



FAMILY BEHAVIORAL RESOURCES
FAMILY FOCUSED THERAPY

After the Diagnosis:



A Comprehensive Guide to Additional Resources for Families Affected By Autism (Revised Summer 2006)

If you do not see a resource or listing for your area,
please contact your local FBR office, the Family Support Coordinator,
or the Corporate Director of Autism Services.

We will make every attempt to meet your needs.

Family Behavioral Resources - Autism Services
Toll Free Number: 1-866-4-FBR-ASD
Fax Number: 724-861-0444
Email address: FBRAutism@aol.com
www.familybehavioralresources.com



Introduction

This guide is meant to support those individuals who have received a diagnosis of an Autism spectrum disorder; this may include Autism, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger's Syndrome and other related diagnoses. Our target audiences for this guide are those individuals and family members who have begun to "navigate the system." For example:

- ✓ Your child has seen a psychologist or other evaluator
- ✓ Your child has an ACCESS card (or applied for Medical Assistance)
- ✓ You have selected a wraparound provider and had their initial Interagency Service Planning Team (ISPT) Meeting)
- ✓ You have begun to accept the diagnosis, and would like additional supports and information
- ✓ You are ready to take the "next steps" in treating your child – through early intervention/preschool, outpatient therapies, and more

It is our hope that families will find our guide educational and informative. We have made extensive efforts to provide the most comprehensive information and listings in relation to Autism treatments, therapies, and providers. We realize that we may have overlooked some organizations, facilities, or important resources. If this is the case, please let us know what we have missed so we may share that information with the community.

Family Behavioral Resources is dedicated to providing support to children and families affected by an Autism spectrum disorder. We believe that Autism is treatable with early intervention and treatment. Our team of Regional Directors of Autism Services and Autism Coordinators are committed to providing support to children on the spectrum not just through wraparound services, but also by training and supervising other clinicians in a variety of modalities. Our Family Support Coordinator partners with the Autism Team to develop community outreach efforts, such as partnering with school districts to develop Autism support classrooms, offer workshops, and provide resource packets that promote Autism awareness and education.

If you would like more information about Autism, or about the services that FBR can provide to you and your family, please do not hesitate to contact:

Rick J. Murray, LSW, BCBA, Corporate Director of Autism Services
Catherine A. Hughes, Family Support Coordinator
8960 Hill Drive
North Huntingdon, PA 15642
1-866-4-FBR-ASD or 724-861-4700 (Office)
724-861-0444 (Fax)
FBRAutism@aol.com (Email)
www.familybehavioralresources.com

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If you have general concerns about behavioral healthcare in Pennsylvania, contact:

Department of Public Welfare – Office of Mental Health and Substance Abuse
Health & Welfare Building
Room 502, PO Box 2675
Harrisburg, PA 17105-2675
717-787-6443
www.dpw.state.pa.us/omhsas/dpwmh.asp

Department of Public Welfare – Office of Mental Retardation
Health & Welfare Building
Room 512
PO Box 2675
Harrisburg, PA 17105-2675
717-787-3700
www.dpw.state.pa.us/omr/dpwmr.asp

PA Health Law Project
Toll-Free HelpLine 1-800-274-3258
www.phlp.org

Behavioral Health – Managed Care Organizations:

You can contact your local behavioral health managed care organization, and ask for your Care Manager if you have questions about the efficacy of your child’s behavioral services provided by *HealthChoices*. A managed care organization is set up for every county in Southwestern PA, and they service families who receive medical assistance for their child resulting from a formal diagnosis from an approved practitioner.

Community Care Behavioral Health
One Chatham Center
Suite 700, 112 Washington Place
Pittsburgh, PA 15219
(Allegheny County only) 1-888-251-CCBH (2224)
www.ccbh.com

Value Behavioral Health
520 Pleasant Valley Road
Trafford, PA 15085
Armstrong 1-877-688-5969
Beaver 1-877-688-5970
Butler 1-877-688-5971
Fayette 1-877-688-5972
Greene 1-877-688-5973
Indiana 1-877-688-5974
Lawrence 1-877-688-5975
Washington 1-877-688-5976
Westmoreland 1-877-688-5977
www.valueoptions.com

Early Intervention:

Early Intervention, or EI units can help you find preschool classrooms for children with developmental delays and special needs. An independent evaluator typically assesses developmental needs and delays by screening the child by means of a Multi-Disciplinary Evaluation. EI units can also assist families with arranging occupational, speech, and physical therapy evaluations, as well as vision and hearing tests. Therapeutic preschool classes are completely funded for children ages three to five who present at least a 25% cognitive delay. These classrooms typically emphasize play skills and socialization. Most children with an Autism spectrum disorder qualify for these services.

Allegheny Intermediate Unit
(Allegheny County)
475 East Waterfront Drive
Homestead, PA 15120
412-394-5700
www.aiu3.org

Alliance for Infants and Toddlers
(Allegheny County)
The Hough Building
2801 Custer Avenue
Pittsburgh, Pennsylvania 15227
412-885-6000
www.afit.org

ARIN Intermediate Unit 28
(Armstrong and Indiana Counties)
2895 W Pike
Indiana, PA 15701-9769
724-463-5300
www.iu28.org

Beaver Valley Intermediate Unit
(Beaver County)
225 Center Grange Road

Aliquippa, PA 15001
724-774-7800
www.bviu.org

Midwestern Intermediate Unit IV
(Butler County)
453 Maple Street
Grove City, PA 16127
724-458-6700
www.miu4.k12.pa.us

Intermediate Unit 1
(Fayette, Greene, and Washington Counties)
One Intermediate Unit Drive
Coal Center, PA 15423
1-800-328-6481 or 724-938-3241
www.iu1.k12.pa.us

Westmoreland Intermediate Unit
(Westmoreland County)
RR12 Box 205
Donahue Road
Greensburg, PA 15601
724-836-2460
wiu.k12.pa.us

(You can also contact your local school district for additional information)

Occupational Therapy, Physical Therapy, or Speech and Language Therapy (Outpatient):

Children with an Autism spectrum disorder can benefit immensely from a variety of interventions. This includes outpatient treatments such as occupational, speech/language, and physical therapies.

Speech and language therapy is necessary to address the communication needs of diagnosed children. Children in speech and language therapy (SLT) do not just learn how to say words; they can learn how and when to use functional language, how to communicate wants and needs, and how to converse with others. Other age-appropriate skills can be addressed too, such as social skills, reading/writing, play skills and more.

Non-verbal (and sometimes verbal) children may use picture schedules (PECS) or basic sign language to communicate.

Occupational therapy (OT) can teach or reinforce activities of daily living, play skills, social skills, as well as fine and gross motor skills. Many occupational therapists today implement a sensory integration approach, since many children with Autism have sensory processing difficulties. This means the way they process their environment – through their five senses – is different than that of typically developing peers. For example, an autistic child may become increasingly aggravated from a loud fire alarm, bright fluorescent lighting in a grocery store, or tight fitting sneakers.

Physical therapy (PT) is used for some children with Autism to address more significant fine or gross motor delays, motor planning, and/or low muscle tone (hypotonia). Physical therapy and exercise can be combined with occupational therapy to address stereotypical behaviors, sensory needs, and sometimes social skills.

Often, a child is enrolled in more than one type of therapy to address their variety of needs. Here is a listing of some of the outpatient facilities or independent providers in Southwestern Pennsylvania. Cities listed are where offices are based, however providers often service a region or count(ies).

Aspire Pediatric Therapy
OT and SLT
McKees Rocks, New Kensington
412-458-0798

AVID Learning Center
OT, SLT, Advocacy, and more
New Kensington
724-594-1090 or 724-594-1091
www.avidlearning.org

Barclay Rehab Pediatric Therapy Center
PT, OT, and SLT
Youngwood
724-925-6700

Bollman Behavior and Speech Services, Inc.
SLT
Bellevue/Emsworth
412-761-1485

The Children's Institute of Pittsburgh
PT, OT, SLT, and Functional Feeding Clinic
Squirrel Hill, Monroeville, Greentree, Wexford
412-420-2113
www.amazingkids.org

Children's Therapy Center
PT, OT, and SLT
McMurray
724-537-1490 (SLT)
724-527-1263 (OT)
724-941-6200 (Main)

Crossroads Speech and Hearing
Canonsburg, West Mifflin, and Wexford
724-941-4434

Nathan Speech Services
SLT, Advocacy, Social Skills Groups
Pittsburgh
412-363-8388

Neurological Therapy Specialists
PT, OT, and SLT
Greensburg and Indiana
1-800-945-0023
www.neurological-therapy-specialists.com

Pediatric Therapy Specialists, Inc.
PT, OT, and SLT
Sharpsburg
412-787-1180

Positive Steps
PT, OT, and SLT
Gibsonia
724-444-5333
www.positivestepstherapy.org

Rehabilitation Specialists
SLT
Allison Park, Bellevue, Robinson, and Zelienople
412-761-6062
www.rehabspecialists.net

RSI of Pennsylvania
PT, OT and SLT
Carnegie
412-429-7760
www.rehabspecialistsinc.com

Therapeutic Specialists, Inc.
South Hills
Provides PT and OT in School Settings
412-833-6663
www.tsot.com

Your local ARC chapter can offer information about advocacy, community resources, outpatient therapists, and support groups in your hometown:

Achieva
(Formerly ARC of Allegheny County)
711 Bingham Street
Pittsburgh, PA 15203
412-995-5000

ARC of Armstrong County
309 Market Street
Kittanning, PA 16201
724-545-3426

ARC of Beaver County
3582 Brodhead Road
Suite 202
Monaca, PA 15061
724-775-1602

ARC of Butler County
Pullman Commerce Center
Suite 202
112 Hollywood Drive
Butler, PA 16001
724-282-1500

ARC of Fayette County
80 Old New Salem Road

Uniontown, PA 15401
724-438-8416

ARC of Greene County
197 Dunn Station Road
Prosperity, PA 15329
724-627-5511

ARC of Indiana County
2340 Warren Road Suite 106
Indiana, PA 15701
Telephone: (724) 349-8230

ARC of Washington County
Foxpointe Centre Suite 200
201 S. Johnson Road
Houston, PA 15342
724-745-3010

ARC of Westmoreland County
R. D. 12, Box 227
Donohoe Road
Greensburg, PA 15601-9357
724-837-8159

www.thearcpa.org

✚Autism Specific Resources – Western PA ✚

Once your child is enrolled in wraparound, EI, outpatient therapies, and more, you may find yourself looking for support for yourself and your family. You may also look for more information about types of interventions – behavioral as well as alternative. Families often find that the best way to learn more about Autism and treatments is by connecting with other parents who are already experienced with the disorder. Often, parents cope with the diagnosis by researching and learning about anything and everything related to Autism. Information is certainly available through an array of resources. Here is a listing of some of those organizations and publications – on local and national levels.

ABOARD – Advisory Board on Autism and Related Disorders

35 Wilson Street
Suite 100
Pittsburgh, PA 15233
412-781-4116
www.aboard.org

An organization committed to “*maximizing potential, maximizing possibilities*” for children, adolescents, and adults with Autism. ABOARD is proud to offer information dissemination, a lending library, 56 support groups in 36 counties, media communications (such as the ABOARD E-Gram), and workshops and conferences regarding everything from IEPs (Individualized Education Plans), behavior management and sensory integration to featuring adults with Autism such as the famous Dr. Temple Grandin and Kim Peek (the original “Rain Man”). Members of ABOARD benefit by receiving quarterly issues of “The All ABOARD News,” and receive discounts on presentations and workshops. ABOARD can be supported through their Autism awareness nights (such as the “Night at the Races” or Golf Outing), volunteer work, and donations. ABOARD also established F.A.A.C.E. (Forum Advancing Autism Excellence) to coordinate with other Autism organizations and further promote Autism awareness.

AutismLink

376 Wagon Wheel Trail
Wexford, PA 15090-9329
412-377-8778
www.AutismLink.com

A national non-profit organization, founded in Pittsburgh, offering a comprehensive website that provides an array of information about Autism support, resources, and links to national and local organizations across the state of Pennsylvania. The AutismLink listserv gives members up-to-the-minute information about Autism news on national, regional, and local levels. Online chat rooms (offered nightly at 9PM) and discussion groups (on the site as well as on Yahoo) and forums connect families directly affected by Autism, and professionals who service such children, presenting the opportunity for collaboration on formal and informal levels. Parents of newly diagnosed children may opt to take advantage of the mentoring program, which links such families with those experienced with the “ins and outs” of the wraparound system, and also how to cope with the diagnosis. Holiday parties and picnics, giveaways for families such as trips to the movies, the zoo or sporting events to promote community inclusion, free parent conferences and support groups are just a few of the many others resources now offered. AutismLink is “*for parents, by parents,*” staffed solely by volunteers who have children with Autism, and is free of charge to the community.

Autism Society of Pittsburgh

4371 Northern Pike
Monroeville, PA 15146
412-856-7223 (or 7224)
www.autismsocietyppgh.org

A local chapter of the Autism Society of America (ASA), the ASA of Pittsburgh offers information, a library with a variety of legal, medical, nutritional, educational and psychological materials (the Danny Cope Autism Library) information and support, newsletters, workshops, a referral system, legal information, parent support, and more. Founders of the first Spectrum Charter School providing vocational training as well as a unique educational experience for autistics aged 14 to 21, S.P.E.A.K. (Summer Program for the Education of Autistic Kids), and an ESY (Extended School Year) program that teaches basic living skills, recreation, community training, and IEP objectives. The ASA of Pittsburgh offers information to families about traditional as well as alternative modalities of intervention. The Board of Directors and Advisory Board are compiled of doctors and even Pittsburgh celebrities such as Myron Cope, Wayne Van Dine, and Adam Lynch.

Autism Speaks (NAAR and Autism Speaks Working Together)

Beth Whitehouse – Greater Pittsburgh Regional Director

4068 Mt. Royal Blvd.

Allison Park, PA 15101

412-487-6851

www.autismspeaks.org and www.autismwalk.org/pittsburgh

The National Alliance for Autism Research (NAAR) formed back in 1994 by Eric and Karen London, two parents who were determined to donate money to Autism research to help children like their son, Zachary. Once they learned that there was no national non-profit organization dedicated to funding Autism research, they formed NAAR. In February 2005, Bob and Suzanne Wright formed Autism Speaks to help raise awareness, much needed funding, and to support the thousands of families across the nation who are affected by Autism Spectrum Disorders. In February 2006, the National Alliance for Autism Research merged with Autism Speaks to unite forces in the fight against Autism.

In 2000, families located right here in Pittsburgh formed the first “Walk FAR for NAAR.” Now known as the “Walk for Autism Research,” this grassroots effort raises millions of dollars each year to fund biomedical research.

This united organization demonstrates that it just takes “one family, one voice” to make a difference in the lives of others. Families are invited to participate in the Pittsburgh Walk for Autism Research, held annually in late spring.

Fighting Autism

351 Ivy Drive

Gibsonia, PA 15044

412-641-7383

www.fightingautism.org

This organization’s mission is “to improve the quality of life for children with Autism through research, education, advocacy and treatment.” Fighting Autism hosts an annual conference where scientists and physicians present the most current innovative research and biomedical treatment options for those with Autism. They hold monthly biomedical support group meetings in our FBR office located in Gibsonia. Their website offers a graph of the most current rates of Autism in the U.S. and other related statistics, links to scientific research abstracts, and a list of doctors who support a biomedical approach to treatment. Fighting Autism’s co-founder, Dr. Laura Hewitson, was awarded a two-year grant by NAAR (National Alliance for Autism Research) for her study, “Autism Models in Transgenic Primates: Molecular Mechanisms Investigated by Functional Brain Imaging and Behavior.”

Local Online Support Groups or Forums

groups.yahoo.com/group/pittsburgh_autism

groups.yahoo.com/group/pittsburgh_autism_friends

groups.yahoo.com/group/butler_autism

groups.yahoo.com/group/The_Alle-Kiski_Valley_Autism_ABOARD_Support_Group

www.autismlink.com/chat.shtml

*Many new discussion boards are offered through AutismLink regarding general discussions about ASDs, parental and marital stresses, biomedical, traditional therapies, Autism in girls, and boards for every state including PA.

Autism Specific Resources – Nationally Recognized Organizations and Useful Websites

(New Sites Added Summer 2006)

ABA Resources - Richard Saffran's Website - rsaffran.tripod.com

AutismInfo – www.autisminfo.com

Autism Network for Dietary Intervention (ANDI) – www.autismndi.com

AutismOne Radio - www.autismone.org

Autism Research Institute (also home of *Defeat Autism Now!*) - www.autism.com/ari

Autism Society of America – www.autism-society.org

Autism Speaks – www.autismspeaks.org

Autism Today – www.autismtoday.com

Dr. Carbone (Verbal Behavior) - www.drcarbone.net

Christina Burk – www.christinaburkaba.com (Applied Verbal Behavior)

Cure Autism Now – www.canfoundation.org

Dana's View from the Inside – www.danasview.net

Defeat Autism Now – www.autism.com/ari

Developmental Delay Resources – www.devdelay.org

Do 2 Learn – www.do2learn.com (Offers ASD information and picture schedules)

Exploring Autism - www.exploringautism.org

Families for Early Autism Treatment – www.feat.org

First Signs – www.firstsigns.org

Generation Rescue – www.generationrescue.org

Monarch Educational Materials – www.monarchmaterials.com

National Autism Association – www.nationalautismassociation.org

OASIS (Asperger's Support) - www.udel.edu/bkirby/asperger/

Relationship Development Intervention (Dr. Steven Gutstein) – www.connectionscenter.com

Talk About Curing Autism – www.tacanow.org

Unlocking Autism – www.unlockingautism.org

Yahoo! Groups – www.yahoo.com

Over 700 chat rooms and message boards related to Autism can be found by using the search engine in the “Groups” section of the Yahoo! Homepage. *This is an excellent way to connect with other families affected by Autism.*

Autism Publications

The Advocate – www.autism-society.org

This newsletter is available through the Autism Society of America.

Autism/Asperger’s Digest Magazine- www.autismdigest.com

This monthly magazine offers information about Autism, Asperger’s Syndrome, and Pervasive Developmental Disorder, and is the only magazine all about Autism. Autism/Asperger’s Digest is made possible by Future Horizons.

Exceptional Parent - www.eparent.org

This monthly magazine for parents of children with special needs features “*EP On Autism.*”

Future Horizons - www.futurehorizons-autism.com

Future Horizons is a leader in Autism and Asperger’s specific publications. They offer catalogs, newsletters, books, audiotapes, videos, and a laundry list of conferences.

Mothering Magazine – www.mothering.com

A natural family living magazine, this publication often features columns and stories about families affected by Autism Spectrum Disorders.

Schafer Autism Report - home.sprynet.com/~schafer

This daily email report is perhaps the most comprehensive publication on the latest news about anything and everything related to Autism.

National Online Support Groups or Forums for Parents of Autistic Children – Autism Specific

groups.yahoo.com/group/children_with_autism

groups.yahoo.com/group/autism_in_girls

groups.yahoo.com/group/autism-aspergers

groups.yahoo.com/group/parenting_Autism

groups.yahoo.com/group/AspergersSupport

groups.yahoo.com/group/P2ParentsChat

www.udel.edu/bkirby/asperger/messageboards.html

National Online Support Groups or Forums for Parents of Autistic Children – Related Disorders and Treatment Approaches

groups.yahoo.com/group/abmd – Autism Biomedical Discussion, for parents and professionals to discuss research and biomedical treatments for Autism

groups.yahoo.com/group/DTT-NET – A group for parents and professionals to discuss behavioral interventions for Autism such as Applied Behavioral Analysis, Verbal Behavior, Natural Environment Training, Discrete Trial Training

groups.yahoo.com/group/GFCFKids – For parents who are considering or are already implementing a gluten-free, casein free diet for their children

groups.yahoo.com/group/IEP_guide – This group is for families with children with special needs (not Autism-specific). However, many autistic children have an IEP (Individualized Education Plan). This group discusses IEPs, IDEA (Individuals with Disabilities Education Act), a “504 plan” (based on section 504 under IDEA), NCLB (No Child Left Behind), and general educational advocacy

groups.yahoo.com/group/NewRecoveredKids – For parents of children who have recovered or are on the road to recovery from the symptoms of Autism

groups.yahoo.com/group/sensoryintegrationgroup – This group provides information, education, and support to families who have children affected by Sensory Integration Disorder (or Dysfunction), or that have sensory issues related to Autism.

groups.yahoo.com/group/VerbalBehavior – This group is for parents and professionals to discuss Verbal Behavior, an approach taught within an ABA program based on the book by B. F. Skinner. The list is moderated by Christina Burk, M.A., CBA.

Educational Advocacy:

When a child is diagnosed with Autism in Pennsylvania, they usually qualify for special education services. Typically these services follow an early intervention program (if the child is diagnosed early). An IEP, or Individualized Education Plan, is developed for the child to meet his

or her specific needs and academic goals. It is important to advocate for the child's best interests, and ensure that he or she receives all the services that are necessary to achieve academic success and a FAPE, or Free and Appropriate Public Education. Each child is *legally entitled* to these services.

The best advocates for children are parents and caretakers. Here's how to better prepare yourself as an advocate:

- Attend workshops and conferences regarding IEPs offered by ABOARD, the ASA, AVID Learning, the PEAL Center (open January 2006 in Pittsburgh) or other organizations.
- Learn about your rights to special education in Pennsylvania by referencing the Education Law Center (www.elc-pa.org) – access manuals that can be downloaded to your computer, newsletters, and a HelpLine that offers information about legal advocacy.
- Read books about IEPs and advocacy such as:
 - ✓ *The Complete IEP Guide: How to Advocate for Your Special Needs Child* by Lawrence M. Siegel
 - ✓ *Wrightslaw: From Emotions to Advocacy – The Special Education Survival Guide* by Peter and Pamela Wright
 - ✓ *I Need Help with School!* by Rebecca A. Moyes
- More books and manuals are available through Amazon.com
- Take the time to build a professional rapport with your school district. You should get to know the officials involved with the planning of your child's educational needs. However, you are the leader(s) of your child's IEP team. Informed, dedicated parents are important components of the team.

Would you like an experienced child advocate to help you ensure that your child is receiving the special education services that he or she qualifies for? You have options:

- ✓ Contact your local ARC chapter
- ✓ Contact AVID Learning (owned by nationally recognized author/advocate Becky Moyes)
- ✓ Contact your Base Service Unit/Service Coordination Unit
- ✓ Contact FBR Autism Services – A list of educational advocates/consultants and a number of free publications from various sources are available in one combined packet. This is especially for parents who need to better understand the IEP process. Call today!

You can also speak to experienced parents:

- ✓ Consult www.autismadvocate.org - AutismLink's Ask-The-Advocate website offers a listserv, discussion board, glossary of terms, IEP tips, informational links, and panel of experienced parents who can offer answer to general questions about IEPs and special education.
- ✓ Join Yahoo! Groups "IEP_guide" message board at groups.yahoo.com/group/IEP_guide. The board consists of experienced parents and advocates. The group's *Files* section contains a listing of links, advocacy tips, sample IEPs, and useful forms/handouts relating to IEPs, 504 plans, or No Child Left Behind (NCLB).

More About Advocacy:

As parents and caretakers navigate “the system”, they often learn that advocacy does not begin or end with school districts. Advocating and fighting for your child’s rights and physical or mental health needs is imperative for a variety of situations, which may or may not include:

- Doctor’s appointments – Including:
 - Psychologists
 - Psychiatrists
 - Developmental pediatricians
 - Neurologists
 - Primary Care Physicians / General Pediatricians
 - Other medical specialists such as nutritionists, GI doctors, and more
- Interagency Service Planning Team Meeting (ISPTs) for wraparound services
- Evaluations for outpatient therapies (OT, SLT, PT and more)
- Appointments with the DPW or Social Security offices
- Any formal meeting or appointment regarding services or treatment for your child

How can a parent become a good advocate?

Here are some tips from our Family Support Coordinator, a parent of a child with Autism:

- ❑ ***Accept the diagnosis.*** Autism is a life-long disability – there is no cure for the disorder, though recovery from many symptoms is possible.
- ❑ ***Develop your own “filing system” for your child’s records.*** For example, have a folder for psychological reports, one for outpatient therapies, one for early intervention, etc.
- ❑ ***Request copies of everything.*** This includes any and all reports or records pertaining to your child. Not only will therapists and doctors find this helpful, this is also a good way track your child’s progress. You need to become your own “secretary” of sorts.
- ❑ ***Bring recent reports from other evaluators to every relevant appointment.*** For example, when you attend your child’s quarterly psychological evaluation, bring your child’s OT evaluation from last month, or a copy of your child’s new IEP from early intervention. Comprehensive information gives evaluators and physicians a well-rounded overview of your child’s progress and current interventions and needs.
- ❑ ***Offer information about Autism to your child’s psychologist or pediatrician.*** Though it isn’t a parents’ job to educate physicians about alternative treatments, or why sensory integration is beneficial to children with Autism, many professionals are grateful to parents who offer such information that they can share with those in their practice. Parents are often quick to blame doctors (especially PCPs) who are not educated about the latest information or treatments about Autism. Doctors usually have hundreds of patients with a variety of needs, may work 50-60 hours a week along with being on-call on evenings and weekends, and often have their own families and children to raise. Experienced parents and professionals know that new Autism information is available virtually every day. Doctors simply do not have time to read new information available on the internet or in medical journals. By offering information to your child’s doctor(s), you are saving them a lot of time, and building a rapport with them at the same time. However, some doctors are unfortunately closed-minded, and brush off parental concerns.
- ❑ ***Find a doctor(s) who will listen.*** When building a treatment team, everyone needs to be on the same page. Parents need the support of every team member – from wraparound,

- EI, school districts, outpatient facilities, and doctors – when treating their child. Though most parents are not scientists, researchers or physicians, it is often the parents that spend endless hours reading and learning about alternative or behavioral treatments. Often, parents that act as “amateur scientists” find the right treatments for their child. Some therapists and doctors may not see eye to eye with parents who would like to try, for example, a gluten-free, milk-free diet or intensive Discrete Trial therapy. Parents are often chastised for asking about mercury-free vaccinations, food allergy testing, or referrals to various specialists. Open-minded doctors recognize the important role that families play in the treatment of an autistic child.
- ❑ ***The same goes for therapists and other paraprofessionals!*** Offer the same information to other members of your child’s team. Information that you offer to members of your wraparound team or your child’s OT, for example, may be useful to some of their other clients with Autism. Sharing information benefits everyone.
 - ❑ ***Connect with other parents.*** Again, sometimes the best sources of information are parents of children with Autism who know how to navigate the system and have spent the time researching and learning about the disorder. Let those parents save you some time and energy, and let them inspire you. Often they can answer your questions quickly and efficiently. Experienced parents make excellent mentors ... and advocates!
 - ❑ ***Know your role as the leader of your child’s team.*** It’s common for parents to feel intimidated when master’s level clinicians, paraprofessionals, and medical doctors surround them. Parents often feel that the BSC or psychologist should head the child’s team. It’s the parents who ultimately lead the team, since they are working to recover their *own child* from the symptoms of Autism.
 - ❑ ***Speak up!*** If you feel an approach or treatment is not appropriate, say something! It is your right, and your child’s right, to refuse any type of intervention that is not acceptable to you. However, know the difference between being open and closed minded.
 - ❑ ***Promote awareness about Autism.*** Many people do not know that Autism is the second most common disability in children today. Rates of Autism are now as high as 1 in 150, and in some areas it is more prevalent. Very possibly, someone you know – a neighbor, an old friend from college, a co-worker – knows of someone who is affected by Autism. If they do not, it is very likely they will in the future (according to the staggering rates of the disorder).
 - ❑ ***Mentor others who are new to the diagnosis.*** Once you have “learned the ropes,” you may find that you are able to help others navigate the system. Helping others such as yourself is rewarding, and somewhat therapeutic.
 - ❑ ***Never, ever give up hope, and inspire others to do the same.*** Some children who are more severely affected do not respond as quickly to therapy or treatments. Parents can easily become frustrated and aggravated, and feel as if they should just give up when their child is not responding. Be patient – no therapy or approach works overnight. We should hold onto the hope that children with Autism can reach their fullest potential. Everyone deserves that chance.

How can a parent learn more about their children’s rights as consumers?

Families in Southwestern Pennsylvania, whose children participate in HealthChoices , are able to access confidential services from the Mental Health Association’s Ombudsman program free of charge. An **Ombudsman** provides information about managed care organizations, helps families to understand their rights, and helps consumers solve problems by assisting them in filing complaints and grievances, investigating claims as needed. They cannot act as individual advocates; however, they can refer families to advocates as needed.

Families who have questions, concerns, or need to file a complaint or grievance against a managed care organization or another providers offering services to children should contact an Ombudsman.

Allegheny: 1-877-787-2424
Armstrong: 1-888-329-0468
Beaver: 1-800-496-4388
Butler: 1-888-329-0468
Fayette: 1-877-213-3031

Greene: 1-888-642-6767
Indiana: 1-800-871-4445
Washington: 1-888-642-6767
Westmoreland: 1-800-871-4445

✚ Therapy Acronyms and Basic Terminology of Therapeutic Approaches ✚

You can find out what most abbreviations stand for and definitions of many “Autism-related” terms by visiting www.Autism-resources.com/Autismfaq-glos.html

Here are some definitions of just some of the therapies offered or supported by Family Behavioral Resources:

Applied Behavioral Analysis, or ABA, is a discipline devoted to the understanding and improvement of human behavior. It focuses on objectively defined observable behaviors of social significance. It seeks to improve the behavior under study while demonstrating a reliable relationship between the procedures employed and the behavior improvement. It uses methods of science – description, quantification, and analysis. ABA is a compilation of teaching procedures. ABA provides structured programming that provides positive reinforcement, therefore increasing appropriate behaviors. Data is collected and analyzed by a behavioral specialist. This methodology can benefit children of any age, beginning around 2 years old.

Discrete Trial Training is one of many teaching procedures that fall under the “ABA umbrella.” DTT follows the guidelines set forth by Dr. Ivar Lovaas. FBR does not believe in using punishments or aversives in our approach. Rather, we concentrate on task analysis, and breaking down skills into small, measurable steps that can be reinforced in a positive manner. The format used is *Sd* (the antecedent), *R* (the child’s response), and *Sr* (Reinforcement/consequence) – every discrete trial must have these three components.

Applied Verbal Behavior is another method that focuses on the language element of learning, based on the studies of B.F. Skinner. It promotes the teaching of language in a functional manner. In a verbal behavior approach, a child starts to understand the true meaning or value of words, rather than using simply a rote labeling vocabulary. A child learns to repeat words, label them, describe them, request them, respond to others using the word, read them, and write them. Clearly, language, verbal and non-verbal, affects all aspects of interacting with others. A child’s language needs can be met by having their behavioral consultant complete The Assessment of Basic Language and Learning Skills, or ABLLS assessment. This comprehensive protocol can determine the basic foundation for a DTT program with VB components.

Dr. Steven Gutstein created the ***Relationship Development Intervention (RDI)*** model of teaching a child about relationships with others. It teaches a child about how to relate to those around them, how to understand what other people are feeling, and how to identify their inner feelings and needs. Children learn about human emotion, sharing, and empathy, thus learning to connect more with their world.

Sensory Integration (or sensory processing) is a large factor in determining the functions of a child’s behavior. The way a child processes their environment, by use of the five senses, is often dysfunctional in a child with Autism. They are usually hypersensitive or hyposensitive to touch, light, sounds, smells, and tastes. Children with SI dysfunction (what is now known as Sensory Processing Disorder) usually have aversions to certain textures, such as only wearing cotton clothing and eating crunchy, salty foods, just to

give an example. In regard to touch, they may shudder at another person slightly brushing up against them, or jump on the bed for long periods of time to seek out input for their bodies. Often, those with SI needs have poor motor skills, and have difficulty with such tasks as dressing, writing, and “motor planning (resulting with trouble in areas such as balance and coordination.” Approaches of occupational therapy are often used to treat this area of behavioral needs, but can also be treated by ABA. By analyzing the child’s sensory behaviors, the team can help the family to determine what the child needs to improve in sensory integration. The concept of developing a plan for sensory needs is called a “sensory diet.”

Every child learns and develops through play. *Play Therapy (or Floortime)* is useful for children with social and emotional needs. By observing a child’s play, one can gain insight into a child’s true feelings about themselves and the world around them, not to mention how they interpret their environment. Through this method of therapy, the child can also learn important social skills.

Common Misconceptions and Concerns about the Wraparound System and Its Treatment Approaches: Answers from a Parent and Professional

Myth/Concern: Wraparound, sometimes referred to as “in-home” therapy, is intrusive.

Fact: A true wraparound approach is not always applied just in the home. Treatments can be given in a child’s home, community setting such as a daycare or preschool, sometimes a school, or in extracurricular activities (such as a social skills development group). Therapy for a child is not meant to be intrusive. Rather, its goal is to enable the child and in turn, the family to function more independently.

Myth/Concern: I have to go to the welfare office to get an ACCESS card? People will think I’m poor!

Fact: Medical assistance provided to children who have a disability is *not income-based*. The ACCESS card pays for wraparound services, along other outpatient therapies and various medical services. Many children who have an ACCESS card also keep their previous insurance carrier.

Myth/Concern: Wraparound is inconvenient, and takes over your life.

Fact: Though parental involvement is required for the team to treat your child, it does not need to be overwhelming in a negative way. Therapeutic sessions, especially those conducted in the home, are scheduled per the family’s needs. There is much room for flexibility. Treating a child and addressing their needs is indeed time consuming, physically as well as emotional. However, in time, most parents feel that their time invested in wraparound is worth their child’s improvement and well being.

Myth/Concern: If a parent of a child with Autism accepts wraparound, then they have failed as parent. They must have done something wrong!

Fact: Autism is a complex developmental disorder with a genetic, neurological, and/or biological basis. The term “refrigerator mother” coined in the 1960’s has long-since been proven completely false. “Bad parenting” does not cause Autism. Nobody knows what the cause is, and there is no cure. However, accepting help from trained experts who can employ of variety of treatments based in the scientific method is one way of giving a child a better chance at leading a normal life.

Myth/Concern: I’m not having a therapist follow us around on community outings. Let’s draw even more attention to the fact that our family and my child have a problem!

Fact: As mentioned previously, a goal of wraparound, as well as of most other types of outpatient therapy, is to teach the child skills and enhance inner abilities so that they may function independently. A child better prepared to function in their natural environment and in the “real world” is less likely to draw attention to themselves that a child who has had little or no intervention. Though recovery is not promised,

we strive to help your child achieve his or her highest potential. Observing a child across several domains, and especially providing treatment in natural and outside settings, will help to achieve that goal.

Myth/Concern: Discrete Trial and ABA are robotic forms of training. I don't want my child to be a robot!

Fact: Initially, the ways of teaching the child through this process is repetitive. Gradually, as the child acquires skills, maintains them, and generalizes such concepts, the program has room for flexibility and the means to become more natural. Positive reinforcement, a vital necessity for a true DTT program, is recommended for all children to increase desired behaviors. Everyone needs be rewarded for his or her work, and that includes adults. Discrete Trial Training offers the child a chance to learn in a structured environment that promotes success.

Myth/Concern: You can't guarantee that "this" method of therapy works. Prove it! There's so many "treatments" for Autism.

Fact: Numerous institutions and current studies confirm that the best way to intervene with an autistic child is to offer early intervention. We don't employ just one type of therapy or method when we treat a child with Autism. Rather, we spend time identifying a child's current level of functioning, and strengths as well as areas of concern, to develop a treatment plan tailored to your child's needs. Much of what we do is based on the ABA model, which addresses several needs: communication, behaviors, self-monitoring, social skills, sensory needs, and play skills. Many children with Autism have deficits in each of these areas and every diagnosed child has deficits in at least some of these areas. If they did not, they would not meet the criteria for Autism.

Myth/Concern: I don't want my child to have a "label." If people hear that my child is autistic, he'll be treated differently. Giving my child wraparound services just emphasizes the Autism.

Fact: Yahoo's discussion group *IEP_Guide* points out that "behavior labels a child, and the diagnosis gives one hope to help (him or her) appropriately." Parents who deny their child services because they fear the "scarlet letter" is really putting their child at a disadvantage. Treatment for the symptoms and behaviors manifested by Autism is encouraged. Early intervention has shown to be a child's best chance at best recovery, or perhaps alleviation of some symptoms. At the worst, children who have not responded to therapy at least have parents that exhausted all possibilities and had their child's best interests at heart. That's still something to be admired.

A Few Brief Thoughts from a Parent and Professional

At Family Behavioral Resources, we emphasize “Family Focused Therapy.” Per the principles of the Child and Adolescent Service System Program, or CASSP, we recognize that the family is the most important part of the treatment team and decision-making process for a child with a diagnosis. We encourage a mutually beneficial collaborative effort between parents and professionals in order to produce improvements and a better quality of life for your loved one.

As a parent of a child with Autism, I strongly encourage you to enthusiastically accept assistance from experienced professionals, and build a team that ultimately benefits your son or daughter. When a child receives a diagnosis of Autism, a parent has two choices: (1) ignore the problem or (2) make every attempt to overcome it. Many parents feel that they must “grieve” for the child that they feel they have lost. It’s important to remember that all children have incredible potential. Wraparound is one method of bringing out that potential within. Families in Pennsylvania are so fortunate to have such services available to them through a Medical Assistance program with no income guidelines, as there are very few states that have services comparable to ours.

Parents need to become advocates for their children, and research every avenue until they find the multi-system approach that best fits their needs. Accepting and implementing the wraparound team is one important step in achieving this. I was once quoted as saying, “My wraparound team is intrusive, invasive, and inconvenient... and they are saving my child’s life.” I have absolutely no regrets when it comes to my child’s wraparound team. I have nothing but the highest hopes and expectations for my son. The sky’s the limit and possibilities are endless.

-- Catherine Hughes, Family Support Coordinator for FBR

Overview of Autism Services Offered by Family Behavioral Resources

Specialized Autism Services

Family Behavioral Resources recognizes the unique needs of children with Autism Spectrum Disorders. Our approach to treating children with Autism builds upon the concepts of collaboration and teamwork in ensuring the highest level of clinical integrity in the support we provide to children with Autism.

The Autism Team

An Autism Director or Coordinator is identified for each office of FBR. The Autism Director or Coordinator provides complete clinical oversight of the Autism Services within their region. The Autism Directors or Coordinators provide weekly Clinical Consultation and Collaboration (CCC) Sessions to Behavior Specialist Consultants (BSC) who serves as Lead Clinicians for the children we serve. The Autism Directors or Coordinators are also available to provide support to any child's program at any point in treatment and often participate in the initial program development for new consumers.

The Autism Team have had extensive experience in the field of clinical programming for children with Autism. The team includes persons with substantial education and training in Applied Behavior Analysis, Occupational Therapy (Sensory Integration), Speech and Language Pathology, Education, Mental Health, Verbal Behavior Programming, Discrete Trial Instruction, Precision Teaching, and the Picture Exchange Communication System (PECS).

Staff Training

FBR recognizes the value of training all levels of staff in ensuring that each child served receives the highest quality treatment available to date. All staff at FBR has access to a variety of trainings including Foundation Trainings in Autism that explore diagnosis to specific treatment approaches. Trainings are also available in Applied Behavioral Analysis, Sensory Integration, Discrete Trial, Visual Supports, Social Skill Development, and Applied Verbal Behavior Programming.

Commitment to Community

Our team at FBR takes pride in its commitment to meeting the individual needs of each community we serve. We offer Parent Support Groups, Sibling Support Groups, Social Skill Groups, and Play Groups in communities where needs have been identified. In addition to these ongoing groups, FBR holds Helping Others Potential Expand (H.O.P.E.) for Tomorrow Focus groups to identify needs within communities we serve.

Survey of Parent and Child Needs Related to Autism Spectrum Disorder

It is our hope that our guide to family resources has proven useful to you. If there's an area of information that we missed, we would greatly appreciate that feedback. We can then improve our introductory package to better serve other families like yours. We would also appreciate it if you could take just a few moments and fill out the following survey, so we can better meet the needs of the Autism community.

What would you like to see offered by Family Behavioral Resources that is not already offered in your area?

- | | |
|---|---|
| <input type="checkbox"/> A Family Support Group | <input type="checkbox"/> Yoga Therapy for Kids |
| <input type="checkbox"/> A Sibling Support Group | <input type="checkbox"/> Therapeutic Fitness Group |
| <input type="checkbox"/> A Social Skills Group | <input type="checkbox"/> Respite Care Program |
| <input type="checkbox"/> A Play Group | <input type="checkbox"/> Parent Training Workshops |
| <input type="checkbox"/> A Sensory Integration Group | <input type="checkbox"/> IEP and Child Advocacy Workshops |
| <input type="checkbox"/> A Biomedical Support Group | <input type="checkbox"/> Child Advocates |
| <input type="checkbox"/> Art Therapy | <input type="checkbox"/> Lending Library |
| <input type="checkbox"/> Music Therapy | <input type="checkbox"/> Asperger's Support Group |
| <input type="checkbox"/> Additional conferences or workshops specific to Autism; please list below: | |
-

Would you be willing to participate in a H.O.P.E. for Tomorrow Focus Group? Please list your contact information below. All information will be kept confidential:

Name: (Last, First): _____

Address: _____

Phone: _____ - _____ - _____ Email Address: _____

How Do I Contact FBR?

Would you like to speak to a member of the Autism team? Please feel free to contact us:

Either Rick Murray or Catherine Hughes would be happy to assist you personally, or put you in contact with your local Regional Director of Autism Services or Autism Coordinator for support in regard to specific resources in your area. For your convenience, here is a listing of our office locations that offer wraparound services, and our outpatient clinics offering outpatient therapy and medication management.

FBR OFFICE LOCATIONS

BEAVER - 999 Third Street, Beaver, PA 15009
724-775-1362 / 724-775-3793

◆ **BRENTWOOD** – Brentwood Towne Square,
101 Towne Square Way, Suite 239, Pittsburgh, PA
15227
412-881-2400 / 412-881-6400

BUTLER - Warner Center 200 Renaissance Dr.,
Suite 401, Butler, PA 16001
724-282-9010/ 724-282-9019
(*OFFERS FAMILY-BASED SERVICES)

CRANBERRY – Two Landmark North, 20397 Rt.
19 Suite 310; Cranberry Twp., PA 16066
724-772-2677/724-772-2669

GIBSONIA - 4156 Kenneth Dr., Gibsonia, PA
15044
724-449-9222 / 724-449-9221

◆ **GREENSBURG** - One Corporate Circle, Suite
2000, Greensburg, PA 15601
724-850-7300 / 724-850-8011

◆ **INDIANA/ARMSTRONG** - 1380 RT. 286 Hwy
East, Suite 524, Airport Prof. Center, Indiana, PA
15701
724-465-0369 / 724-465-1081

MONROEVILLE - 2526 Monroeville Blvd., Suite
200A, Monroeville, PA 15146
412-824-4005 / 412-824-4006

MOON - Airport Professional Office Center, Suite
606, 600 Commerce Dr., Moon Twp, PA 15108
412-262-5300 / 412-262-5577

◆ **NEW KENSINGTON**- 943 4th Ave., New
Kensington, PA 15068
724-335-9733 / 724-335-9734

◆ **NORTH HUNTINGDON** - 8960 Hill Drive,
North Huntingdon, PA 15642
724-861-9200 / 724-861-5926

◆ **UNIONTOWN** - 253 S. Mt. Vernon Ave.,
Uniontown, PA 15401
724-438-4960 / 724-438-1809

◆ **WASHINGTON** - 75 E. Maiden St., Suite 103,
Washington, PA 15301
724-229-0311 / 724-229-3277

WAYNESBURG
(Providing BHRS in Favette and Greene Co.)
1470 E. High Street, Waynesburg, PA 15370
724-627-0290 / 724-627-0212

◆ = Outpatient Clinic Available