



My Child May Have Autism – WHERE DO I TURN?

A Comprehensive Guide to Introductory Resources for Families (Updated January 2010)

If you do not see a resource or listing for your area,
please contact your local FBR office, the Family Support Coordinator,
or the Chief Operating Officer.

We will make every attempt to meet your needs.

Family Behavioral Resources - Autism Services

Local Phone Number: 724-850-8118, Ext. 25

Toll Free Number: 1-866-4-FBR-ASD

Fax Number: 724-850-9500

autismservices@familybehavioralresources.com

www.familybehavioralresources.com

Visit us on  – Become a fan of “Family Behavioral Resources”!



Introduction

This guide is meant to support those individuals who suspect that their child may be diagnosed with a form of autism spectrum disorder. This may include Autism, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger's Syndrome or another similar developmental delay. Our target audiences for this guide are those individuals and family members who need help in learning how to "navigate the system." This guide will show you:

- ✓ The general warning signs for Autism
- ✓ Where to go to determine whether or not your child has a diagnosis
- ✓ What to expect from the evaluator
- ✓ Steps to take after a child is diagnosed
- ✓ How to obtain the ACCESS card and SSI denial letter
- ✓ A brief overview of the wraparound model

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 there may be some organizations, facilities, or important resources that still need to be added. 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 Autism Directors and Coordinators work tirelessly to treating children with autism 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, Chief Operating Officer
Catherine A. Hughes, Family Support Coordinator
PO Box 879
Greensburg, PA 15601
1-866-4-FBR-ASD or 724-850-8118, Ext. 25 (Office)
724-850-9500 (Fax)
autismservices@familybehavioralresources.com (Email)

Please be sure to visit us on the web at **www.familybehavioralresources.com**.

Table of Contents

Is Your Child at Risk for Autism? – 4

Who Diagnoses My Child? – 5

How is My Child Diagnosed? – 5

How Long Does it Take to Get An Appointment? – 5

What Should I Do in the Meantime? – 6

The Day of the Appointment – What to Expect, What to Do – 6-7

Diagnosed – Now What? – 7

The Next Steps –7-8

Parent “To-Do” List for Obtaining Services – A Summary – 9

What is Wraparound? – 9

What Can FBR Offer To My Family? – 10

A Few Brief Thoughts From a Parent and Professional – 11

How Do I Contact FBR? - 12

“Is Your Child At Risk For Autism?”

Does your 18-month-old child's language development seem slow?
Has he lost words that he had once mastered?
Is he unable to follow simple commands such as "Bring me your shoes?"
When you speak to him does he look away rather than meet your gaze?
Does he answer to his name?
Do you or others suspect hearing loss?
Does he have an unusually long attention span?
Does he often seem to be in his own world?

At 18 months old, a child will typically do the following:

- * Point to objects
- * Interact with his siblings
- * Bring you items to look at
- * Look directly at you when you speak to him
- * Follow your gaze to locate an object when you point across the room
- * Engage in "pretend play" such as feeding a doll or making a toy dog bark

Autism is a developmental disability that impairs social and language development. It occurs in families from every class, culture and ethnic background. It is not a mental illness and it is not caused by trauma - it is neurobiological and its symptoms can be greatly reduced by early diagnosis and treatment.

If you are concerned about your answers to some of the above questions, speak to your pediatrician about an Autism screening.

An Early Diagnosis Provides the Best Chance for Success.

Excerpted from *Unraveling the Mystery of Autism and Pervasive Developmental Disorder: A Mother's Story of Research and Recovery*, by Karyn Seroussi. Published by Simon & Schuster. **Reprinted by permission.** Courtesy of www.Autismndi.com, and the ANDI Poster Project.

Who Diagnoses My Child?

To receive a diagnosis of an Autism Spectrum Disorder that qualifies your child for services, you must see a credentialed provider, such as:

- ✓ A licensed psychologist
- ✓ A licensed psychiatrist
- ✓ A child development unit (such as the unit at UPMC Children's Hospital)
- ✓ A master's level clinician working under the direct supervision of a doctoral level clinician

How Is My Child Diagnosed?

Your child's diagnosis will be based on observation, family interviews, several Autism or behavior checklists, and developmental screenings that may or may not include:

Childhood Autism Rating Scale (CARS)
Gilliam Autism Rating Scale (GARS)
Autism Diagnostic Observation Scale (ADOS)
Autism Diagnostic Interview, Revised Edition (ADI-R)
Aberrant Behavior Checklist (ABC)
Behavior Assessment System for Children (BASC)
Vineland Adaptive Behavior Scales
Peabody Developmental and Motor Scales
Wechsler Scales (WPPSI, WISC III, etc.)
Developmental Test of Visual-Motor Integration (or the Berry-Buktenica Test)
Clinical Evaluation of Language Fundamentals--3 (CELF-3)

Families complete some of the checklists, while other checklists and test are completed by the physician or licensed professional in collaboration with the family.

How Long Does it Take to Get An Appointment?

Unfortunately, many doctors and child development units have waiting lists – some are several months in length, and some are even at a year. **The best thing to do is to call several licensed providers, and get on their waiting lists.** Sometimes, families are fortunate enough to obtain an opening from a cancellation. Schedule several appointments if need be, and take the first available appointment. Of course, cancel the other appointments once you finally see a provider – remember that there are hundreds of other families in your position! The earlier the diagnosis, the sooner the child can be treated.

What Should I Do in the Meantime?

- ✓ Before your child's appointment, you may want to take advantage of the Autism Treatment Evaluation Checklist (ATEC), available free of charge through www.Autism.com/ari. For families who do not have internet access, please contact FBR Autism Services at 1-866-4-FBR-ASD. Our Family Support Coordinator can assist you with completion of this assessment.
- ✓ Network with other families in the autism community. Experienced parents who have "been there" are truly your best resources. Of course, they cannot diagnose your child, but they can usually confirm some of your suspicions. They can also help you prepare for the introduction of services, get through the "red tape," and more. Families also offer an incredible amount of support when you finally do receive a diagnosis. You can connect to other families through the Advisory Board on Autism and Related Disorders (ABOARD,) the Autism Society of America, Autism Help Network, Autism Speaks and AutismLink.
- ✓ You can research the internet and read books about autism. You might not want to immerse yourself in information, however, until you are sure that your child has a diagnosis. The system is long and complicated, and information will overwhelm you.
- ✓ Contact or visit your local DPW office to obtain a form for Medical Assistance. Start to gather birth certificates, social security cards, and income information. Please keep in mind, though, that **INCOME WILL NOT DETERMINE ELIGIBILITY**. The assistance that you will apply for is not income-based. Ask your DPW office for the application for a child with disabilities. If you have internet access, you can download the application in PDF format at www.dpw.state.pa.us/General/FormsPub/003670865.htm and click on the *Application for Cash, Food Stamps, and/or Medicaid (PA 600)*
- ✓ Contact the local Social Security office and ask for a checklist of items you need to apply for Supplemental Security Income. If you have internet access, you can link to the list by visiting www.ssa.gov/notices/supplemental-security-income/ and clicking on *Understanding SSI*.
- ✓ Be sure to have your private insurance information available. Your child may be covered under Act 62. To learn more about Act 62, please refer to our guide on *Medical Assistance*.

The Day of The Appointment – What to Expect, What to Do

- ✓ Take your spouse or partner, a family member or friend with you to your child's appointment. If and when you receive the diagnosis, you will need someone to support you.
- ✓ If you completed the ATEC or any other checklists for the doctor, don't forget them! You've come this far; you don't want to delay the process because you forgot paperwork in the shuffle!

- ✓ Bring copies of any pertinent medical records (neurological exams, genetic testing) or other developmental screenings that may have been completed to date.
- ✓ Be honest with the provider - don't hold anything back! Even if you think a detail about your child's development is not important, mention it anyways.
- ✓ Insist on leaving that day with an answer. Do not walk out without your suspicions being confirmed or denied. Leaving with uncertainty and an appointment six months later will prevent a child in need from receiving services.
- ✓ There is a chance that you will leave the doctor's office that day with a diagnosis of an Autism Spectrum Disorder.

Diagnosed – Now What?

- ✓ Accept support from those who love your child as much as you do, and from other families of children diagnosed with autism. Other parents affected by autism are incredible allies – they have been in your position, and know exactly how you feel.
- ✓ Many parents feel the need to grieve for the child that they feel they have “lost” or the child that they feel will “never be.” This leaves feelings of guilt and sadness. Know that it is okay and normal to feel this way.
- ✓ Some parents are relieved that they finally know “what is wrong” with their child and can now treat them. Nonetheless, families are devastated to learn that their loved one has a lifelong disability.
- ✓ Do not try to learn everything about autism in one day. It will take you several months to adjust to the diagnosis and to the introduction of services and therapies.
- ✓ Realize that your life is about to take a 360-degree turn. The next several weeks will consist of paperwork, phone calls, appointments, and meetings. The work will subside. However, know that by obtaining services, you will hold a strong, involved role in the treatment of your child. You will be responsible for many things.
- ✓ Ask for help from family, friends, and neighbors as you attend appointments and meetings, make phone calls, fill out endless paperwork, and take a well-deserved break.

The Next Steps

- ✓ **You must apply for SSI disability benefits.**
 - Gather your completed application, identification papers, income verification, and your child's psychological evaluation along with any other pertinent medical records such as developmental screenings, neurological exams, records from other specialists, genetic tests. A good rule of thumb is if you think it looks important – bring it with you.
 - Unlike the ACCESS coverage, **SSI is INCOME-BASED.**
 - If you are denied, ask for the denial letter.
 - If you are accepted, ask for an introductory acceptance letter. It can take up to 90 days to start receiving SSI payments.

- **A denial of SSI does not mean that your child will be denied MA/ACCESS.**
- ✓ **The next thing to do is obtain the ACCESS card, or Medical Assistance. Even if your child receives private coverage under Act 62, you must apply for MA which covers your co-pays as well as provides coverage after your private coverage is exhausted.**
 - Again, take all of your paperwork with you – don't forget anything!
 - Take everything to your local DPW office, and give them the application. Tell them you would like to wait to see a caseworker.
 - When you meet your caseworker, explain that you are there to obtain assistance for your child with disabilities. This is commonly referred to as the “loophole insurance.”
 - If you are told to wait “a few weeks” for a reply: Politely tell your caseworker that you are aware that it will take some time to receive your card in the mail and choose a specific provider through HealthChoices, but that you *will not leave that day* without a ten digit ACCESS number. If they continue to give you the runaround, ask to see their supervisor immediately.
 - You will be told to submit “the letter from SSI.” Give your approval or denial letter to the caseworker.
 - The ten-digit MA/ACCESS number is needed to start the process for a number of services. Write it down in a safe place once you receive it.
- ✓ **Plan on spending one or two days taking care of these two tasks. Sometimes you can do both in one day – if you start first thing in the morning! The DPW and SSA offices are usually open after 7AM.**
- ✓ **Once you have applied for SSI and MA *and you have your ACCESS number*, you are now ready to obtain services for your child.**
- ✓ **In most areas, you call a Service Coordination Unit (or the Base Service Unit), and ask someone to open a case for your child. A Case Manager or Support Coordinator will help you to coordinate a number of services for your son or daughter and may attend interagency team and other meetings necessary to plan for your child's treatment.**
- ✓ ***You are now ready to schedule your first interagency team meeting and choose a wraparound provider. In Allegheny County, your provider attends the initial meeting. In surrounding counties, the provider is not permitted to attend the first meeting. When selecting a provider, be sure to also have your private insurance information available, if applicable to your situation.***

Parent “To-Do” List For Obtaining Services – A Summary

- ___ Step 1: Schedule a psychological evaluation with an approved professional
- ___ Step 2: Slowly start to research Autism and connect with experienced families
- ___ Step 3: Once diagnosed, prepare yourself and your family for the road ahead
- ___ Step 4: Gather all of your child’s paperwork and information
- ___ Step 5: Apply for SSI
- ___ Step 6: Apply for Medical Assistance
- ___ Step 7: Call a Service Coordination Unit
- ___ Step 8: Schedule your child’s first Interagency Service Planning Team (ISPT) Meeting
- ___ Step 9: Select a wraparound provider specializing in autism

What is Wraparound?

Wraparound services, or Behavioral Health Rehabilitation Services for Children and Adolescents (BHRSCA), can be provided to children with a qualifying diagnosis, which includes those with an Autism Spectrum Disorder. Bachelor’s and Master’s level clinicians, following guidelines set forth by Child and Adolescent Service System Principles, provide services through a wraparound agency.

There are three levels of services offered within a wraparound agency. Your child’s psychological evaluation will recommend a number of hours per week (occasionally, per month) for one or more of the following:

- **Behavioral Specialist Consultant** – A Master’s level clinician who works with a family to develop a treatment plan for the child. The plan will recommend any number of interventions that are based on intensive behavioral modification, acquiring age-appropriate skills, developing positive relationships through social skill development, and more. The BSC consults with parents, and does not work one-on-one with the child. They visit the home, as well as observe classrooms, daycares, or community settings, attend psychological evaluations and the quarterly team meetings. A typical prescription is anywhere from 1-6 hours.
- **Mobile Therapist** –A Mobile Therapist is, again a Master’s level clinician. MTs counsel family members as well as the affected child in the home. They are usually assigned to higher-functioning children, since the child is an active participant in this therapy. In some cases, the MT may write a treatment plan (if the child is not recommended for BSC). A typical prescription is 2-4 hours.
- **Therapeutic Staff Support** – TSS are Bachelor’s level (Associate’s level in cases where the individual has three years of direct experience with children) clinicians who carry out the interventions recommended in the treatment plan written by the BSC. They work one-on-one with the child in either the family home, community, or school. Parents should observe TSS sessions to ensure consistency of interventions (behavior modification, etc.). A typical prescription for TSS is anywhere from 10-30 hours (can be more or less). Young children may be recommended for a smaller number of hours, and slowly work up to a full prescription.

Research shows that children with Autism benefit immensely from early, intensive intervention. There are many treatments for Autism – behavioral as well as unconventional options based primarily on anecdotal evidence. However, the only intervention truly proven to benefit children with Autism is behavioral intervention, based on the principles of Applied Behavioral Analysis. Accepting wraparound services for your child and your family is an individual decision. However, these services are strongly recommended so that your child can receive treatment at an optimal age. To get started, simply call your Base Service Unit and set up an initial Interagency Service Planning Team (ISPT) Meeting with the name of your selected provider (if appropriate).

What Can FBR Offer To My Family?

Family Behavioral Resources is proud to offer **Specialized Autism Services** to families in Southwestern Pennsylvania. You can call your local FBR office and speak to a Clinical or Administrative Supervisor to initiate services.

Your office's Regional Director of Autism Services or Autism Coordinator will play a role in child's treatment from the initiation of services. The Autism Team assists in ensuring that your child has a comprehensive, skill-based clinical program. This may involve consulting with the BSC, meeting with your child and family, and participating in the development of the treatment plan. The Autism Team provides weekly Clinical Consultation and Collaboration Sessions to BSC's to provide them with new intervention approaches identified within the field and to assist with ongoing monitoring and development of your child's program.

FBR is very committed to supporting families, through wraparound as well as through community outreach efforts. Before working with a child with a form of Autism, our staff must complete a Introductory training in autism, and also received training in a variety of treatment modalities that include but are not limited to Applied Behavioral Analysis, Discrete Trial Instruction, Applied Verbal Behavior, Therapeutic Play, Positive Behavior Supports, Sign Language, Social Skill Development, Visual Supports, and more. These trainings enable staff to implement a unique, individualized treatment plan targeted to your child's specific needs. Additionally, we have a consulting Occupational Therapist that offers support to staff whose clients utilize elements of sensory integration. We also have a Consulting Speech Therapist.

FBR's community outreach includes family and sibling support groups, social skill/play groups, *H.O.P.E. for Tomorrow* focus groups, resource packages, and dedication to fundraising efforts such as the annual Walk Now for Autism Speaks, ABOARD Gala, and the Highmark Walk for a Healthy Community.

After your initial meeting, you'll soon be ready to learn more about advocacy, additional treatments for your child, and support groups. Learn about these options and more in our second guide, ***After The Diagnosis: A Comprehensive Guide To Additional Resources for Families Affected By Autism.***

You may contact any of our offices (page 12) , or contact a member of the FBR Autism Team by calling FBR Autism Services – 1-866-4-FBR-ASD or 724-850-8118, Ext. 25. You can also send email to autismservices@familybehavioralresources.com.

Questions or concerns can be directed to Rick Murray, Chief Operating Officer, or Catherine Hughes, Family Support Coordinator.

We will be glad to support you in any way we can.

At Family Behavioral Resources... *caring is everything.*

A Few Brief Thoughts from a Parent and Professional

(Taken from our “After the Diagnosis” Guide)

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 previously diagnosed 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 is important to remember that all children have incredible potential.** The wraparound model 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

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.

ARMSTRONG – 206 Fifth Avenue, Suite B, Ford City, PA 16226
724-763-1002/724-763-1031

1-866-4-FBR-ASD / 724-850-9500
(*OFFERS AUTISM SERVICES AT THIS TIME)

BEAVER – 1301 Riverside Drive, Beaver, PA 15009
724-775-1362 / 724-775-3793

LATROBE-3576 Rt. 30W, Suite 7, Latrobe, PA 15650
724-537-8100 / 724-537-2070

BEDFORD – 9528 Lincoln Highway, Suite 1, Bedford, PA 15537
814-623-5077 / 814-623-5405

MERCER - *Colonial Square; 701 North Hermitage Road; Suite 10; Hermitage, PA 16148
(* 2/5/2010, moving to: 197 N. Buhl Farm Drive)
724-981-4462/724-981-4558

BLAIR – 764 Plaza Rt 764, Suite 2, Duncansville, PA 16635
814-695-2282 / 814-695-2460
(*OFFERS AUTISM SERVICES AT THIS TIME)

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

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

NEW KENSINGTON BHRS- 4 Kensington Square, Suite A, New Kensington, PA 15068
724-339-1134 / 724-339-1554

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

NEW KENSINGTON CLINIC- 3 Kensington Square, Suite B, New Kensington, PA 15068
724-335-9733 / 724-335-9734

CAMBRIA – 313 West High Street, Suite 209, Ebensburg, PA 15931
1-866-4-FBR-ASD / 724-850-9500
(*OFFERS AUTISM SERVICES AT THIS TIME)

NORTH HILLS-8035 McKnight Road, Suite 102, Pittsburgh, PA 15237
412-366-8342 / 412-366-8346

CRANBERRY – One Landmark North Suite 101, 20399 Rt. 19, Cranberry Twp., PA 16066
724-772-2677/724-772-2669

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

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

ROBINSON- Park West One; 1000 Cliff Mine Road, Suite 100; Pittsburgh, PA 15275
412-788-4224 / 412-788-4553

◆ **INDIANA BHRS** - 1380 RT. 286 Hwy East, Suite 526, Airport Prof. Center, Indiana, PA 15701
724-463-3600 / 724-463-3633

SOMERSET – 140 West Union Street; Somerset, PA 15501
814-444-0620 / 814-444-0640

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

◆ **UNIONTOWN** - 253 S. Mt. Vernon Ave., Uniontown, PA 15401
724-438-4960 / 724-438-1809
(Serving Fayette and Greene Counties)

LANCASTER– Sycamore Court, 245 Centerville Road, Suite 11, Lancaster, PA 17603

WASHINGTON – 90 West Chestnut St., Millcraft Center, Suite 110 LL, Washington, PA 15301
724-229-0311 / 724-229-3277

◆ = Outpatient Clinic Available

