Pennsylvania. Services include Individual and Classroom consultative services; Direct services; and In-service training. For more information, contact Kendra Peacock at 717-835-0310 or visit the website at www.thevistaschool.org.

“One doctor’s Asperger Syndrome is another doctor’s PDD-NOS is yet another doctor’s high-functioning autism, is a speech pathologist’s semantic-pragmatic disorder, is an educational consultants’ nonverbal learning disability, is a psychologist’s personality disorder.”

The OASIS Guide to Asperger Syndrome

 **Dietary Intervention Information**

Gluten-Free & Casein-Free Diet

Background Information

The gluten and casein free diet is usually considered *the first dietary intervention* to be tried with a child. There are many researchers who believe there is a link between diet and autism; that is, that certain foods can cause some autistic behaviors. Primarily, the researchers believe gluten (the protein in wheat, rye, oats and barley) and casein (the milk protein) are extremely problematic for children with ASD. Many parents (including a number of local parents) have seen dramatic improvement in their children after starting the diet. Call ASD HOPE at (717)732-8400, ext. 8120 or email ASDHOPE1@yahoo.com to talk with a parent whose child is on this diet and who can help you get started.

Recommended Reading

- ❖ **Unraveling the Mystery of Autism and Pervasive Developmental Disorders**
by Karyn Seroussi
One mother's story of research and recovery for her son. Explains the casein and gluten-free diet in great detail.
- ❖ **Special Diets for Special Kids** by Lisa Lewis
Excellent cookbook for getting started and for keeping with the diet. Also has a very informative beginning section on the diet and vitamin therapies.
- ❖ **Children with Starving Brains** by Jacquelyn McCandless, MD.
A Medical Treatment Guide for Autism Spectrum Disorder. Written by a physician, this book provides a treatment guide for parents and doctors based upon the understanding that ASD is a complex biomedical illness resulting in significant brain malnutrition.
- ❖ **The Label Reader's Pocket Dictionary of Food Additives** by J. Michael Lapchick
A pocket-sized comprehensive quick reference guide to more than 250 of today's most common food additives. This book is out of print but some of the internet book stores (e.g. Amazon.com) are often able to locate copies.

Web sites for research

- ❖ www.autismNDI.com
- ❖ www.tacanow.com

Web sites for Gluten-Free Casein-Free Foods

- ❖ www.allergygrocer.com
- ❖ www.glutenfreepantry.com
- ❖ www.glutenfreemall.com
- ❖ www.ener-g.com

Feingold Diet

Background Information

This diet is based on the avoidance of all artificial colors and flavors, certain preservatives and a small but precise list of foods. Behavioral problems, such as hyperactivity, have been reduced or eliminated by adherence to this diet.

Recommended Reading

❖ **Why Your Child is Hyperactive by Ben Feingold**

Avoidance of all artificial colors and flavors, two preservatives and a small but precise list of foods. These are a lot of the “phenol” foods mentioned in the Serrousi book. Book has several good case studies and some recipes.

❖ **Why Can't My Child Behave? by Jane Hersey**

This book is an update to the 1974 book by Dr. Feingold and comprises 25 years of experience in the Feingold Association. You can view the table of contents and read the first 50 pages on the website listed below.

Web sites for research

- ❖ www.feingold.org

Specific Carbohydrate Diet (SCD)

Background Information

The Specific Carbohydrate Diet™ was designed for patients with intestinal diseases, but has been found by parents of children with autism to be beneficial, particularly those that have persistent or severe intestinal yeast overgrowth. This is more restrictive than the gluten and casein free diet.

Recommended Reading

❖ **Breaking the Vicious Cycle by Elaine Gottschall**

In order to effectively implement the Specific Carbohydrate Diet™, it is necessary to read Breaking the Vicious Cycle. The diet is not merely one of substituting one group of foods for another. The diet begins with a limited number of foods and gradually adds more foods as the intestinal tract heals.

Web sites for research

- ❖ www.pecanbread.com

Low Oxalate Diet

Background Information

There is some new research being brought to light by Susan Owens, a biomedical researcher, regarding oxalates. There seems to be a large number of individuals with Autism Spectrum Disorder, and consistent gut issues, who also have high oxalates. Susan is currently conducting studies finding that many individuals with high oxalates are responding very well, and very quickly, to a low oxalate diet.

Web sites for research

❖ <http://www.autismsolutioncenter.com/solution/diet.htm>

“If you’ve tried the diet and your child is a diet “responder,” you have great reason to be hopeful. If your child has a different sub-type of autism, it is up to you to look for his or her “magic bullet”—don’t wait for the medical community to do it for you! I believe the answers are out there, and that someday every form of autism will be found to be treatable. But I also believe it is the parents of these children who will lead us to the answers.”

From Unraveling the Mystery of Autism and Pervasive Developmental Disorder
by Karyn Seroussi

 **Biomedical Treatment Information**

Background Information

The majority of ASD children have underlying medical issues that are actually responsible for many of the autistic symptoms and behaviors. Treating these medical problems can provide dramatic improvements. This is a highly specialized area of medicine and therefore most family doctors and pediatricians will not be familiar with the treatment protocols. Currently there are 2 main choices for finding these uniquely qualified physicians:

DAN! Doctors

Since its establishment in 1967, the Autism Research Institute has had as a major priority the tracking of promising treatments for autism. Intensive study of the scientific literature, and analysis of case reports from thousands of parents of autistic children convinced ARI that there is much that can be done NOW to help many ASD children. Defeat Autism Now! (DAN!) conferences are held each Spring and Fall to further advance the treatment of autism.

The DAN! philosophy is that autism and related problems are the symptoms of dysfunction of the neural, immune and/or digestive systems which occur in individuals genetically sensitive to such factors as sub-optimal nutrition, food intolerances, microbial overgrowth and toxins. Appropriate treatment entails identifying and alleviating the problems causing the symptoms in that individual, rather than merely attempting to suppress the symptoms through the use of psychoactive drugs. ARI believes that a variety of educational and sensory integration methods are important therapies for ASD children but their primary interest and expertise is in the biomedical aspects of treatment. The current understanding of the biology of autism focuses on the following interrelated factors:

- Nutritional deficiencies
- Gut Dysfunction
- Microbial overgrowth
- Toxins
- Food intolerances
- Abnormalities in detox chemistry and immune function

A list of physicians and other practitioners who qualify as DAN! doctors can be found at <http://www.autismwebsite.com/ari-lists/danus.html>.

Pfeiffer Treatment Center

The Pfeiffer Treatment Center (PTC) is a not-for-profit medical research and treatment facility in Warrenville, Illinois specializing in research and treatment of biochemical imbalances. PTC is staffed by a team of physicians, practitioners, chemists and other professionals who specialized in the effects of biochemistry on behavior, thought and mood.

During each initial outpatient visit, a physical exam, a medical and social history, and laboratory tests are done to identify specific imbalances. An individualized treatment program is then created with the goal of restoring proper biochemical functioning. Treatment programs usually include vitamins, minerals, and amino acids. The biochemical treatment that Pfeiffer provides, based on the fact that each person has unique biochemistry, is result of extensive research and has proven very effective for patients. One of the few centers in the world with this biochemical focus, PTC has grown into a thriving clinic with patients from 70 countries. In addition, the center evaluates patients in other states during its outreach Clinics, one of which is held in Annapolis, MD.

Web sites for research

- ❖ www.autism.com
- ❖ www.hriptc.org
- ❖ www.greatplainslaboratory.com
- ❖ www.autismone.com

Autism IS treatable.

2004 DAN! Conference

Golden Nuggets

There are many other pieces of information that ASD HOPE members have learned simply through their experiences. The following outlines some important information that you might not necessarily find other places. They are arranged in **four categories: Financial Help/Information, Items You May Want To Buy, Additional Resources Not Elsewhere Listed and “Good to Know.”**

Financial Help/Information

❖ **Diaper cost coverage**

If your child is over three years of age and not yet potty trained, check with your Medical Assistance Insurance provider. They will most often cover the cost of diapers or pull-ups and you can have them delivered monthly to your home. You will need a prescription from your child’s primary care physician that must specify how many diapers per day and what size. Also if a specific type of diaper is needed due to allergies or any other reason, the physician will also have to write this on the prescription.

❖ **Family Driven/Family Support**

Ask your EI Service Coordinator or your MR Supports Coordinator if you are eligible to access family driven/family support dollars. These dollars are administered by the County Mental Retardation program and are very limited. If dollars are available, they can be used to help assist in related costs.

❖ **Family Grants**

The National Autism Society Helping Hands program offers financial grants of up to \$1500 to provide caregivers with financial assistance in getting necessary biomedical treatments, supplements and therapy services for their child with autism, as well as basic living expenses for families under extreme financial stress. Priority is given to single-parent families. For more information, contact them at 1-877-622-2884 or visit their web site at www.nationalautismassociation.org/helpinghand.php.

❖ **Insurance Tip**

Always ask anyone providing services or therapy for your child to use a diagnosis code specific to the reason for services, rather than simply listing autism.

❖ **Lower cost books**

Consider trying ebay, half.com or “Used Books” at amazon.com to purchase autism-related books. Many times parents will sell their copies of books after they have read them. Also, check out the local Autism Society of America lending library at 1-800-244-2425, ext. 8408 or your local community library.

❖ **Pfeiffer Treatment Center Hope Fund**

PTC has a charitable financial assistance program to help defray the cost of their medical and laboratory evaluation for qualifying recipients. For more information, call (630)505-0300 x222 or visit <http://www.hriptc.org/hope.html>.

❖ **Respite**

Some respite services, both in-home and out-of-home, may be available to CBHNP members. Eligibility can depend on the type of care currently being received, the type of respite needed and the funds available within the program. Respite Brokerage Services are administered through PA MENTOR, who can be reached at 1-800-765-0438 x120. Please see www.thementornetwork.com or call (717)657-2073 for more information.

❖ **Set up a Special Needs Trust**

A special needs trust is a way that money can be made available to a person with disabilities without jeopardizing government funding (like Social Security Income and/or Supplemental Security Income) and medical (like MEDICAID) benefits. An experienced lawyer can draw up the trust to prohibit its use in providing life or medical benefits, but allow its use for specified special needs. Proper legal wording is necessary so that no incidents of ownership can be construed to apply to the trust's beneficiary. The trust itself belongs to neither the grantor nor the beneficiary. It is a separate legal entity; a paper person, if you will. The trust directs the Trustee how to use its assets to provide for the special needs of the beneficiary. Two resources for more information: www.mcandrewslaw.com and www.specialplanning.com.

❖ **Transportation coverage**

If your child has a current active Medical Assistance Card (ACCESS), he or she may qualify for the Medical Assistance Transportation Program for the county in which you live.

Through this program, your child may be eligible for mileage reimbursement to help pay for the cost of taking him or her to medical appointments and therapy appointments. This program may also be able to provide transportation to your child's appointments if you do not have any other form of transportation available. Contact your county's Transportation Authority for information.

- In Dauphin County, call 1-800-309-8905 or (717)232-6104.
- In Cumberland County, call Cumberland County Transportation at 1-800-315-2546 or (717)240-6340.
- In Lancaster County, call (717)291-1243 or 1-800-892-1122.
- In Perry County, call Perry County Transportation Authority at 1-877-800-7433 or (717)567-2490.
- In York County, call York County Transportation Authority at 1-800-632-9063 or (717)845-7553.

❖ **WIC Benefits**

Parents and caregivers may be eligible to receive WIC benefits without regard to family income if they have a child with special needs who is under the age of 5 and if they have a PA Access Card for the child. The WIC program gives families monthly food packages that may include milk, fruit juice, peanut butter, cheese, eggs, dried beans and peas, cereal, infant

formula and special formula when medically necessary. Health and immunization screenings are also included in WIC services. If you are interested in finding out more about this program and to find a WIC office near you call 1-800-942-9467.

Items You May Want To Buy

❖ **Autism Awareness “Business Cards”**

If your child has meltdowns in public that cause others to stare and/or pass judgment, you can buy or create "business cards" to hand to onlookers.

Sample language includes: *Our son has Autism, a severe language and behavioral disorder. He sometimes becomes confused, disoriented, or upset and may throw temper tantrums or scream. We are committed to teaching him how to function in the community and would appreciate your patience and understanding. If you would like to learn more about Autism please feel free to contact us or the American Autism society (1-800-3Autism).*

You can do an internet search for "My Child Has Autism business cards" if you want to purchase some pre-made ones or find other sample language to use in printing your own.

❖ **Autism Awareness Jewelry**

Sharon Spears
Artisan Adornments
1460 Ryland Dr, Mechanicsburg
www.autismawarenessjewelry.com
gardenmirth@yahoo.com

Offers a variety of autism awareness products and jewelry, with several original, hand-made designs.

❖ **Autism Awareness Material**

You can get a lot of autism-related items including awareness bracelets, t-shirts and pins, along with books, videos and occupational therapy items at www.autismshop.com. NOTE: There are other shops on the internet; this seems to be one of the more comprehensive sites. ASD HOPE does not endorse this site over any other on-line store, nor does ASD HOPE take any responsibility for your experience with this vendor. This information is simply provided for your convenience.

❖ **Curvy Herbie and Straight Nate: A Lesson in Curved Line Thinking**

This book was written and published by a local mom of a child with autism, based on a concept used by her son's speech therapist. It is available through the Exploding Pen Productions website at http://www.joeybearsmom.com/wst_page4.html or by calling (717)877-3853.

❖ **Different Roads to Learning**

Sells learning materials for children with developmental delays and challenges.
www.difflearn.com

❖ **GFCF Playdough**

Discount School Supply has a product called Colorations Wheat- and Gluten-free Dough. They can be reached at www.discountschoolsupply.com or by calling 1-800-627-2829.

❖ **Identification tags**

If your child is prone to wandering off, you may want to consider some form of identification that would give your child's diagnosis and/or any other special needs as well as name and address information. Some professionals recommend a medic alert bracelet. You can also consider a tag that could be placed on his or her belt loop or shoes. For bracelets that cannot be removed, see www.projectlifesaver.org. There is also an electronic monitoring system, called Angel Alert, which beeps when your child strays outside a certain radius. (Search "Angel Alert" on the internet for providers.) Lastly, there are also child safety harnesses that can be used to keep your child close by when you are outside the home.

❖ **Language Development Videos/DVDs**

For excellent video tapes and DVDs that help to promote language development visit www.babybumblebee.com or call 1-888-984-5500. There is also a video tape entitled "Talking Hands" that teaches children sign language. For more information about the "Talking Hands" video call 1-800-521-5311 or visit www.small-fry.com

❖ **Social Songs CD**

"My Turn, Your Turn" is an excellent CD developed to "gently address the needs of children who find social interaction confusing or challenging...Songs touch on empathy, asking for help, handling anger, and other daily social skills." Visit www.rivannamusic.com.

❖ **Speech & Skill Development Resources**

Special Kids is a company founded by the parent of a child with autism which has produced several videos and other materials to assist with learning necessary skills and vocabulary. An example is the DVD "Let's Go To", which highlights trips to the doctor, dentist, haircut, grocery store, library and more. They also have a free e-newsletter. Visit them at www.special-kids.com or call 1-800-KIDS-153.

❖ **Super Duper Inc.**

www.superduperinc.com This is an excellent web site for buying educational materials that are fun and creative and specifically designed for children of all ages and learning abilities. Products range from flash cards to software. You can specifically target troublesome learning areas such as pragmatic skills, fluency, grammar, math, etc.

Additional Resources Not Elsewhere Listed

❖ **Alternative sources for gross motor skill development**

Consider alternative approaches to supplement any occupational therapies your child may receive. Local gymnastics centers, martial arts programs and/or children's gyms can offer excellent programs that help a child with gross motor skill development.

❖ **Government contacts**

In your role as an advocate for autism-related issues, you may at some point want to contact a member of your legislature. Here are some helpful sites to help you determine how to contact your government representatives.

- www.legis.state.pa.us
Site contains a link so you can find your state legislators.
- www.house.gov
Contains a link so you can find your Representative in Congress.
- www.senate.gov
Contains a link so you can find your Senator in Congress.

❖ **Monitor your child's progress**

Your child's services will most likely come from a variety of sources. In order to effectively evaluate the progress, he or she is making, keep notes on your child's development and progress. Videotape your child if possible.

You may also want to create your own form that tracks progress of the particular area you are working on. For example, you might want to have all of your child's service providers provide comment on areas such as eye contact, social interaction and/or focus for that particular session or class. Use information from a diagnostic evaluation to determine what areas you'd like feedback on. A standardized form (that you'll probably have to create) can help provide you with valuable clues regarding your child's progress in certain areas.

Another helpful place to track the success of a certain intervention is on the ARI website. They provide an Autism Treatment Evaluation Checklist (ATEC) that can be used by parents, doctors and/or researchers to track the success of virtually any autism treatment. For more information and the on-line scoring form, see <http://www.autism.com/ari/atec/index.htm>.

❖ **Other web sites of interest**

There are MANY web sites with a great deal of information. However, here are some sites of interest that have been identified as helpful sources of information by ASD HOPE parents.

- www.autismlink.com
Provides a place on the internet that gathers information from ALL organizations and puts it in one place. Offers a way to meet and talk to other parents in your area as well as a network of parents of children with autism who can help guide you.
- www.childnettv.com
This site has info and videos—you can view of presentations by such noted experts as

Temple Grandin or parents like Dan Marino. The videos change periodically. An easy way to "attend" a presentation from your home!

- <http://home.att.net/~coultervideo/index.htm> or www.coultervideo.com
Excellent videos on Asperger's Syndrome.
- http://www.learningabledkids.com/IEP_training/IEP_training_sitemap.htm
An online course designed to familiarize parents and teachers with IEPs, including what information is supposed to be included and what requirements exist for each section. It also discusses how to write each section properly.
- www.oddsandfriends.typepad.com/askanaspie
Students at the University of Chicago who have Asperger's Syndrome and High Functioning Autism will answer your questions from an "Aspie's" point of view. Email any questions to AskAnAspie@gmail.com.
- www.poac.net
Based in New Jersey, this organization does have sites in York, PA. Founded in 1999, POAC's mission is to improve the lives of children and adults with autism by providing scientifically-based training to parents, teachers, and other direct service providers.
- www.temple.edu/lss/cpie
This is a consortium for Parent Information and Education. It is helpful in understanding the public school system and services.
- www.wrightslaw.com
Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities. Wrightslaw includes thousands of articles, cases, and free resources on dozens of special education topics.

❖ **Printable Charts & Crafts**

DLTK's Sites, www.dltk-kids.com, has customizable charts that can be used for chores, homework, potty training or many other uses. Click on "Search DLTK's" and type in charts. They also have coloring pages, crafts and other resources.

❖ **Potty Training help**

See www.tinkletonz.com for information on a new special training pant that is being developed specifically for children with autism. Visit the website and click on "toilet-potty training for autistic children."

❖ **Sibling Support**

For some excellent information on helping children deal with a sibling who has autism, check out the web site <http://www.thearc.org/siblingsupport/welcome>.

❖ **Social Stories**

Social stories can help your child adjust to his or her environment and also learn to better adjust to new circumstances and transitions, if needed. Many therapists will use this approach. However, if you would like to create your own, you can visit the web site www.do2learn.com. Also, there is an excellent resource book for school-related social stories, called "The Social Skills Picture Book" by Jed Baker.

“Good to Know”

❖ **Amusement Park Help**

If your child has significant difficulty waiting in line, many theme parks will allow you to use the handicapped entrances that bypass a long wait in line. You must have a doctor’s note to use this option at most parks. ASD HOPE strongly encourages you to use this benefit ONLY if your child NEEDS this additional help in order to enjoy his/her time at the amusement park. Some amusement parks, such as Hersheypark, will allow a parent of a child with a disability who is purchasing a season pass for him or herself to have it designated as a “Companion Pass.” This pass would not have the parent’s photo and could be used by another adult who is taking the child to the park.

❖ **Be prepared for meetings**

Prepare for meetings with service providers and medical professionals by reviewing your notes and writing down your questions. Also, consider bringing someone else along to assist you or your child during any meetings or doctor’s visits.

❖ **“Child Finder” Window decal**

You may want to contact your local fire company to get a "child finder" decal for your child's bedroom window and to alert them there is a person with a disability at your address. You can also explain any specific concerns regarding your child and how he or she might react in an emergency situation. It is also a good idea to notify your local police. In Cumberland County, you can register so that any 911 call from your address will trigger special information to those responding and better prepare them for dealing with your child.

❖ **One at a time**

While it may be tempting to try a number of different interventions at one time, it’s important to only start one treatment option at a time. By doing so, you can evaluate the effectiveness of that particular treatment.

❖ **Paperwork tips**

You will need to refer to various documents about your child quite often. In order to do this effectively, set up a filing system and keep everything, including records of all phone conversations, meetings and conversations about your child. Put all requests in writing. Go by the philosophy, “If it’s not written down, it doesn’t exist.”

❖ **Premise Alert form**

A new “Premise Alert form” gives families with special needs the ability to notify first responders before a crisis and have critical information on file at the 911 center in their area. This form assists first responders by giving them advanced information, both medical and behavioral, that helps them be better prepared and knowledgeable before they enter a residence or interact with an individual with special needs. This advanced knowledge leads to more accurate assessments of the situation. The more first responders know about a situation or individual before hand the more likely they will achieve a positive outcome during the interaction. You can access this form through the www.asaphilly.org website by clicking on

the Police and Safety button. For more information, contact Susan F. Rzucidlo at (610)274-2364.

❖ **Special Diet tip**

If you are using a special diet, have your doctor write a "prescription" for the diet that will allow you to bring your child's special food into many different places without a problem.

Most of the frustration in raising an autistic child comes at the moments of hopelessness. When it feels as if nothing can be done. When Fate seems overwhelming and unmerciful. The burden of raising a special child became easier when we acknowledged that there was a job for us as well, an important and valuable job. Life became lighter when we realized that we could make a difference.

“The Dragons of Autism: Autism as a Source of Wisdom”
by Olga Holland

Action Plan

Once you have heard about all the treatment options and interventions available to you, it can seem to be even more overwhelming in deciding what to do next. ASD HOPE recommends that you take time to plan what steps you will take. To do this you can create an action plan that identifies specifically what you will do and by when. To create a successful action plan, you want to write your plan so it is:

Specific (The more specific you can get, the better off you'll be.)

Measurable (Determine a way that you'll know when you've met the goal.)

Achievable (Create an action plan step that you know you can accomplish.)

Realistic (Consider your schedule and needs to make it a reasonable goal.)

Timebound (Identify a date "by when" you will accomplish the action plan steps.)

Action Step #1:

What specifically do you want to accomplish?

How will you measure it?

Is it achievable and realistic?

By when will you accomplish it?

Action Step #2:

What specifically do you want to accomplish?

How will you measure it?

Is it achievable and realistic?

By when will you accomplish it?

Action Step #3:

What specifically do you want to accomplish?

How will you measure it?

Is it achievable and realistic?

By when will you accomplish it?

Appendix A – “Autism 101”

Autism 101: Some Basic Information

Autism is a complicated disorder, and it sometimes seems as if there are more questions than answers. If you are new to the diagnosis, you may have questions about the diagnosis itself. Your family and friends will more than likely ask questions when you tell them about it. In this Appendix, we would like to share some basic information about the diagnosis.

What Is The Definition of Autism?

The definition of autism is really rather simple.

Autism is a neurodevelopmental disability.

Simple. But what does it mean?

'Neuro' means the brain and all of the nerves and the entire nervous system. Development refers to the growth process of an organ or the body over time. And finally, a disability is an impairment affecting day-to-day living.

So, autism is a condition that affects the normal growth of the brain so that the individual has difficulty with day-to-day living....

And the good news is that **treatments are available** to improve the function of the brain!

In addition, autism is the **general term for the five Pervasive Developmental Disorders (PDD)**.

The word 'autism' is derived from the Greek word 'autos' which means self. Your child often appears to exist in a **world of their own**.

The neurological impairments occur in the areas of **communication skills, social skills, and repetitive and stereotypic behaviors (stimming) , activities and interests**. Each individual will exhibit various symptoms in different degrees over the course of their development.

“What Is The Definition of Autism” copied with permission from
<http://www.autism-in-the-christian-home.com/definition-of-autism.html>

Autism is a *spectrum disorder*, which basically means that each individual is affected differently in specific areas and in severity of symptoms. You may hear the term Pervasive Developmental Disorder (PDD) used to describe the entire category because this is how it is labeled in the diagnostic manual. The more correct term is **Autism Spectrum Disorder (ASD)**.

Under the umbrella of ASD, there are different labels that professionals use to distinguish the severity or number of “autistic” traits in an individual. These labels include Autistic Disorder, Asperger’s Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Rett’s Syndrome and Childhood Disintegrative Disorder. Each of these disorders has specific diagnostic criteria which have been outlined in the American Psychiatric Association's Diagnostic & Statistical Manual of Mental Disorders (DSM-IV-TR).

No matter what the specific diagnosis is, an individual with any of these labels is considered to be on the autism spectrum because they have some of the following traits:

- Insistence on sameness; resistance to change
- Difficulty in expressing needs, using gestures or pointing
- Repeating words or phrases in place of normal, responsive language
- Laughing (and/or crying) for no apparent reason showing distress for reasons not apparent to others
- Preference to being 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
- Spinning objects
- Obsessive 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
- Non responsive to verbal cues; acts as if deaf, although hearing tests in normal range.

(List taken from the Autism Society of America website – www.autism-society.org)



Autism Spectrum Disorder
Help, Options & Parent Empowerment

PARENT INFORMATION BOOKLET EVALUATION FORM

Please take a few moments to complete the following evaluation form in order to help us better serve families of children with an Autism Spectrum Disorder.

1. In general, how helpful was this Parent Information Booklet?

Very Helpful Helpful Somewhat Helpful Not helpful

2. Which part of this Parent Information Booklet was most helpful to you?

3. Did this booklet provide you with the information you were anticipating?

4. Do you feel the information provided will be beneficial to you and/or your family? Please explain.

5. Do you have any suggestions as to ways in which ASD HOPE could change this booklet to better serve you and your family's needs?

6. How did you find out about the ASD HOPE Parent Information Booklet?

Please mail completed form to ASD HOPE, P.O. Box 1501, Mechanicsburg, PA 17055.

Thank you!