



**PARENT INFORMATION
BOOKLET**

*A Message of Hope
For You and Your Child*

www.autismharrisburg.org

Autism 2014 Edition



About The Autism Society

Mission Statement

Our Mission

Improving the lives of all affected by autism

Our Vision

The Autism Society is the leading voice and resource of the entire autism community in education, advocacy, services, research and support. The Autism Society is committed to meaningful participation and self-determination in all aspects of life for individuals on the autism spectrum and their families. The Autism Society accomplishes its ongoing mission through close collaboration with a successful network of affiliates, members and supporters.

Autism Society Mission Areas – Core Competencies

The development of five “core competencies” as a means to implement the Autism Society’s Mission and Vision is proposed in the Autism Society’s new strategic plan. Those areas include: *Advocacy, Education, Support, Services, Research*

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Disclaimer: This information booklet includes information Autism Society parents “wish we had known when our children were first diagnosed.” It comes from a variety of sources and, while we believe 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.

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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.** 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 AS parents and caregivers have learned through experience.

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!

Personal Stories

The following are personal stories from two moms with kids on the spectrum:

Kathleen's story:

Our first shock was having twins (boy & girl). The second shock came when our son was diagnosed with autism at 33 months. We already had a speech and occupational therapist coming in to work with him because of his delays. Five weeks later I stumbled across the book "Unraveling the Mystery of Autism and PDD" by Karyn Seroussi, which detailed the casein and gluten, free diet and how her son recovered.

After 3 days off of dairy my son started pointing at things he wanted and saying "this or "that." Four days off of dairy the ST and OT remarked that his eye contact was "phenomenal." A week later we removed the gluten (plus artificial colors, flavors and preservatives) and everything began dramatically & quickly improving. The fog had started to lift and we saw an increase in muscle tone, social interaction, energy, sleep and his constipation was gone. All four of us adopted his diet and have never looked back.

Six months later we started our journey with the supplements from the Pfeiffer Treatment Center. And more drastic improvements followed. One week after starting the B12 shots, he came home from preschool and could tell us everything that happened. We have been working with a DAN! doctor the last several years in addition to Tomatis listening therapy, which greatly improved his attention and focus in school. Today, at 10, he is and has been in regular education, is happy, outgoing and enjoying life.

Do we believe in recovery through biomedical interventions? Absolutely! Thousands of families across the country have a child that is living proof. While we do have a few hurdles or speed bumps to cross, we know for sure that he wouldn't be anywhere near where he is today without the gf/cf diet and vitamin supplements. There is a proven connection between the gut, individual biochemistry and neurological functioning. You can piece that puzzle together for your child too!

Kathleen Haigh

Parent

President, Autism Society

Seble's story:

My son was 4 years old when he was diagnosed with Autism. At that time, even if we were aware of the signs that are considered red flags we had logical explanations to justify and brush off most concerns. Like most families the diagnosis was a huge shock. When we left the office, we were confused, shocked, in denial and experienced all kind of emotions and didn't know where to start to look for answers. I'm very thankful that we were given the copy of Autism Society Parent Information Booklet because it gave me an idea of where to start. I read Kathleen's and Trish's stories of message of hope multiple times as I began my search. Their stories gave me the hope I desperately needed at that time.

Few days after the diagnosis, we took casein away from his diet and he started responding when we were calling his name right away. A week later we took gluten from his diet and within few weeks the clouds covering him were lifted. After a month of being gluten/casein free, we started biomedical treatment under the care of a doctor. With Methyl B12 injection and individualized biomedical treatment plan(supplements) we saw continuous progress in social interaction, speech, focus and attention. In addition, we witnessed dramatic gain in auditory processing after Berard AIT. These interventions allowed other conventional treatments such as speech therapy and social skills achieve notable results.

From our own and others experience throughout the world, we have seen to believe that autism is not only a neurodevelopmental disorder. Many times there are underlying biological, toxicological, immunological and gastrointestinal conditions and when these problems are treated the results are phenomenal.

Today he is a happy, joyful, funny, loving, caring child who likes to play and be around his family and peers. He is a quick learner and a delight to be around. He continues to surprise us with something new he does or learns each day. We can't say the journey has been easy, but the results are what any parent could possibly hope for. Autism is treatable. And yes, with treatment comes hope and recovery.

Seble Getahun
Parent

“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 68 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 guidebooks 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? Autism Society'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 Autism Society 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. The Autism Society 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.

The Autism Society 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 50 children 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 (888) 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 or Lebanon County, call the Lancaster-Lebanon Intermediate Unit at (717) 606-1600.
- 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 that The Autism Society believes may be helpful 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 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 (866) 366-3361 (Monday-Friday 8am-12pm 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.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** – We are the largest and oldest national organization advocating on behalf of Americans with autism. The Greater Harrisburg Affiliate 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 our website at www.autismharrisburg.org. The National 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 AS 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. The Autism Society sells this book at cost for \$10. If you have read the book and want help getting started and/or maintaining the diet, contact The Autism Society 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.org 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:

- **“MAPS Doctors”** are physicians who have taken the place of the former DAN! Protocol. MAPS (The Medical Academy of Pediatric Special Needs), is dedicated to focus on the testing and treatment of individuals with ASD so they are able to better understand the disorder, and have more knowledge on how to treat it. This organization wishes to ensure that the care your child will be receiving will be from factual and evidence based information, and that all physicians using this approach will deliver the best quality care possible. For more information, visit www.medmaps.org.
- **The Pfeiffer Medical Center**, successor to Pfeiffer Treatment Center, is an outpatient facility for children and adults specializing in the evaluation and management of biochemical imbalances, which may be associated with the symptoms of developmental, learning, and behavior disorders or anxiety, depression or mental illness. Their innovative approach of using vitamins, minerals, and other nutrient supplements to treat biochemical imbalances has helped thousands of patients lead a more productive and rewarding life.

PMC has more than 20 years of experience in personalized biochemical therapy to safely restore the balance of nutrients required for normal function of the brain as well as many other organs and tissues. Combined with behavioral, educational, medical, and dietary therapy, biochemical therapy is a critical piece of the puzzle to treat the symptoms of autism. Their caring medical team includes physicians, nurses, and pharmacists to support you and your child. In addition, the center (located in Warrenville, IL) evaluates patients in other states during its outreach clinics, one of which is held in Annapolis, MD. PMC can be reached by calling (630) 505-0300, (866) 504-6076 or by visiting www.hriptc.org.

- **The Great Plains Laboratory, Inc.**, also offers outreach clinics for children and adults with Autism, PDD, ADHD, Allergies, Immune Dysfunction, Behavior Disorders, Lyme Disease and Chronic Fatigue. To find out if more information, log onto www.greatplainslaboratory.com or call (800) 288-0383.

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.

The PA Autism Insurance Act (Act 62) does require some employers to include autism as a covered diagnosis. You can obtain more information about this act and what it may mean for you at www.dpw.state.pa.us/foradults/autismservices/paautisminsuranceact62 .

Please see “Resources for Obtaining a Medical Assistance (ACCESS) Card” in this information booklet for more details on this process.

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 APPROVED** for Medical Assistance (see number 6 above) before you can apply for Behavioral Health Rehabilitation Services.

Once your child is approved for Medical Assistance, you can contact your area’s Behavioral Health Plan to begin accessing services for your child and/or family. 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 the Autism Society 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 Autism Society Helpline at 1 (800) 244-2425 Ext. 8408 or email at www.autismharrisburg.org 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-(888) 727-2706. The local number for this region of Parent to Parent is (717) 540-0263. 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.

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.

The Autism Society 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**

P.O. Box 5959
2432 N 7th Street
Harrisburg, PA 17110-0959
Phone: (717) 787-2324 or (800) 788-5616
Fax: (717) 787-3040

❖ **Cumberland County Assistance Office**

33 Westminster Drive
Carlisle, PA 17013-0599
Phone: (717) 240-2700 or (800) 269-0173
Fax: (717) 240-2781

❖ **Lancaster County Assistance Office**

P.O. Box 4967
832 Manor Street
Lancaster, PA 17604
Phone: (717) 299-7411 or (800) 732-0018
Fax: (717) 299-7565

❖ **Perry County Assistance Office**

P.O. Box 280
100 Centre Drive
New Bloomfield, PA 17068
Phone: (717) 582-2127 or (800) 991-1929
Fax: (717) 582-4187

❖ **York County Assistance Office**

P.O. Box 15041
130 N Duke Street
York, PA 17405-7041
Phone: (717) 771-1100 or (800) 991-0929
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 or Screen for 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/PAselfservice to compare the four plans. Currently there are four insurance plans to choose from. These insurance companies are:
 - Aetna Better Health 1-866-638-1232
www.aetnabetterhealth.com/pennsylvania/default.aspx
 - AmeriHealth Caritas Pennsylvania 1-888-991-7200
www.amerihealthcaritaspa.com
 - Gateway Health Plan 1-800-392-1147
www.gatewayhealthplan.com
 - United Healthcare Community Plan 1-800-414-9025
www.uhcommunityplan.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

NOTE: 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 an outpatient or community therapist may also assume this role, 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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Note: Some children may qualify for a Home Health Aid or Nurse. Please see additional information in Therapy resources.

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

The Stepping Stones is one of the first 1:2 clinically and therapeutically based programs to be offered to children/adolescents who are diagnosed with an Autism Spectrum Disorder. The program was created as an alternative to traditional, more intensive (1:1) in home BHRS services. Staff works with participants in 1:2 ratio, in both the structured group setting and the community setting. The Stepping Stones Program is specialized for children/adolescents ages 3-14 who are diagnosed with an Autism Spectrum Disorder. Sessions are grouped by age 3-7 and 8-14. Participation must be deemed medically necessary by a licensed evaluator and may be prescribed a maximum of 15 hours per week. Stepping Stones can be provided in conjunction with BHRS services.

The **NHS Stepping Stones Program** provides participants with opportunities to transfer learned skills to a new environment. The site-based component of the program is highly structured and allows participants to transition within small peer groups throughout a variety of targeted activities. Interactive play skills are enhanced through participation in large group activities. Community-based activities offer participants the opportunity to generalize their skills across a variety of community settings, as well as increase their tolerance to changes in routine and enhance their safety awareness.

This service can be approved in addition to other wraparound services, but it must be listed as a specific recommendation on your child's evaluation. For more information, contact Cumberland County at (717) 243-6033 or Dauphin County at (717) 238-1565

Mental Health/Intellectual & Developmental Disabilities Offices. (formerly Mental Health/Mental Retardation)

For additional help, you can contact your county's Mental Health/Intellectual & Developmental Disabilities (MH/IDD) 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/Intellectual & Developmental Disabilities (MH/IDD)**

Phone (717) 240-6320 or (888) 697-0371 ext. 6320

❖ **Dauphin County Mental Health/ Intellectual Disabilities (MH/ID)**

Phone (717) 780-7050

❖ **Franklin/Fulton County Mental Health/Intellectual Disabilities/Early Intervention Program (MH/ID/EI)**

Phone (717) 264-5387 or (800) 841-3593

How to Apply for Behavioral Health Rehabilitation Services

❖ **Lancaster County Mental Health/ Intellectual Disabilities/Early Intervention (MH/ID/IE)**

Phone (717) 299-8021

❖ **York-Adams County Mental Health/ Intellectual & Developmental Disabilities (MH/IDD)**

Phone (717) 771-9618 or 1-800-441-2025 (press 3, then 4)

The following outlines the process that will occur in order to request Behavioral Health Rehabilitation Services:

1. The first thing you will need is a psychological or psychiatric evaluation in which specific services will be recommended for your child. You can contact your Behavioral Health Plan directly to locate an evaluator or arrange the evaluation with the help of your child's MH/MR caseworker (if you have one).
2. At the evaluation, you will be given a provider choice form. You can take it home to review, but the process will be delayed until it is returned. If a BHRS provider is doing the evaluation, you may want to choose them just to make the initial process go smoothly. (You can always switch providers at a later date if you wish.)
3. The evaluator will write up the evaluation and forward it to the chosen provider. That agency will then schedule a meeting to discuss the recommendations in the evaluation with you and any others who are working with your child, such as a preschool teacher or daycare provider.
4. 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.
5. If services are denied, there is an appeal process. Once services have been approved, your chosen provider will contact you to schedule an intake and assign staff to your child.
6. Things to Know:
 - Make sure to request that a copy of the evaluation be sent or given to you directly. This is not automatic, and your BHP cannot give it to you.
 - You can easily switch BHRS providers at any time if the one you have chosen does not have staff or there are problems that cannot be resolved. Your BHP can also assist with complaint resolution if needed.
 - In Pennsylvania, these services can be authorized for up to twelve months for individuals with an Autism Spectrum Disorder. The evaluator must include this request in the final evaluation, or the parents/caregivers will need to have services re-approved every four months.

How to Apply for Behavioral Health Rehabilitation Services

BHP Contact Information:

- The BHP for Cumberland, Dauphin, Lancaster, Lebanon and Perry Counties is PerformCARE, formerly known as CBHNP (Community Behavioral HealthCare Network of Pennsylvania). 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.
- The website for PerformCARE is <http://pa.performcare.org>.

“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.org>
- ❖ <http://www.autism-resources.com/advice-to-parents.html>
- ❖ <http://www.autism.com/autism/first/adviceforparents.htm>
- ❖ <http://www.tonyattwood.com.au>
- ❖ <http://www.autismone.org>

*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
Asperger's...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. 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 - <http://www.isaac-online.org>

Auditory Integration Training (AIT)

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

The Sound of a Miracle by Annabelle Stahl

Society for Auditory Intervention Techniques - www.berardaitwebsite.com/sait

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)/Floor time

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

Floor time 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)

Healing the New Childhood Epidemics: Autism, ADHD, Asthma, and Allergies: The Groundbreaking Program for the 4-A Disorders by Kenneth Bock and Cameron Stauth

Facilitated Communication (FC)

Facilitated Communication Institute –

soe.syr.edu/centers_institutes/institute_communication_inclusion/

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

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.autismtreatmentcenter.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.nvic.org
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

The Autism Notebook – (South Florida)

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

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 9).

Biomedical and Dietary Interventions

❖ MAPS Doctors

To find a MAPS doctor near you, visit www.medmaps.org and proceed to “clinician directory”.

❖ The Pfeiffer Medical Center

The Pfeiffer Treatment Center (PMC) 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.

❖ The Great Plains Laboratory, Inc.

The Great Plains Laboratory has also offered outreach clinics for children and adults with Autism, PDD, AD (H) D, Allergies, Immune Dysfunction, Behavior Disorders, Lyme disease and Chronic Fatigue. To find out if more information, log onto www.greatplainslaboratory.com or call (800) 288-0383.

❖ Center for Holistic Medicine

- Dr. “Kathy” Ferraro
Dr. Ferraro is an MD that is board certified in emergency medicine and integrative holistic medicine. Her services include treatments for Autism, nutrition, holistic medicine, and more
9 Brookwood Avenue, Carlisle, PA 17015
(717) 243-0616
www.cnrholisticmed.com

❖ Homeopathic Therapy

- R. Eric Doerfler, PhD, CRNP
Nightingale Health and Wellness Services
1521 Cedar Cliff Drive, Suite 203, Camp Hill
(717) 761-6902

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) 901-9906

- NHS Autism Schools
Carlisle: 898 Waggoners Gap Rd, (717) 249-4525
<http://schools.nhsonline.org/Carlisle.html>

Chambersburg: 2593 Philadelphia Avenue, (717) 261-1163
<http://schools.nhsonline.org/chambersburg.html>

Harrisburg: 6003 Jonestown Road, (717) 657-0149
<http://schools.nhsonline.org/harrisburg.html>

York: 3151 West Market Street, (717) 792-2304
<http://schools.nhsonline.org/york.html>

- The Vista School
1021 Springboard Dr.
Hershey, PA 17033
(717) 583-5102
www.thevistaschool.org

- Soaring Heights School
Leg Up Farm
480 N. Sherman St. Ext.
(717) 384-6490
www.soaringheightsschool.com/york/about-us

❖ Tutoring

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

Supplemental Therapies

❖ Aqua therapy

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

www.beckerchiropractic.com

Gentle adjustments on children, if necessary, focusing on restoring proper blood flow to the brain and optimum functioning of the central nervous system

➤ Susquehanna Chiropractic
Tonia Hess DC
423 Limekiln Dr.
Chambersburg, PA 17021
(717) 263-3345 or (717) 263-0533 (fax)
www.susquehanna-chiropractic.com

➤ Camp Hill Family Chiropractic
Dr. Jeff Ludwick
157 S 32nd Street
Camp Hill, PA 17011
(717) 761-8840
www.camphillchiro.com

Dr. Jeff is a wellness and pediatric Chiropractor, certified educator, nutritional consultant, wellness and motivational speaker. His focus is to enhance the health of families by improving their spinal structure, nervous system and nutrition naturally.

❖ CranioSacral Therapy

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.

➤ Search for local therapists in the area that provide this specific therapy.

❖ Cognitive Therapy

➤ William Thomas, psychologist
10 Curtis Drive, Carlisle
(717) 249-1419

Therapy can also be done at Trindle Rehab on Trindle Road in Mechanicsburg

❖ **Hippo therapy and Therapeutic Horseback Riding**

- Capital Area Therapeutic Riding Association (CATRA)
New Day Equestrian Center, Grantville
(717) 469-7517
www.catra.net.
- Camp Hebron
957 Camp Hebron Road, Halifax
(717) 896-3441, toll free 1-(800)-864-7747, or hebron@camphebron.org
- Chasing Rainbows Therapeutic Equine Facility
6844 Wertzville Road, Enola
(717) 433-0768
www.chasingrainbow.org.
- Franklin County Therapeutic Riding Center
181 Franklin Farm Lane, Chambersburg
(717) 263-0443
<http://www.horseridingtherapy.org>.
- Greystone Manor Therapeutic Riding Center (Lancaster County Therapeutic Riding)
1063 Hartman Station Road, Lancaster
(717) 615-9222 Call to schedule a visit.
<http://greystonemanortrc.org>.
- Quest Therapeutic Services
461 Cann Rd, West Chester
(610) 692-6362
www.questtherapeutic.com.
- Therapeutic Riding Association of Cumberland County (TRACC), Carlisle
(717) 701-7331 or ridewithtracc@gmail.com
www.ridewithtracc.org.
- Graceful Acres, Non-profit.
193A Ridge Rd, Halifax PA.
Call owners Jon Mattis (717) 215-1768 or Adam Mattis (717) 805-2348

❖ **Hyperbaric Oxygen Therapy**

- Center for Holistic Medicine
Dr. "Kathy" Ferraro
9 Brookwood Ave
Carlisle, PA 17013
(717) 243-0616
www.cnrholisticmed.com

- 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 developmental and therapeutic center in York County for children with special needs and their families.

4880 N. Sherman St
Mount Wolf, PA 17347
(717) 266-9294 or www.legupfarm.org.

❖ **Listening Therapies**

- The Davis Center
19 State Route 10 E, Ste 25,
Succasunna, NJ 07876
(862) 251 4637
www.thedaviscenter.com/
- HealthSouth of Mechanicsburg
(717) 691-3700
They offer both Therapeutic Listening and Interactive Metronome Therapy.
- MyndWorks, Inc.
3333 N. Front St
Harrisburg, PA 17110
(717) 233-1681
<http://www.jfsofdbg.org/>
Programs offered include Therapeutic Listening, SAMONAS, auditory training based on the Tomatis method, Earobics, Fast ForWord, and Interactive Metronome.
- 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

❖ **Play Therapy**

The P.L.A.Y Project has a location in Lancaster County, which has licensed providers of what is called The P.L.A.Y. Project (stands for Play and Language for Autistic Youngsters), which is a DIR/Floor time based model of treatment. (717) 371-7953

❖ **Social Skills Groups**

- Mynd Works
207 House Ave, Ste 105B
Camp Hill, PA 17011
(717)909-3773
www.myndworks.org

- Therabilities
4210 Linglestown Road, Harrisburg
www.therabilities.com
(717)540-9218
Offers social skills groups for ages 4-15.

- Stauffer Psychological Services
500 Rising Sun Rd
Millersburg, PA 17061
www.spsychserv.com
(717) 692-5200
Small groups for mild difficulties on the spectrum. These services include after school groups and private pay summer groups.

- 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
Enola, 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 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

❖ **Accessible Playgrounds**

- Adventure Park Playground is located at 1775 Lambs Gap Road in Hampden & Silver Spring Townships. Visit www.adventurezoneplayground.com for more information.
- Daniel's Den is located on the campus of Manor Church, 530 Central Manor Rd, south of Mountville. More information is available at www.danielsdenplayground.org/.
- Possibility Place is located at the intersection of Nyes Road and Heatherfield Way in George Park in Lower Paxton Township. For more information, visit www.possibilityplace.org.

❖ **Advocacy and Resources for Citizens with Cognitive, Intellectual and Developmental Disabilities (ARC).**

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

- **ARC, Cumberland/Perry Counties**
71 Ashland Avenue
Carlisle, PA 17013
Telephone: (717) 249-2611
- **ARC, Dauphin/Lebanon Counties**
2551 Walnut St
Harrisburg, PA 17103
Telephone: (717) 920-2727
- **ARC, Lancaster County**
630 Janet Ave
Lancaster, PA 17601
Telephone: (717) 394-5251
- **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
- 3300 Trindle Rd, Camp Hill, PA 17011
(717) 731-5485
ahedd.org/Harrisburg

❖ **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.

❖ **ASERT (Autism Services, Education, Resources, and Training)**

ASERT is a statewide initiative funded by the Bureau of Autism Services, PA Department of Public Welfare. PAautism.org is designed to bring together existing resources for families, providers, and self-advocates, and allow them to access a broad array of information to help meet the needs of those living with or serving people with autism.

For more information, visit their website at www.pautism.org or call (877) 231-4244.

❖ **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:

8 Penn Center – Suite 1600
1628 John F. Kennedy Blvd
Philadelphia, PA 19103
(267) 322-5800

❖ **Autism Spectrum Connections**

The mission of ASC is to provide families and professionals opportunities to network with the support of local resources, while fostering awareness of individuals with autism throughout the Susquehanna Valley. For more information, visit their website at www.autismspectrumconnection.org or contact:

Liz Carotto
(717) 471-4530
liz@autismspectrumconnections.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 at 6pm. They also offer two message boards on Google Groups. 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 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 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.

➤ **Camp Hill**

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.

➤ **Dillsburg**

This division practices one night a week and then plays other Challenger teams. For information, contact Mike Junkins at (717) 503-6537.

❖ **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 <http://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.cci.org

❖ **Center for Autism and Developmental Disabilities**

This is an outpatient program based in Lebanon 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) 273-8871 or (800) 932-0359.

❖ **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. 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.

❖ **Dentists**

These local dentists have been recommended by other parents as being good with children on the autism spectrum. You will need to contact each office to discuss your child's individual needs, as well as confirm payment and insurance information. You can also contact your MA health plan directly to obtain an authorization for a dentist that can work with your special needs child.

➤ **Children's Dental Centre of York**

York: (717) 741-0848

Will accept Medical Assistance/Gateway

They have several accommodations for sensory needs, including a Velcro “caterpillar” wrap, lead blankets, nitrous-oxide, and private, dimly-lit rooms.

➤ **Dr. Blummenfield**

Hamilton Health Center, Harrisburg: (717) 230-3909

He will often refer ASD children to Dr. Cramer in Hershey.

➤ **Dr. Robert Cramer**

Hershey: (717) 520-0123

Office sets aside a certain time for appointments for special needs kids.

Will accept Medical Assistance/Gateway with a referral.

➤ **Dr. Grater**

Harrisburg: (717) 657-3326

➤ **Kearns and Ashby**

Harrisburg: (717) 558-9830

Mechanicsburg: (717) 737-5834

Office sets aside a certain time for appointments for special needs kids.

➤ **Dr. Rana Mathias**

Parkside Dentistry, Elizabethtown: (717) 367-2423

Will accept Medical Assistance/Gateway

➤ **West Shore Family Dentistry**

Camp Hill: (717) 737-4321

Will accept Medical Assistance/Gateway.

❖ **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, Suite C

Harrisburg, PA 17103

1-800-692-7443

www.drnpa.org

❖ **Easter Seals**

The Easter Seals mission is to provide "exceptional services, education, outreach, and advocacy so that people living with autism and other disabilities can live, learn, work and play in our communities." Easter Seals Central Pennsylvania offers a variety of Therapeutic Recreation programs such as aquatics, basketball, climbing, cooking programs, a fishing derby, golf, horseback riding, snow skiing, social groups, summer camps, water skiing and much more.

Easter Seals Central PA is currently providing Therapeutic Recreation services in Cumberland, Dauphin, Lancaster, Lebanon, Perry and York counties. For additional information please visit their website, www.eastersealscentralpa.org, or contact them at:

- 3029 N. Front St
Harrisburg, PA 17110
(717) 901-3993

- 2250 Kingston Rd, Suite 219
York, PA 17402
(717) 741-3891

❖ **Education Law Center**

Provides free telephone consultation, technical assistance and limited representation. Call (412) 258-2120 in Pittsburgh or (215) 238-6970 Philadelphia. Or, visit their website at www.elc-pa.org.

❖ **Gluten-Free Casein-Free Bakery**

- Good Eatz Bakery
VF Outlet Center, Designers Place Level 1
739 Reading Ave, West Reading, PA 19611
Contact Rick Allebach at (610) 670-4885 or visit their website at www.goodeatz.org.
Baking business dedicated to gluten-free baking, including some items that are also casein-free.

- Betsy's Bakery
115 St. John's Church Road, Camp Hill, PA 17011
(717) 730-9900
Offers an array of gluten free bakery items.

❖ **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) 600-8006 (York location) or (717) 735-0660 (Lancaster location).

❖ **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. Located at 321 Hummel Avenue in Lemoyne, 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.

- 340 Highland Drive, Suite 200
Mountville, PA 17554
(717) 522-1467
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.

124 Pine Street

Harrisburg, PA 17101

(717) 232-7509

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.

❖ **Links2Care/Loving Care Agency**

Links2Care (sister agency to Loving Care Agency) provides home healthcare services for special needs and medically fragile children and adults. Our highly qualified team includes nurses, pediatric clinicians, homecare aides and therapists. We work with most major insurance plans, managed care organizations, Medicaid and waiver programs and state agencies. Links2Care has offices in Chambersburg, Harrisburg, Lancaster & York. For further information, visit <http://www.links2care.com>.

❖ **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 for 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.outreach.psu.edu/programs/autism

❖ **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 *by providing advocacy services in their home environment* 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, suicide and other problems. They also support organizations and provide information important to the raising of special children. They can be reached by emailing pafamilies@comcast.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 or 1-800-441-5028 (Spanish). 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 (888) 727-2706 and asking for Parent to Parent. The local number for this region of Parent to Parent is (717) 540-0263. 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.net or call (717) 541-4960 or (800) 360-7282.

❖ **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. Contact them at (717) 791-1200, and ask for Linnea Hollander or visit their website at www.daybreakweb.com.

Several other churches in the area that have or are planning to start a special needs ministry:

- Carlisle United Methodist Church, Carlisle. Contact them at (717) 249-1512
- Christian Life Assembly, Camp Hill. Contact them at (717) 737-6560.
- West Shore Evangelical Free Church, Mechanicsburg. Contact them at (717) 697-0226.

❖ **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.

❖ **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.

❖ **Sibling Support Group at Aarons Acres**

Siblings between the ages of 9-12 can attend a support group that will address the challenges that might arise as a result of having a brother/sister with developmental disabilities.

Through a variety of interactive games and activities, the siblings will be able to form a supportive network with others in similar situations. This group will run at the same time as each respite session. The size of the group is limited to 8 children. The Sibling Support

Group currently meets only in Lancaster. Contact Risa Paskoff, Director of Aaron's Acres (717) 917-6101 or risapaskoff@aaronsacres.org

❖ **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, visit <http://ldsoccer.com/home/home.asp?pgm=TOPS>

❖ **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

❖ **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 17093
(717) 732-6756
www.sopam.org

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

❖ **Special Planning, LLC**

Estate planning and financial guidance for families of individuals with special needs. For assistance with special needs planning, including a special needs trust and letter of intent, contact William Parker or Elizabeth Silbaugh Johnides at 1-877-768-2384 or visit www.specialplanning.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) 917-6101 risapaskoff@aaronsacres.org or visit their website at www.aaronsacres.org True North Wellness 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.
- 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) 233-1681 or www.jfsofdbg.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.
- Easter Seals provides multiple programs for individuals with disabilities and their families to have equal opportunities to learn, work, and play in their communities. For more information, call (717) 901-3993 (Harrisburg location) or (717) 741-3891 (York location). Or, visit their website at <http://westernpa.easterseals.com/>
- Summer Therapeutic Activities Programs (STAP's) may be available in your area through Medical Assistance. Contact PerformCARE (formerly CBHNP) or CCBH directly to discuss these, as they can vary from year to year.

❖ **Support Groups**

➤ **Adult Social Groups**

Spectrum Friends adult social groups hold monthly meetings, and organize events and other activities for adults in the area that are on the spectrum. For Spectrum Friends Harrisburg, go to: <http://bandsforautism.com/friends/floor/events/events.php>. For Spectrum Friends Lebanon, contact Dave Knauss at dcknauss@verizon.net.

➤ **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 1st & 3rd Thursdays from 7 - 9 pm. Please contact Ted or Lydia Ann Zeiset at (717) 445-7090 for the location.

- **Asperger/High-Functioning Autism/PDD-NOS Support Group**
This group meets on the 1st Tuesday of each month at the JFS, 3333 N Front St, Harrisburg. Childcare is available. For more information, call Rachel at (717) 233-1681 or email Sally Jo at iteachesl@comcast.net.
- **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 Lori Sadler at (717) 545-7719, or GodsROPEofHope@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. The YWCA Carlisle on 301 G Street is attempting to find a new facilitator for this group, and recommends that you call (717) 243-3818 for more information.
- **Parents of Special Needs Kids (POSNK)** meets monthly 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 a new meeting format and community services. The group meets the Second Wednesday of the month from 6:00 to 8:00PM at 790 New Holland Ave in the Grantview Plaza. Contact Tim and Alison Mekeel at (717) 560-4095 or tmekeel@aol.com .
- ❖ **Swimming**
 - **West Shore Branch YMCA**
410 Fallowfield Road, Camp Hill 17011
(717) 737-0511
email: susan.newman@ymcaharrisburg.org
Offers individual/special needs swimming lessons and a Special Olympics swimming program.
 - **Schreiber Pediatric Rehabilitation Center**
625 Community Way, Lancaster, PA 17603
(717) 393-0425
Offers 1/2-hour private lessons with certified Water Safety instructor – 6-week sessions.
- ❖ **United Cerebral Palsy of 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** 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 Disability Services**

Offers a network of programs that assist individuals with disabilities to become integrated into all aspects of life and areas of our society.

Phone: (717)397-1841, or Toll Free (800) 995-9581

www.udservices.org.

➤ **Access Program**

The 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) 397-1841.

➤ **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

<http://www.udservices.org/newLife.asp>

➤ **Youth Sports and Recreation**

United Disabilities Services will be developing a Challenger Football league in the Lancaster County area. If you would like more information please contact Ray Bianchini at 717.397.1841 or rayb@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

❖ **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 consultant’s 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 the AS at 1-(800)-244-2425 ext. 8408 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.

Web sites for research

❖ www.autismNDI.com

❖ www.tacanow.org

Web sites for Gluten-Free Casein-Free Foods

❖ www.glutino.com

❖ <http://www.celiac.com/glutenfreemall/>

❖ www.ener-g.com

❖ www.vitacost.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

- ❖ <http://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
❖ <http://www.bachflower.com>
❖ <http://strongestminds.com>

“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:

MAPS 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. After much research, the ARI had decided to conclude the “Defeat Autism Now” approach, and begin a new organization: “MAPS”.

“**MAPS Doctors**” are physicians that were created in place of the DAN! (Defeat Autism Now) protocol. MAPS (The Medical Academy of Pediatric Special Needs), has dedicated to focus on the testing and treatment of individuals with ASD so they are able to better understand the disorder, and have more knowledge on how to treat it. This organization wishes to ensure that the care your child will be receiving will be from factual and evidence based information, and that all physicians using this approach will deliver the best quality care possible. While MAPS continues to test different information, the current understanding of the biology of Autism remains the same by focusing on the following factors:

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

MAPS doctors can be found at www.medmaps.org and proceeding to the “clinician directory” to find a MAPS doctor near you.

Pfeiffer Medical Center

The Pfeiffer Medical Center, formerly known as the Pfeiffer Treatment Center, is a not-for-profit medical research and treatment facility in Warrenville, Illinois specializing in research and treatment of biochemical imbalances. PMC 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, PMC 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

- ❖ <http://autism.com/>
- ❖ www.greatplainslaboratory.com

Autism IS treatable.

2004 DAN! Conference

Golden Nuggets

There are many other pieces of information that we 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

❖ **Andrew’s Gift**

Andrew’s Gift is a nonprofit publicly foundation which provides benefits for individuals of all ages with autism spectrum disorders (ASD) who live in Dauphin, Cumberland and Perry counties. Grants are provided for a variety of areas, focusing on technology, therapies and respite care. For more information, visit www.andrewsgift26.com.

❖ **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/family-support/programs/helping-hand/

❖ **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. TACA has a good article with lots of informative links on the topic of insurance:

<http://www.tacanow.org/family-resources/health-insurance-coverage-on-a-budget/>

The PA Dept of Public Welfare has also set up a website to provide ongoing information on the PA Autism Insurance Act (Act 62), which went into effect July 1, 2009. The address is www.dpw.state.pa.us/foradults/autismservices/pautisminsuranceact62/s_000937

❖ **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.

❖ **Respite:**

One of the greatest needs that a parent, or primary caregiver, of a person with a disability has is the need for respite – a break from providing care 24 hours a day, seven days a week.

➤ **Cumberland Perry Respite (CPR)**

CPR was formed when a group of parents along with The ARC of Cumberland and Perry Counties (CPARC) and United Cerebral Palsy of Central PA (UCP) were confronted with the need for increased services. CPR provides a safe, secure, and stimulating social setting for individuals with intellectual disabilities, granting family members much-needed respite.

• ***UCP of Central PA Friday Evening Program***

Children ages 3 and up, and adults with disabilities can join UCP’s Friday Evening program. Respite runs from 6 – 10 pm at 3 locations: Mechanicsburg and Shippensburg run on the 1st and 3rd Friday of each month; Carlisle on the 2nd and 4th Friday. Participants must fill out an application at <http://www.cumberlandperryrespite.com/apps/documents/> before scheduling attendance. For more information, or to schedule attendance, contact Kathy Seiderer at 717-737-3477 or kseiderer@ucpcentralpa.org. The cost for this program is **\$37 per participant**, per Friday night. Available funding options:

1. **Autism Society Greater Harrisburg Area.** Current Autism Society (National) members can attend FREE of charge 12 times a year*, siblings included. Proof of AS membership must be provided during application. (*policy subject to change)
2. **Department of Public Welfare Autism Mini Grant.** The DPW through the Bureau of Autism Services is offering up to \$500 in mini-grants which can be used for respite care. www.dpw.state.pa.us/foradults/autismservices/index.htm
3. **Cumberland & Perry County I.D.D. Base Funds.** If you are registered (have a case) with the Cumberland Perry County Office of Intellectual and Developmental Disabilities, contact your Support Coordinator to find out about base funding for the Friday Evening Respite Program or go to <http://www.ccpa.net/index.aspx?NID=2518>.

• ***UCP of Central PA Overnight Program***

UCP’s Overnight Program at Branch Creek Neighbors Program in Shippensburg. Overnight respite is designed to give you an extended break from care giving. Contact Barry Claypool of UCP at 717-737-3477 for details.

➤ PA MENTOR/Respite Brokerage Services

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

➤ The ARC of Dauphin County

The ARC of Dauphin and Lebanon Counties' respite program using The ARC's Harsco House is available for use by residents of Cumberland and Perry counties. Limited base funding is available and is given on a first come first serve basis. To schedule your respite or for further information: <https://www.box.net/shared/4ucizpvtvfmtx91k9xu3>

➤ Easter Seals Central PA Respite Programs

Easter Seals offers a variety of respite programs from camps to recreational opportunities.

Contact **Liz Bunting**, Program Coordinator for further information at 717-591-7027 or ebunting@eastersealscentralpa.org.

➤ Youth Advocate Program (YAP)

Youth Advocate Program provides respite care for all ages. If you qualify for behavioral health services (BHRS), or currently receive services (such as TSS support) through PerformCARE (CBHNP), you can receive FREE in-home respite services or out-of-home respite services. For further information, contact YAP at 717-232-3786

❖ 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

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. We do not endorse this site over any other on-line store, nor do we 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 www.explodingpenproductions.com/ or http://www.joeybearsmom.com/wst_page4.html or by calling (717) 877-3853.

Curvy Herbie and Straight Nate also have a MySpace page:
http://www.myspace.com/curvyherbie_straightnate

❖ **Different Roads to Learning**

Sells learning materials for children with developmental delays and challenges.
www.difflern.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 personalized wristbands that emit a tracking signal, see <http://projectlifesaver.org/site/>.
- 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 videotape entitled "Talking Hands" that teaches children sign language.

- Teach 2 Talk
Teach 2 Talk provides resources that assist with speech, language, play, and social skills. They have an array of DVDs available for whatever your child's needs may be. For more information, please call 1-888-683-2242, or visit www.teach2talk.com.

❖ **Model Me Kids Video Modeling DVDs and Social Skills Curriculum**

Model Me Kids videos demonstrate social skills by modeling peer behavior at school, on a play date, at a birthday party, on the playground, at a library, restaurant, and more. Real children model and narrate each skill. Visit <http://www.modelmekids.com/> for more info.

❖ **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. 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 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://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.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."

❖ **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. We strongly encourage 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 beforehand 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 (610) 358-5256.

❖ **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. We recommend 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)

