



A
HANDBOOK
FOR
PARENTS
OF CHILDREN
WITH
AUTISM
SPECTRUM
DISORDERS

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INTRODUCTION

Developmental delays can take on many different forms. Autism and the various Autism Spectrum Disorders are forms of developmental delay. Autism is a neurobiological disorder. Children who have Autism show impairment in social skills, communication skills, and play, as well as evidence of restricted, repetitive, and stereotypical behaviors. These impairments can range from mild to severe, which is why they are often referred to as Autism Spectrum Disorders.

Determining whether a child may have special needs can be difficult and overwhelming. This handbook was developed to help parents and caregivers navigate the Pennsylvania mental health system and answer many of the questions that often arise when children receive initial evaluations or begin to receive services. It was written from a parent's perspective and was designed to provide basic information for parents about the behavioral health services available to their children and how to access these services.

While there is a great deal of information included in this handbook, parents or caregivers should use the guide in any way that they choose. We hope that this handbook will make it easier for parents and caregivers to understand both the nature of available services and the processes involved in accessing these services.



Autism Spectrum Disorders (ASDs) are a group of developmental disabilities that can cause significant social, communication, and behavioral challenges. People with ASDs handle information in their brain differently than other people.

"Autism itself is not the enemy... the barriers to development that are included with Autism are the enemy. The retardation that springs from a lack of development is the enemy. The sensory problems that are often themselves the barriers are the enemy. These things are not part of who the child is... they are barriers to who the child is meant to be, according to the developmental blueprint. Work with the child's strengths to overcome the weaknesses, and work within the Autism, not against it, to overcome the developmental barriers."

—A person with Autism

ANSWERS TO YOUR QUESTIONS



As early as infancy, a baby can begin to show the three hallmark features of Autism: communication challenges, impaired social interactions, and repetitive behavior.

I think my infant or toddler may have developmental delays. How do I know?

The following red flags may indicate that your child is at risk for developmental problems and is in need of a developmental evaluation. A child exhibiting any of these “red flags” should be screened to ensure that he or she is on the right developmental path.

Social and Communication Red Flags

If your baby or toddler is showing any of the following signs, ask your pediatrician or family practitioner for an immediate evaluation:

- No big smiles or other warm, joyful expressions by six months or thereafter.
- No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months or thereafter.
- No babbling by 12 months.
- No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months.
- No words by 16 months.
- No two-word meaningful phrases (without imitating or repeating) by 24 months.
- Any loss of speech, babbling, or social skills at any age.

The primary care physician or pediatrician can provide a developmental screening in order to determine whether the child has a developmental delay. **See Appendices A-C** for the full diagnostic criteria for Autism and related disorders.

The Academy of Pediatrics recommends a developmental screening during each visit. There is a specific screen designed to detect the early signs of Autism.

What should I do first? Where do I start?

If your child is between the ages of birth and 5, you may want to have him or her evaluated to determine whether Early Intervention Services would be of benefit. Early Intervention Services will assess your child and screen for the signs of Autism to determine whether a referral for further evaluation is necessary.

Each county has its own process for obtaining Early Intervention Services. Please **see Appendix H** for county-specific contact information.

Note: The services mentioned above are county-based services. Please call your local Community Care customer services representative (see Appendix G) for assistance.



Autism occurs in 1 in every 110 births. Boys are 4.5 times more likely to have Autism than girls. For boys, the rate of Autism is 1 in 70 births; for girls, the rate is 1 in 315 births.

ANSWERS TO YOUR QUESTIONS



"Push to make your child with Autism the best, most successful person he or she can be, and you may just be surprised by the results."

—A person with Autism

What other evaluation options are available for my child?

Psychoeducational Evaluation

If your child is school-aged, you can request that the school psychologist conduct a psychoeducational evaluation to diagnose your child and create an Individualized Education Plan (IEP). An IEP includes the specific accommodations and/or modifications that must be made in order for your child to have appropriate education. The cost of this evaluation is covered by the school district; it is of no cost to you.

Outpatient Provider Evaluation

A diagnosis can be obtained through a community mental health provider or a private psychiatrist, psychologist, or neuropsychologist. A licensed psychologist and/or psychiatrist will meet with your child and complete a psychological or psychiatric assessment that includes a diagnosis and recommendations for services.

Private Physician or Pediatrician

Further assessment can be obtained through your private or developmental pediatrician, neurologist, or other qualified licensed physician. This cost is often covered through commercial insurance (the private insurance that you or your spouse may receive through your employment). There may be some instances where private pay is required. It is recommended that you talk with your physician regarding your concerns.

I have heard that I can get other types of services. How do I get these services? How do I pay for them?

There are various types of behavioral health services available to children with Autism. Medical Assistance often covers these services. Medical Assistance is state funding that is available if your child has a disabling diagnosis. Autism, Pervasive Developmental Disorder NOS, Asperger's, and numerous other diagnoses are considered "disabilities."

I have heard of Medical Assistance. What is it?

Pennsylvania has a unique system in which parents of a disabled child can qualify for Medical Assistance regardless of the parents' income. In other words, services traditionally provided only to individuals who fall below a certain income level are available to children diagnosed with a disability regardless of the family's income. Medical Assistance pays for many of the services commonly provided for children with Autism.

How can my child qualify for Medical Assistance?

In order to be eligible for Medical Assistance, your child must have an assessment and be diagnosed with a disability that qualifies him or her for this benefit. The list of qualifying diagnoses can be found on the Internet at <http://www.ssa.gov/disability/professionals/bluebook>. Such diagnoses include, but are not limited to, Autism, Pervasive Developmental Disorder, and Asperger's Disorder. The most common ways of obtaining a diagnosis are mentioned above.

How do I obtain Medical Assistance for my disabled child?

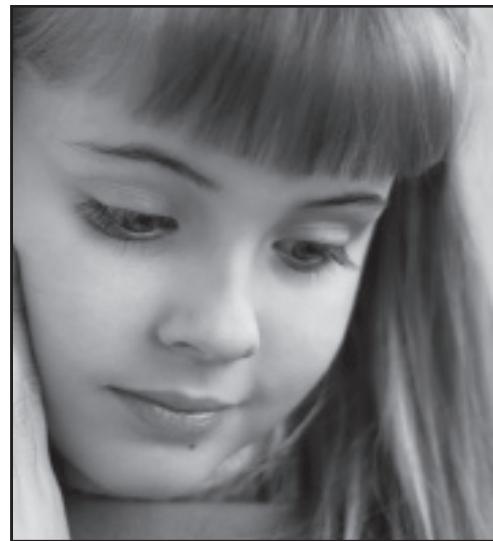
In order to apply for Medical Assistance, you must complete an application form, the PA-600. The quickest way to obtain an application form is to call your local County Assistance Office. You can also apply online using the COMPASS application.

What other information might help me to complete the application form?

It helps to write "Medical Assistance for the disabled child" at the top of the first page. Even though only your child is being reviewed, all persons in the household should be listed, including their birth dates. The Social Security numbers of the parents and the child should be included.

Parental income is not taken into account. However, your child's income, if any, is taken into account when reviewing eligibility. Verification of your child's income should be included. This includes any resources that generate income, such as interest on bank accounts in your child's name. Effective September 1, 2000, court-ordered child support and Social Security Survivor's benefits for the child are not considered.

Even though parental income is not considered, the implementation of Act 7A/2002 requires that the custodial parent or legally responsible adult provide this information in the application. Medical Assistance will be denied if the information is not provided. This income information is used to determine whether a parent must apply for Supplemental Security Income/Social Security Disability Insurance (SSI/SSDI) for the child through the Social Security Office.



Autism is the third most common developmental disability following Intellectual Developmental Disabilities and Cerebral Palsy—it is more common than Multiple Sclerosis, Cystic Fibrosis, or childhood cancer.

ANSWERS TO YOUR QUESTIONS



Autism spectrum disorders affect each person in different ways, and can range from very mild to severe. People with ASDs share some similar symptoms, such as problems with social interaction. But there are differences in when the symptoms start, how severe they are, and the exact nature of the symptoms.

What other information might help me complete the application form? (continued)

If your child is covered under any medical insurance, this should be noted on the application. A copy of the front and back sides of insurance cards should be sent. Medical documentation of the child's disability should be attached to the application, including diagnosis, severity, duration of disability, impact on child's functioning, and current treatment plan. This information is required by the Medical Review Team (MRT) who will determine the disability in the event SSI/SSDI benefits are rejected based on parental resources. This documentation must be signed by a medical doctor (MD), psychiatrist, or psychologist. (See note below.)

What criteria must my child meet to qualify as a disabled child?

To qualify as a disabled child, your child must meet one of the following criteria:

- Receiving Social Security Disability (SSD) benefits.
- Certified disabled based on SSDI/SSI criteria. This is done by the MRT in Harrisburg. No disability decision is made at the county level. A medical evaluation is authorized if all verifications are received and eligibility is established in all areas except medical determination. The MRT reviews the child's case using the same criteria as the Social Security Administration (SSA). The MRT sends a certification or rejection of disability to the County Assistance Office. If rejected, the County Assistance Office must send a notice to close.
- Received SSD/SSI and was certified disabled. If the SSA terminated for reasons other than disability, there is no need to recertify if the disability certificate is still valid.

NOTE: The County Assistance Office is not requiring that parents go to the Social Security Office to receive a denial letter unless their monthly income is under \$3,000 per month. This is a change—previously parents were required to obtain the letter from SSA before authorization. In some cases, clients may be required to apply for SSI if income is between \$3,000-\$5,000. The County Assistance Office will make a referral to Social Security and a representative will contact the parents.

How does the verification process work?

An interview is not required and everything can be done by phone or through the mail. If verifications are incomplete or missing, the caseworker will contact the parents.

Cases are reviewed once a year by mail and/or phone. Parents are sent a form to update their child's case. The form must be completed and returned, along with any requested verifications.

Are Medical Assistance benefits retroactive?

The effective date of eligibility is the date the application is received and date-stamped in the County Assistance Office. If a parent is requesting retroactive medical coverage for a previous medical expense in the three months prior to the effective date, the parent must submit medical documentation that the disability existed during that period.

The retroactive period cannot be approved until the MRT certifies that the child has met SSA disability criteria. Ongoing medical coverage can be authorized with the MRT certification pending but not retroactive coverage.

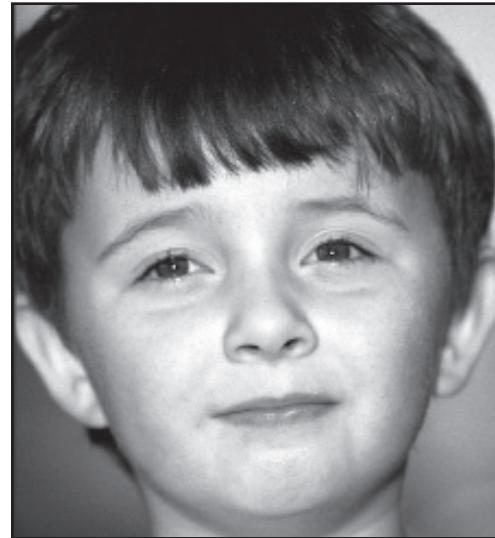
Will my child be enrolled in an Health Management Organization (HMO)?

Children receiving Medical Assistance will be enrolled in an HMO, a Medicaid Fee-for-Service program, or a HIPP program. These HMOs and Fee-for-Service programs provide benefits for the physical health of your child. Community Care manages all behavioral health services.

HIPP stands for Health Insurance Premium Payment. A child will qualify for HIPP if he or she is an active Medical Assistance recipient who has access to medical insurance through employment (or the family's employment). HIPP representatives conduct a cost analysis based on who is eligible for the employer insurance, the amount of the premium, and the policy benefits. If the anticipated Medical Assistance costs of the clients are greater than the cost of the employer insurance, the child is enrolled in a HIPP program.

Will I need to reapply once my child is receiving Medical Assistance?

Eligibility for a child receiving Medical Assistance must be reviewed at yearly intervals. The PA600-CH-L is used along with a letter from the caseworker explaining the review process. Parental income must be reported at reapplication, along with the other information required by Act 7A.



"Autism is happy and sad. I like Autism. Autism makes me different from my friends. That's OK."

—A person with Autism

ANSWERS TO YOUR QUESTIONS



Behavioral therapies and medical interventions are some of the treatments effectively being used for individuals with Autism.

What information is needed to meet the Act 7A requirement?

For the Department of Public Welfare to submit an annual report to the General Assembly as part of the requirements of Act 7A, the following information is needed from families applying for "Medical Assistance for the Disabled Child":

- Family size (parent's statement).
- Household income (parent's statement). Parents must verify their income.
- County of residence (parent's statement).
- Length of residence in Pennsylvania (parent's statement).
- Third-party insurance information (insurance card needed).
- Diagnosis.

Who is responsible for the documentation?

When applying for Medical Assistance under the disabled child provision, it is the parent or guardian's responsibility to assemble the documentation of the child's disability or condition. It is not enough for a child to have a disability, a specific diagnosis, or an IEP in order to qualify for Medical Assistance under the disabled child provision. The child's disability must meet the Social Security childhood disability standards. The disability verification is sent to the Medical Review Team (MRT) to review for a disability determination.

It is necessary for parents to provide documentation of the nature, severity, frequency, and duration of the limitations in addition to the medical or psychiatric condition that causes the limitations (diagnosis). Important sources of documentation include the child's doctors, therapists, teachers, guidance counselors, and school records. IEPs are not enough because they focus only on educational issues.

Psychologists certified by the Pennsylvania Department of Education or licensed by the state of Pennsylvania can provide the necessary documentation for a disability determination for a child applying for Medical Assistance under the disabled child provision.

As the parent of a child with Autism, you need to know about a law that has changed the way your child's Autism-related services are covered. This law is called the Autism Insurance Act, or Act 62.

What is Act 62?

ACT 62 changes the way that Autism services are covered through the Medical Assistance program and private health insurers.

ACT 62:

- Requires many private health insurance companies to cover the cost of diagnostic assessment and treatment of autism spectrum disorder and services for children under the age of 21, up to \$36,000 per year;
- Requires the Pennsylvania Department of Public Welfare (DPW) to cover the cost of services for individuals who are enrolled in the Medical Assistance program and do not have private insurance coverage, or for individuals whose costs exceed \$36,000 in one year; and
- Requires the Pennsylvania Department of State to license professional behavior specialists who provide services to children.

Who is covered by the Act 62?

ACT 62 covers children or young adults under age 21 with a diagnosis of an Autism Spectrum Disorder who are covered by:

- An employer group health insurance policy (including HMOs and PPOs) that has more than 50 employees and the policy is not a "self-insured" or "ERISA" policy;
- Medical Assistance; or
- Pennsylvania's Children's Health Insurance Program (CHIP) or adult Basic.

What does ACT 62 cover?

ACT 62 covers diagnostic assessment and treatment of autism spectrum disorders, including:

- Prescription drugs and blood level tests.
- Services of a psychiatrist and/or psychologist (direct or consultation).
- Applied behavioral analysis.
- Other rehabilitative care and therapies, such as speech and language pathologists as well as occupational and physical therapists.



Specialist education and structured support can really make a difference to the life of a person with Autism, helping to maximize skills and achieve full potential.

ANSWERS TO YOUR QUESTIONS



Children with ASD often have other associated problems that can include sensory impairment, gastrointestinal problems, sleep disturbances, and seizure disorders, as well as often appearing to have cognitive impairment. At the same time, they may also show special skills in certain areas like drawing, math, music, or memory.

What are the requirements for treatment to be covered by ACT 62?

The treatment:

- Must be for an Autism Spectrum Disorder;
- Must be medically necessary;
- Must be identified in a treatment plan;
- Must be prescribed, ordered, or provided by a licensed physician, licensed physician assistant, licensed psychologist, licensed clinical social worker, or certified registered nurse practitioner; and
- Must be provided by an autism service provider or a person, entity, or group that works under the direction of an Autism service provider.

Where will I find more information about Autism insurance?

Additional information about Autism insurance is available on the Internet at www.PAAutismInsurance.org. If you have a more specific question or need more clarification about the Autism Insurance Act, you can e-mail your questions to ra-in-autism@state.pa.us.

What does Medical Assistance cover for my child?

Medical Assistance covers various behavioral health services not covered under commercial insurance, including Behavioral Health Rehabilitation Services (BHRS) and Therapeutic Staff Support (TSS) services.

What are BHRS services?

BHRS or “wraparound services” are the most commonly recommended services for children with Autism and other Pervasive Developmental Disorders and include a range of individualized behavior management, treatment, and rehabilitation services provided in community settings. Settings may include the child’s home or school, as well as other settings such as camps, recreational venues, or commercial establishments.

Which types of professionals deliver BHRS services?

BHRS are most widely utilized in the treatment of children with Autism Spectrum Disorders. BHRS treatment consists of services delivered as medically necessary by one or more of the professionals listed below.

Behavior Specialist Consultants (BSC)

BCSs are master's or doctoral-level staff who assess and analyze behavioral data, develop child-specific treatment plans, and consult with the treatment team concerning the implementation of the treatment and behavioral plans.

Mobile Therapists (MT)

MTs are master's or doctoral-level staff who provide intensive individual or family therapy services to children with Autism Spectrum Disorders and their families in settings other than a provider agency or office. MT services are provided in the child's home or in a school, church, community center, neighbor or extended family member's home, or other community setting. MTs provide child-centered, family-focused individual and family psychotherapy, as defined in the treatment plan and agreed upon by the therapist and the family, using formats that may vary according to the individualized needs of the child.

Psychotherapy in the home or community setting may include sessions with the child individually, the entire nuclear family, the family and a community resource (such as a minister, Scout Master, community leader, mentor), the family and teacher, a guidance counselor or principal, or subsystems of any of the above, such as sibling groups, as clinically indicated, agreed upon, and identified in the treatment plan.

Therapeutic Staff Support (TSS)

A TSS worker provides direct services to a child with an Autism Spectrum Disorder under the supervision of a master's-level clinician (typically the BSC or MT). These staff members are educated at the bachelor's degree level and have at least one year of applicable experience in human service fields as providers of care. TSS workers implement interventions as defined in the treatment plan. Their role is to teach the interventions, skills, and techniques in the treatment plan to the adults in the child's life so that at some point these natural supports will have the skills to manage the child's behavioral needs. The other role of the TSS is to collect data to document the child's progress on the treatment plan.



Autism has nothing whatsoever to do with the way parents bring up their children.

ANSWERS TO YOUR QUESTIONS



There isn't one specific cause of Autism. Research has focused on whether chemical imbalances, differences in the brain, genetics, or problems with the immune system play a role in causing the disorder.

How do I get BHRS or wraparound services?

In order to obtain BHRS, you can have your child evaluated at one of the mental health providers in the county (**See Appendix I**). An evaluation will be offered within seven days of the initial phone call.

What will happen at an evaluation for BHRS?

Before the evaluation, a master's-level clinician will ask you questions about your child's developmental history and current and past behaviors, including definitions of the behaviors, the frequency and intensity of the behaviors, past medical history review of strengths, current school or preschool placement if relevant, drug and alcohol history if relevant, family psychiatric history, past treatment, and medical history. You should bring as much information as possible to this appointment.

The clinician will make a level-of-care determination for BHRS and/or another level of care that will address your child's needs.

What is a Functional Behavioral Analysis and should one be completed for my son/daughter?

A Functional Behavioral Analysis (FBA) is an attempt to look beyond the obvious interpretation of behavior and determine the specific function that it may be serving for a child. Truly understanding why a child behaves a certain way is the first and best step to developing strategies to stop the behavior.

An FBA includes the gathering of information through interviews of caregivers as well as direct observation and data analysis of when the behaviors occur. During the FBA process, the family, school staff, and a BHRS BSC (trained in the FBA process) will observe your child in several of the settings in which the behavior occurs. The BSC notes what comes before the behavior (also called the "antecedent"), the behavior, and what happens after the behavior (also called the "consequence") over a period of time. The BSC also interviews teachers, parents, and other caregivers who work with the child to evaluate how the child's diagnosis may affect behavior and manipulate the environment to see if there is a way to avoid the behavior (for example, providing a child with a sensory tool such as a chewy tube to avoid having the child chew on inedibles in his or her environment). This information becomes the basis for a behavior plan. The behavior plan will include specific treatment interventions to replace destructive, disruptive, or distracting behaviors with more socially appropriate, acceptable behaviors.

As a parent, what is my role in the FBA process?

As the parent, you have an important role of helping the team understand your child's behavior. You have an abundance of information about the specific behaviors exhibited by your child and the frequency of such behaviors. In order to provide a complete picture of your child's behaviors, the team may request that you observe and collect information about your child's challenging behavior as you observe it in the home and in community settings. Your observations will help the team develop specific interventions/strategies to use in your child's behavior plan. Eventually, you will be trained to utilize these strategies so that you can more effectively manage your child's behavioral concerns.

Is my preschooler too young to have an FBA?

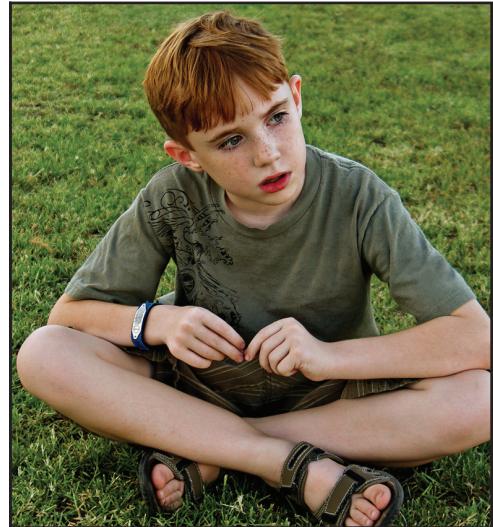
Even if your child is very young, an FBA should be completed. The earlier that identified challenging behaviors are addressed, the more likely they can be rectified and replaced with more appropriate behaviors. For example, it is far easier to teach a two- or three-year-old to request items using a picture card than it is to teach a much older child who has used tantrums to obtain what he or she wants. The older child has likely "learned" (through reinforcement or reward of the behavior with the desired object) that tantrumming is how to get that specific need met and may be more challenging to address.

Will the FBA help my adolescent enjoy more activities within the community and perhaps maintain a volunteer or paid job?

Yes, it is much more likely for someone to participate in school and community activities of their choice and maintain a paid job or be a successful volunteer if they have acceptable behaviors in those settings. If a person engages in challenging behaviors as a means of getting what they need or want, they are not as likely to get along well in community or work settings. The FBA will help uncover the function of the challenging behaviors and support the development of new skills and strategies your child can employ to get their wants and needs met.

Who should conduct direct observations?

Observations from multiple sources would be best. The professional conducting the FBA, the Behavior Specialist Consultant in BHRS, would work with the team on defining the behaviors, training the team on data collection, and providing an analysis of the data. Depending on where the challenging behavior is occurring, the person conducting the FBA and all those who support the person would observe and collect data. If appropriate, parents may be asked to collect data as well. It is important to observe the person



A person with Autism can be educated. With the right structured support within and outside of school, individuals with Autism can be helped to reach their full potential.



People with Autism are often keen to make friends but, due to their disability, sometimes find this difficult.

across several settings and across varying times of the day to see when the behaviors of concern happen and when they do not. Typically, the process takes a few weeks and data collection may last throughout this time.

Why is it necessary for the behavior specialist to interview people?

It is necessary to interview people to gather as much information as possible that helps describe the problem behaviors that are impeding learning or functioning within the community or home environment. Besides gaining relevant, factual information, an interview also brings out anecdotal information not captured elsewhere and leads to a more complete picture of the child or adolescent across settings and persons.

Who should be interviewed?

Those people who work with the person during his or her day, parents, the individual (as appropriate), and any BHRS staff who work with your child would be valuable to interview. Information gathered from multiple sources is necessary to complete a more holistic picture of the individual.

Why should we seek to define the function of the problem behavior?

Often through the demonstration of problem behaviors, people with ASD are trying to express something or communicate. Through the FBA process, we will understand why the person is engaging in a particular behavior.

We can then teach the individual the skills necessary to more appropriately communicate and have their needs met. For example, a preschooler who is tantrumming during free time at day care when he or she does not know what to do might benefit from learning how to ask for help and a picture menu of the possible activities with pictures breaking down the steps of those activities. A teen who can report that he or she is getting upset might use a hall pass to take a short walk in the hall to escape a problematic period rather than scream or swear in class.

Which forms should I use for the FBA interview and data collection?

If you are participating in observing and gathering data on your child's challenging behaviors, the forms you need will be provided to you by the Behavioral Specialist conducting the FBA. As you are an important part of this process, please feel free to make suggestions or offer ideas. Those ideas you have are bound to be important.

How might I approach my son or daughter's support staff about conducting an FBA?

Approach the issue from a proactive team approach. Explain the reasons you feel the need for an FBA and discuss with the team your concerns moving forward.

How many behaviors should be addressed in a FBA?

It is best to focus in on a minimal number of behaviors. If your child is exhibiting multiple challenging behaviors, it is necessary to prioritize the behaviors accordingly:

1. Destructive behaviors that are affecting the safety of your child and/or others or serious property destruction.
2. Disruptive behaviors interfering with inclusion, acceptance, and overall quality of life.
3. Disturbing behaviors that may be annoying but could cause your child to be teased or limit interactions with others.

What do we do after the FBA is completed?

The behavior specialist will hold a collaborative team meeting with all of the necessary members to review the data (including graphs of the data) and develop a Behavior Support Plan that will be followed by everyone involved in your child's care and support.

What should I look for from the FBA meeting in order to be fully informed and clear on the findings from all of this hard work?

Data may be presented in a variety of forms including graphs and charts. The team will present data, then discuss it further with you and other related caregivers. The perceived "function" of the behaviors will also be discussed to help you to understand the purpose of the behavior for your child. The data gathered from interviews will provide anecdotal information that will help to elaborate on the problem behaviors, the antecedents, etc. Direct observation data will also provide additional information in that it will confirm, dispute, or expand upon information gathered from interviews.

The FBA results will aid the development of interventions included in the behavior plan. For example, if the function of eating inedibles is sensory seeking, the team may develop more appropriate ways to receive sensory input, such as the use of a chewy tube.



There may be many different factors that make a child more likely to have an ASD. For example, children who have a sibling or parent with an ASD are at a higher risk of also having an ASD.



Early Intervention Services can improve a child's development. These services help children from birth to 3 years old learn important skills. Services can include therapy to help the child talk, walk, and interact with others.

What should I look for when selecting a provider to work with my child and family?

If you are working with a licensed mental health agency, the behavioral specialist consultant (BSC) should have successfully completed the FBA training offered by the Department of Public Welfare (DPW), Bureau of Autism Services or be a Board Certified Behavioral Analyst (BCBA). DPW has issued a bulletin, OMHSAS-09-01, Guidance for Conducting Functional Behavioral Assessments in the Development of Treatment Plans for Services Delivered to Children with Behavioral Health Needs Compounded by Developmental Disorders, which instructs licensed providers on expectations for conducting the FBA.

You should expect the results of the behavior plan to reflect the results of the FBA. The FBA should be updated if the plan is unsuccessful or new behaviors are identified. If an FBA has been completed by the school system, the results of this FBA should be also be considered in the development of the behavior plan.

How should I work with the support staff when there is a crisis?

The crisis plan, as outlined in Pages 7 and 8 of the OMHSAS bulletin, should be utilized when the behaviors are so significant that the child or adolescent is a threat to safety of him or herself or others, or there is a threat of serious property damage (torn worksheets do not count). The roles of all persons involved should be outlined in the crisis plan.

Each plan is different as is each child and family, but, for example, if the crisis occurs while in the community the plan might state that the TSS would provide support to the child including moving objects out of the way to keep everyone safe, using the predetermined de-escalation techniques, signaling others that help is needed, asking interested observers to give some space and help keep the scene as private as possible. The parent might be holding the child's hand so they do not run off into the street or otherwise hurt themselves while placing a communication book in range to prompt communication.

The use of the crisis plan indicates that something is not working in the behavior plan. The team should therefore meet to discuss this further and re-evaluate whether changes in the current behavior plan are necessary.

What happens if BHRS is recommended?

A psychologist, psychiatrist, or other qualified individual will conduct an evaluation, which may include questions about your child's behavior, developmental and medical and psychiatric histories, past treatment history, current school placement and/or preschool placement if relevant, behavior in school, and drug and alcohol history if relevant.

Your child will be observed and may be tested using specific noninvasive diagnostic tools. Parents are interviewed and may be asked to fill out various forms and checklists and bring other assessments and/or additional information such as preschool reports and physician reports. Your child's teacher may also be asked to complete some forms.

The evaluator will summarize this information and make recommendations.

What will the recommendations be?

The recommendations for children with Autism Spectrum Disorders can vary. It is common for a child to be prescribed BHRS. Other recommendations, such as a specialized classroom, additional testing, medication, or adjunctive therapies such as occupational therapy, physical therapy, and/or speech therapy may be recommended.

The evaluator may also recommend other services (**See Appendix E**).



Asperger's Syndrome (AS) and Autism are connected. AS is part of the autism spectrum. The only significant difference between the two conditions would be that those with AS seem to have their speech in place by the right time, whereas people with autism have to deal with delayed speech. People with AS are said to generally be very bright and verbal as well, but they are known to have social deficits.

ANSWERS TO YOUR QUESTIONS



People with Autism who have an extraordinary talent are referred to as "autistic savants." Savants are rare. Savant ability is more frequently associated with those having some form of Autism rather than with other disabilities. Current thinking holds that at most, 1 or 2 in 200 individuals with an Autistic Spectrum Disorder might have a genuine savant talent.

What does a recommendation for BHRS look like and what does it mean?

Following the evaluation, the evaluator will summarize his or her findings and make specific recommendations that include a prescription for services. These services are requested in "hours per week." For example, a prescription might state "recommend 3 BSC hours per week and 10 TSS hours per week in the home to address John's off-task behavior and self-stimulatory behaviors." This means that the evaluator is requesting 3 Behavioral Specialist Consultant hours per week and 10 Therapeutic Staff Support hours per week.

These services will be provided over a period of time. Four months is the typical amount of time covered in a prescription period. However, evaluators are also able to recommend up to a 1-year period for these services depending on your child's circumstances. These hours are provided per week and cannot be carried over from week to week if not utilized.

What happens following the evaluation?

The facility that did the evaluation will hold a treatment team meeting with you (commonly known as the Interagency Service Planning Team, or ISPT). The children's intake staff at the agency will begin to identify a provider to accept your child's case if it is authorized.

What is an ISPT?

An ISPT (Interagency Service Planning Team) meeting usually consists of the service providers, family members, school personnel, a care manager from Community Care Behavioral Health Organization (Community Care; a managed care organization), and/or others invited to participate. During this meeting, the child's needs are discussed, along with the impact of services, need for changes in services, and/or other recommendations. The team may discuss the evaluator's recommendations. If the team members are not in agreement, they can request that the evaluator change his or her original recommendations.

What happens after the meeting?

Following the evaluation and ISPT meeting, the evaluation, treatment plan, and related meeting documents will be sent to Community Care to review for authorization. Community Care manages behavioral health services.

Who determines if my child will receive the services recommended?

Community Care reviews the information presented when a request is made for behavioral health services. If the person reviewing the case (known as a “care manager”) feels that the information presented in the packet meets “medical necessity” criteria for the services requested, the packet will then be authorized. The service provider will be contacted and given an authorization number.

If Community Care’s care manager is uncertain about whether the packet meets medical necessity criteria or required information necessary to make a decision is missing, the evaluation will be further reviewed. In this case, Community Care may request more information from the provider or from the person who did the evaluation. The parents are not required to do anything further at this point. This request for information is not an indication that the services will not be approved. It is simply a way to gather more information to better understand your child’s specific symptoms and behaviors. The provider will have five business days to submit the requested information. After receiving the additional information, Community Care will make a decision within two days.

What happens next if recommended services are approved?

If Community Care approves services and a provider has been identified, the provider will then begin to provide services. Providers agree to initiate a member’s treatment if they have the staff and appropriate expertise. The provider then contacts the family and notifies them of a start date. The family can choose a provider but may have to wait longer depending on the provider’s availability. The provider will go to the identified setting and begin working with the child. The BSC will begin the FBA. The goal is to understand the function of each behavior and develop strategies for reducing the identified behaviors in all settings. These services should be provided over the length of the authorization period.

How do I keep getting these services?

Toward the end of the authorized period, the agency that is providing services will request that your child be re-evaluated to determine the impact of services, any changes in behavior, and the continued needs of your child. Another evaluation will be completed along with another ISPT meeting with all relevant team members. This process continues throughout the entire time that your child receives services.



“I believe that every one of us, regardless of our talents, skills, temperament, past experiences, or level of function, is intrinsically worthy of support to reach our fullest potential. I take as my guide for action this vision: that we are, each of us, precious and beautiful.”

—A person with Autism

ANSWERS TO YOUR QUESTIONS



"It is okay, even beautiful, to be a person with Autism."

—A person with Autism

What can I do if some or all of the recommended services are denied by Community Care? What is a grievance?

You can file a grievance. A grievance is what you file when you do not agree with Community Care's decision that a service that you or your provider asked for is not medically necessary.

You can file a grievance if Community Care does any one of these things:

- Denies a covered service.
- Approves less than what was asked for.
- Approves a different service from the one that was asked for.

How do I file a grievance?

You will receive a letter from Community Care if services are not completely approved. The letter will tell you how to file a grievance. *You have 45 days from the date you receive this letter to file a First Level grievance.*

To file a grievance, call your local Community Care customer services representative (**See Appendix G**). Or, write down your grievance and send it to the Community Care office in your region.

Your provider can file a grievance for you if you give your consent in writing to do so.

NOTE: You cannot file a separate grievance on your own if your provider files a grievance for you.

What happens after I file a First Level grievance?

Community Care will send you a letter to let you know your grievance was received. The letter will tell you about the First Level grievance process.

You may ask Community Care to see any information about your grievance. You may also send information that may help with your grievance to the Community Care office in your region. Call your local Customer Service representative for assistance with your grievance.

If you want to be included in the First Level grievance review, you must call Community Care within 10 days of the date on the letter sent confirming receipt of your grievance. You can come to your local Community Care office or be included by phone. You are not required to attend this meeting. If you do not attend, it will not affect the decision.

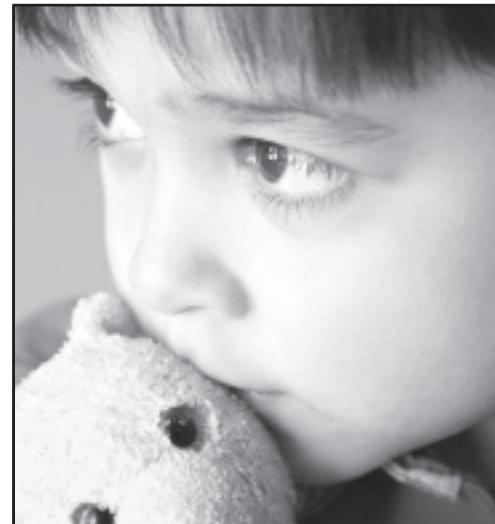
A committee of one or more Community Care staff, including a doctor or licensed psychologist who has not been involved in the issue you filed your grievance about, will make a decision about your First Level grievance. Your grievance will be decided no more than 30 days after it is received. A letter will be mailed to you no more than five business days after Community Care makes its decision. This letter will tell you the reason for the decision(s). It will also tell you how to file a Second Level grievance if you don't like the decision.

How do I keep getting services during the First Level grievance process?

If you have been receiving services that are being reduced, changed, or stopped, and you file a grievance that is hand-delivered or postmarked within 10 days of the date on the letter (notice) telling you that the services you have been receiving are being reduced, changed, or stopped, the services will continue until a decision is made.

What if I do not like Community Care's First Level grievance decision?

If you are not happy with Community Care's First Level grievance decision, you may file a Second Level grievance with Community Care.



"Sometimes it makes me mad to be different, but mostly I like who I am. It doesn't matter that I have a disability. One day I'm going to be a film director. I'm making this documentary to help parents of kids with Autism, and to show other people that kids with Autism can do a lot of things."

—A person with Autism

ANSWERS TO YOUR QUESTIONS



"Autism is a world so difficult to explain to someone who does not have Autism, someone who can easily turn off the peculiar movements and actions that take over our bodies."

—A person with autism

When should I file a Second Level grievance?

You must file your Second Level grievance within 45 days of the date you get the First Level grievance decision letter. Use the same address or phone number you used to file your First Level grievance.

What happens after I file a Second Level grievance?

Community Care will send you a letter to let you know we received your grievance. The letter will tell you about the Second Level grievance process.

You may ask Community Care to see any information we have about your grievance. You may also send information that may help with your grievance to Community Care. You may also ask for help by calling your local Community Care Customer Service Representative (**See Appendix G**).

You can come to a meeting of the Second Level grievance committee or be included by phone. Community Care will contact you to ask if you want to come to the meeting. You are not required to attend this meeting if you do not want to. If you do not attend, it will not affect the decision.

The Second Level grievance review committee will have three or more people on it. The members of the committee will not have been involved in the issue you filed your grievance about. The committee will make a decision no more than 30 days from the date Community Care received your Second Level grievance.

A letter will be mailed to you within five business days after the committee makes its decision. This letter will tell you the reason for the decision. It will also tell you how to ask for an External grievance review if you don't like the decision.

How do I keep getting services during the Second Level grievance process?

If you have been receiving services that are being reduced, changed, or stopped, and you file a Second Level grievance that is hand-delivered or postmarked within 10 days of the date on the First Level grievance decision letter, the services will continue until a decision is made.

What if I still don't like the decision?

If you are not happy with the Second Level grievance decision, you can ask for an External grievance review.

You must call or send a letter to Community Care asking for an External grievance review within 15 days of the date you received the Second Level grievance decision letter. Use the same address and phone number you used to file your First Level grievance. Community Care will then send your request to the Department of Health.

The Department of Health will notify you of the External grievance reviewer's name, address, and phone number. You will also be given information about the External grievance review process.

Community Care will send your grievance file to the reviewer. You may provide additional information that may help with the external review of your grievance, to the reviewer, within 15 days of filing the request for an External grievance review.

You will receive a decision letter within 60 days of the date you asked for an External grievance review. This letter will tell you the reason(s) for the decision and what you can do if you don't like the decision.

How do I keep getting services during the External grievance review process?

If you have been receiving services that are being reduced, changed, or stopped and you request an External grievance review that is hand-delivered or postmarked within 10 days of the date on the Second Level grievance decision letter, the services will continue until a decision is made.



People with Autism
have a normal life
span.

ANSWERS TO YOUR QUESTIONS



Autism occurs in all countries and within all socioeconomic classes.

There are various treatment options to ameliorate the symptoms.

Who can I call if my child's health is at immediate risk?

If your child's doctor or psychologist believes that the usual time frame for deciding a complaint or grievance will harm your child's health, you or your child's doctor or psychologist can call your local Community Care Customer Service Representative and ask that your complaint or grievance be decided faster.

You will need to have a letter from your child's doctor or psychologist faxed to your local Community Care office explaining how the usual time frame of 30 days for deciding your complaint or grievance will harm your child's health. If your child's doctor or psychologist does not fax this letter to Community Care, your complaint or grievance will be decided within the usual 30-day time frame.

A committee of three or more people, including a doctor or psychologist, will review your expedited complaint or grievance. No one on the committee will have been involved in the issue you filed your complaint or grievance about.

The committee will make a decision about your complaint or grievance and inform you of its decision within 48 hours of receiving your child's doctor or psychologist's letter explaining how the usual time frame of 30 days for deciding your complaint or grievance will harm your child's health, or three business days from receiving your request for an expedited complaint or grievance, whichever is shorter. You will also receive a letter telling you the reason(s) for the decision. It will tell you how to ask for an expedited External complaint or grievance review if you don't like the decision.

How do I file an expedited External complaint or grievance?

If you want to ask for an expedited External complaint (by the Department of Health) or grievance review (by a doctor who does not work for Community Care), you must contact Community Care within two business days from the date you get the expedited complaint or grievance decision letter. A decision will be issued within five business days from when we receive your request (**See Appendix F**).

How can Community Care help with the complaint and grievance processes?

If you need help filing your complaint or grievance, a staff member of Community Care will help you (**See Appendix G**). This person can also assist you during the complaint or grievance process. You do not have to pay for the help of a staff member. This staff member will not have been involved in any decision about your complaint or grievance.

Can I have someone else help me with the complaint and grievance processes?

You may also have a family member, friend, lawyer, or other person help you file your complaint or grievance. This person can also help you if you decide you want to appear at the complaint or grievance review. At any time during the complaint or grievance process, you can have someone you know represent you or act on your behalf. If you decide to have someone represent or act for you, tell Community Care, in writing, the name of that person and how he or she can be reached.

You or the person you choose to represent you may ask Community Care to see any information we have about your complaint or grievance.

For legal assistance, you can contact the legal aid office at 1-800-322-7572, or call the Pennsylvania Health Law Project at 1-800-274-3258.

Can I get help if my primary language is not English?

If you ask for language interpreter services, Community Care will provide the services at no cost to you.

Si Ud. necesita la versión en Español de este manual, por favor solicite una a este teléfono 1-866-229-3187.

What help is available for me if I have a disability?

If needed, Community Care will provide the following help (at no cost) in presenting complaints or grievances for persons with disabilities:

- Sign language interpreters.
- Information submitted by Community Care at the complaint or grievance review in an alternative format — the alternative format version will be given to you before the review.
- Someone to help copy and present information.

NOTE: You can request a Fair Hearing from the Department of Public Welfare in addition to, or instead of, filing a complaint or grievance with Community Care.



*"See me beautiful,
look for the best in
me. It's what I really
am, and all I want to
be. It may take some
time, it may be hard
to find, but see me
beautiful. See me
beautiful, each and
every day. Could you
take a chance?
Could you find a way
to see me shining
through in everything
I do and see me
beautiful?"*

—Red Grammer, Singer

ANSWERS TO YOUR QUESTIONS



Common characteristics of Autism include:

Difficulty mixing and relating with other people.

Inappropriate laughing and giggling.

No fear of real dangers.

Apparent insensitivity to pain.

Inappropriate attachment to objects.

Extreme emotional distress for no discernible reason.

What is a Fair Hearing?

In some cases you or your representative can ask the Department of Public Welfare to hold a hearing because you are unhappy about, or do not agree with, something Community Care did or did not do. These hearings are called Fair Hearings. You can ask for a Fair Hearing at the same time you file a complaint or grievance, or you can ask for a Fair Hearing after Community Care decides your First or Second Level complaint or grievance.

What kinds of things can I request a Fair Hearing for, and when do I have to ask for a Fair Hearing?

If you are unhappy because ...	And you ask for a Fair Hearing, you must do so ...
Community Care decided to deny a service because it is not a covered service	within 30 days of getting a letter from Community Care telling you of this decision OR within 30 days of getting a letter from Community Care telling you its decision after you filed a complaint about this issue.
Community Care decided not to pay a provider for a service you received AND the provider can bill you for the service	within 30 days of getting a letter from Community Care telling you of this decision OR within 30 days of getting a letter from Community Care telling you its decision after you filed a complaint about this issue.
Community Care did not decide your First Level complaint or grievance within 30 days of when you filed it	within 30 days of getting a letter from Community Care telling you that we did not decide your complaint or grievance within the time frame we were supposed to follow.
Community Care decided to deny, decrease, or approve a service different than the service your provider requested because it was not medically necessary	within 30 days of getting a letter from Community Care telling you of this decision OR within 30 days of getting a letter from Community Care telling you its decision after you filed a grievance about this issue.
Community Care's provider did not give you a service by the time you should have received it	within 30 days from the date you should have received the service OR within 30 days of getting a letter from Community Care telling you its decision after you filed a complaint about this issue.

How do I ask for a Fair Hearing?

You must ask for a Fair Hearing in writing. Send your request to:

Department of Public Welfare
Office of Mental Health and Substance Abuse Services
Division of Grievances and Appeals
Beechmont Building #32
P.O. Box 2675
Harrisburg, PA 17105-2675

What information should I include in my request for a Fair Hearing?

Your request for a Fair Hearing should include all of the following:

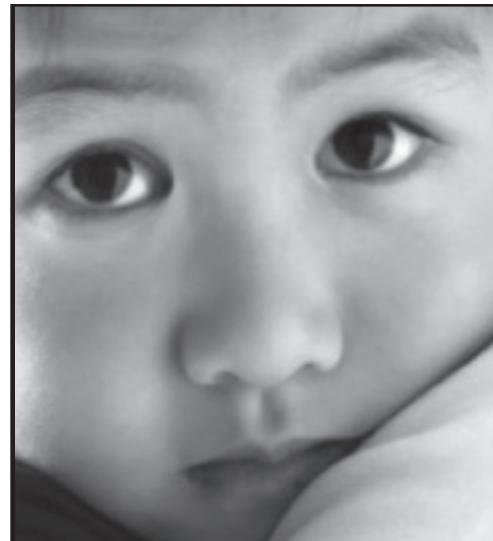
- Your child's name.
- Your child's Social Security number and date of birth.
- A phone number where you can be reached during the day.
- An indication if you want to have the Fair Hearing in person or by telephone.
- Any letter you may have received about the issue you are requesting your Fair Hearing for (provide that information).

What happens after I ask for a Fair Hearing?

You will get a letter from the Department of Public Welfare's Bureau of Hearings and Appeals telling you where the hearing will be held and the date and time of the hearing. You will receive this letter at least 10 days before the date of the hearing.

You may come to where the Fair Hearing is held or be included by phone. A family member, friend, lawyer, or other person may help you during the Fair Hearing.

Community Care will also go to your Fair Hearing to explain why the decision was made or explain what happened. If you ask, Community Care will help you to file for a Fair Hearing. Community Care will give you (at no cost) the records, reports, and other information that are relevant to your Fair Hearing.



Common characteristics of Autism include:

Disturbances in communicating with others.

Repetitive or ritualistic behavior.

Extreme sensitivity (hypersensitivity) in one of the senses, or extremely non-responsive (hyposensitive) to one of the senses.

Selective hearing and may act as deaf.

ANSWERS TO YOUR QUESTIONS



Common characteristics of Autism include:

Resistance to changes in routines.

No eye contact, appears to "look through" people.

Resistance to normal teaching methods.

Uneven gross/fine motor skills.

Marked physical overactivity or extreme passivity.

When will the Fair Hearing be decided?

A decision will be made 60-90 days from when the Department of Public Welfare receives your request. A letter will be sent to you after the decision is made. This letter will tell you the reason(s) for the decision. It will tell you what to do if you don't like the decision.

Whom can I call If my child's health is at immediate risk?

If your child's doctor or psychologist believes that using the usual time frames to decide your Fair Hearing will harm your child's health, you or your child's doctor or psychologist can call the Department of Public Welfare at 1-877-356-5355 and ask that your Fair Hearing be decided faster. This is called an Expedited Fair Hearing.

You will need to have a letter from your child's doctor or psychologist faxed to the Department of Public Welfare at 1-717-772-7827 explaining why using the usual time frames to decide your Fair Hearing will harm your child's health.

If your child's doctor or psychologist does not fax a letter, he or she may testify at the Fair Hearing to explain why using the usual time frames to decide your Fair Hearing will harm your child's health.

When will the Expedited Fair Hearing be scheduled?

The Bureau of Hearings and Appeals will contact you to schedule the Expedited Fair Hearing. The Expedited Fair Hearing will be held by phone within three business days after you ask for the Fair Hearing.

What happens if my child's doctor or psychologist does not send a written letter and does not testify at the Fair Hearing?

If your child's doctor or psychologist does not send a written statement and does not testify at the Fair Hearing, the Fair Hearing decision will not be expedited. Another hearing will be scheduled and decided within 60-90 days.

What happens if my child's doctor or psychologist sends a written letter or testifies at the Fair Hearing?

If your child's doctor or psychologist sends a written statement or testifies at the Expedited Fair Hearing, a decision will be made within three business days after you asked for the Expedited Fair Hearing.

What if I want to file an official complaint against my child's services provider or Community Care? How do I do this?

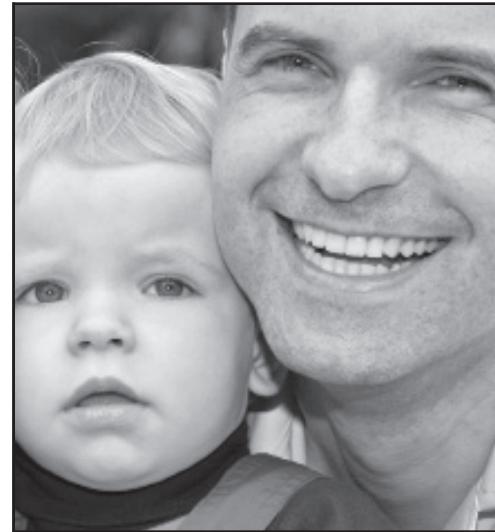
A complaint is when you tell us you are unhappy with Community Care or your child's services provider, or you do not agree with a decision made by Community Care.

Some reasons why you might file a complaint include:

- You are unhappy with the care you and/or your child are getting.
- You are unhappy that your child cannot get the service that you want for your child wants because it is not a covered service.
- You are unhappy that your child has not received services that he or she has been approved to get.

What should I do if I have more questions about the complaint and grievance processes?

Call your local Community Care customer services representative (**See Appendix G**).



Despite all the day-to-day hurdles, many people with Autism lead fulfilling, happy lives on their own or with help from friends and family.

Most teens with Autism like school, and some can attend regular classes with everyone else.

Some people with Autism go on to vocational school or college, get married, and have successful careers.

APPENDIX A: DIAGNOSTIC CRITERIA – AUTISM SPECTRUM DISORDER

The earlier a diagnosis of Autism is made, the better the chances are of a person receiving appropriate help and support.

The “Autism Spectrum Disorder” is widely defined to include the entire range of pervasive developmental disorders that are seen in children and adolescents (from birth up to the age of 21). Autistic Disorder is defined in the current version of the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-IV-TR) as:

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1) and one each from (2) and (3):
 - (1) Qualitative impairment in social interaction as manifested by at least two of the following:
 - a. Marked impairment in the use of multiple nonverbal behaviors, such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
 - b. Failure to develop peer relationships appropriate to developmental level
 - c. A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest).
 - d. Lack of social or emotional reciprocity.
 - (2) Qualitative impairments in communication as manifested by at least one of the following:
 - a. Delay in or total lack of the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
 - b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
 - c. Stereotyped and repetitive use of language or idiosyncratic language.
 - d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.
 - (3) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
 - a. Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
 - b. Apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c. Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).
 - d. Persistent preoccupation with parts of objects.
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:
 - (1) social interaction.
 - (2) language as used in social communication.
 - (3) symbolic or imaginative play.

APPENDIX B: DIAGNOSTIC CRITERIA – ASPERGER'S DISORDER

Asperger's Disorder

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (1) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction.
 - (2) Failure to develop peer relationships appropriate to a developmental level.
 - (3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
 - (4) Lack of social or emotional reciprocity.
- B. Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
 - (2) Apparently inflexible adherence to specific, nonfunctional routines or rituals.
 - (3) Stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements).
 - (4) Persistent preoccupation with parts of objects.
- C. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).
- D. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.
- E. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

It is hard to accept the diagnosis of ASD for a beloved child. There is often a period of denial and grieving. Most people experience these emotions in some way when first given the news.

But then, for many parents, the diagnosis is almost a relief. Suddenly there is a name for the problem —and even a road map to follow to help your child maximize his or her potential.

**APPENDIX C:
DIAGNOSTIC CRITERIA –
PERVASIVE DEVELOPMENT
DISORDER/PDD-NOS**

Give the people around you time to accept your child's diagnosis—once they seem receptive, give them information.

Pervasive Developmental Disorder Not Otherwise Specified (including Atypical Autism)

This category should be used when there is severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific pervasive developmental disorder, schizophrenia, schizotypal personality disorder, or avoidant personality disorder.

For example, this category includes "Atypical Autism" — presentations that do not meet the criteria for autistic disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

APPENDIX D: GLOSSARY

Autistic Spectrum Disorders: Term that encompasses Autism and similar disorders. More specifically, the following five disorders listed in the DSM-IV: Autistic Disorder, Asperger's Disorder, PDD-NOS, Childhood Disintegrative Disorder, and Rett's Disorder.

BHRS/Behavioral Health Rehabilitation Services: Community-based mental health treatment available to children with mental health needs in Pennsylvania.

BSC: Behavior Specialist Consultant, refers to an advanced degree behavioral specialist providing services through BHRS.

DSM-IV-TR: The official system for classification of psychological and psychiatric disorders prepared by and published by the American Psychiatric Association.

Discrete Trial Training: A short, instructional training which has three distinct parts, (e.g., a direction, behavior, and consequence). Many discrete trial programs rely heavily on directions or commands as the signal to begin the discrete trial.

Early Intervention (EI): A state-funded program that is designed to identify and treat developmental problems or other disabilities as early as possible.

Evaluation Report (ER): The comprehensive evaluation completed by 3-5 services through the Intermediate Unit (IU) and forwarded to the school district upon the start of school to formulate the IEP. This may include an IQ test and/or an assessment of your child's current abilities to determine whether he or she is meeting appropriate developmental milestones.

IEP/Individualized Educational Plan: A plan that identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate special education programs and services. It also identifies the methods by which the student's progress will be reviewed. For students 14 years or older, it must also contain a plan for the transition to postsecondary education or the workplace, and help the student live as independently as possible in the community.

You play an extremely important role in helping your child to develop. Like other children, kids with Autism learn primarily through play. So, it's important to join your child in play that you both enjoy.

APPENDIX D: GLOSSARY

Positive ways that you can interact with your child at home include:

Be consistent, have routines in home and when out.

Have a place where your child feels comfortable and secure.

In addition to verbal praise, find other ways to reinforce good behaviors and promote self-esteem. For example, after your child has successfully completed a task, give him or her extra time to play with a favorite toy.

ISPT/Interagency Service Planning Team: A regularly scheduled meeting which occurs throughout BHRS, to obtain input from all members of the treatment team.

MT/Mobile Therapy/Mobile Therapist: Therapy services available through BHRS.

Neurologist: A doctor specializing in medical problems associated with the nervous system, specifically the brain and spinal cord.

NOS/Not Otherwise Specified: see “PDD-NOS”

OT/Occupational Therapist: Individuals who specialize in the analysis of purposeful activity and tasks to minimize the impact of disability on independence in daily living. The therapist then helps the family to better cope with the disorder, by adapting the environment and teaching sub-skills of the missing developmental components. Occupational therapists often provide Sensory Integration Therapy.

OT/Occupational Therapy: This is a therapy provided by an occupational therapist that assists in the individual's development of fine motor skills that aid in daily living. It also can focus on sensory issues, coordination of movement, balance, and on self-help skills, such as dressing, eating with a fork and spoon, and grooming. It can also address issues pertaining to visual perception and hand-eye coordination.

PDD: Pervasive Development Disorder

PDD-NOS or PDD/NOS: Pervasive Development Disorder-Not Otherwise Specified

PECS: Picture Exchange Communication System

Perseveration: Repetitive movement or speech, or sticking to one idea or task, that has a compulsive quality to it.

Psychoeducational Evaluation: An evaluation, consisting of a set of systematic observations obtained under standardized conditions, that is critically important to the determination of eligibility for special education services and is a key component of the comprehensive evaluation report (CER), which is ultimately crafted by the multidisciplinary team. The psychoeducational evaluation is primarily completed by the student's school district but can also be completed through a private practitioner.

APPENDIX D: GLOSSARY

PT: Physical Therapy

Self-Stimulatory: A term for behaviors whose primary purpose appears to be to stimulate one's own senses. An example is rocking one's body. Many people with Autism report that some "self stims" may serve a regulatory function for them (e.g., calming, adding concentration, shutting out an overwhelming sound). Other examples include hand-flapping, toe-walking, spinning, and echolalia, which is the uncontrollable and immediate repetition of words spoken by another person.

Sensorimotor: Pertaining to brain activity other than automatic functions (respiration, circulation, sleep) or cognition. Sensorimotor activity includes voluntary movement and senses like sight, touch, and hearing.

SI/Sensory Integration: This is a term applied to the way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity.

SIT: Sensory Integration Therapy

SLP or S-LP Speech-Language Pathologist: An individual who specializes in the area of human communication. The focus is on communication, not speech, to increase the child's ability to impact and to understand his or her environment.

SSI-DC: Supplemental Security Income-Disabled Child, US program.

STAP/Summer Therapeutic Activities Program: An intensive summer treatment program for children with behavioral and/or emotional issues, often delivered in a camp-like setting.

TSS/Therapeutic Staff Support: Services or worker, refers to direct services available through BHRS.

Present information visually as well as verbally. Combine the spoken word with photographs and pictures, sign language, symbols, or gestures to help your child make his or her needs, feelings, or ideas known.

Try to show your child affection in as many ways as possible. Though some kids with Autism have trouble receiving and expressing affection, they can still benefit from a nurturing parent.

APPENDIX E: LEVELS OF CARE/ TREATMENT AVAILABLE

Inpatient Mental Health Hospitalization — Inpatient units provide a secure/locked setting for the delivery of acute care services for children and adolescents with an Autism Spectrum Disorder, additional serious mental illness, or co-occurring disorders (e.g., Intellectual Disability and drug and alcohol). Such acute care requires coordinated, intensive, and comprehensive treatment that is tailored to the individual's immediate status and needs for the purposes of continued recovery. Inpatient hospitalization is recommended when a child is considered to be a danger to him/herself or others and requires immediate stabilization. This level of care is considered to be the most intensive and restrictive.

Residential Treatment Facilities (RTF) — This level of care includes both facilities that are accredited by the Joint Commission on the Accreditation of HealthCare Organizations (JCAHO) and those that are licensed and supervised by the Department of Public Welfare but are not JCAHO-accredited. These are structured treatment facilities. Although the length of stay is determined by medical need, the average length of stay ranges from four to eight months. RTF services are not typically “first line” services invoked for the treatment of children with Autism Spectrum Disorders. Typically, use of this level of care might indicate significant behavioral problems that cannot be managed in a less restrictive treatment environment.

IRT/CRR Host Home/Therapeutic Foster Care (IRT) — IRT provides a 24 hour/day safe, structured environment within a family setting (host home) including intensive community-based treatment to support the child/adolescent's efforts to meet basic needs, utilize appropriate judgment, exercise coping skills, and comply with treatment. This is an unlocked, less restrictive, and more flexible alternative than inpatient or RTF for the delivery of acute care and for provision of transitional care from an inpatient or RTF setting.

Behavioral Health Rehabilitation Services (BHRS) — BHRS or “wraparound services” are the most commonly recommended services for children with Autism and other Pervasive Developmental Disorders and include a range of individualized behavior management, treatment, and rehabilitation services provided in community settings. Settings may include the child’s home or school, as well as other settings such camps, recreational venues, or commercial establishments.

Family-Based Mental Health Services (FBMHS) — FBMHS, team-delivered services rendered in the home and community, are designed to integrate mental health treatment, family support services, and case management, so that families may continue to care for their child/adolescent with serious mental illnesses or emotional disturbances at home. FBMHS are intended to reduce the need for psychiatric hospitalizations and out-of-home placements by providing services that enable families to maintain their role as the primary caregiver for their children and adolescents. While FBMHS are utilized less frequently for children with Autism Spectrum Disorders, such individuals may be eligible for these services when they are determined to be at high risk for out-of-home placement and involved with multiple systems.

Partial Hospital Services — This level of care provides a less restrictive, more flexible setting than inpatient hospitalization for acute care. It is often used to transition members out of acute care or as an alternative. The primary functions of partial hospitalization services include helping the patient manage the safety of himself, others, and property; reducing acute and chronic symptoms; evaluating and managing medication therapies; helping the child and family build skills that strengthen the child’s ability to function independently; and developing an aftercare plan for less restrictive, less intrusive services. Partial hospitalization is an outpatient service as the child only attends the program for part of the day

APPENDIX E: LEVELS OF CARE/ TREATMENT AVAILABLE

and returns to his or her primary residence daily.

School-Based Partial Hospital Programs (SBPH) — SBPH provides licensed mental health partial hospital services for select children and adolescents with serious emotional and mental health needs. These programs can take place in an approved private school and/or an alternative setting such as an outpatient provider. Placement in such settings is normally initiated by the student's home school district when the district can no longer effectively meet the student's education needs within its programs. Students in SBPH programs have Individualized Educational Plans as well as formal mental health treatment plans covering the range of strengths, needs, and goals of the programs.

Outpatient Services — These types of services include a range of short-term and long-term treatments which vary with the child's diagnosis, severity of illness, coping skills, and available support systems. Outpatient treatment may include medication evaluations, medication management, individual therapy, family therapy, and group therapy, and may include treatments such as positive behavior support, social skills, cognitive based interventions, and communication. Group therapy may be particularly beneficial for children and adolescents with ASD when the focus of the group is to enhance communication and social skill development. While the range of Autism-specific outpatient programs differs widely in different geographic areas, the development of such programs continues to be a focus of many providers statewide.

Resource Coordinator (RC) — This individual helps to link families to services, identifies appropriate supports/resources including both mental health and educational settings, aids in transportation to and from medical/psychiatric appointments, and identifies community supports.

Intensive Case Manager (ICM) — An ICM is very similar to an RC and can link families to services, identify appropriate supports/resources including both mental health and educational settings, aid in transportation to and from medical/psychiatric appointments, identify community supports, and monitor medication compliance. Children involved with an ICM have access to 24-hour on-call ICMs for assistance in a mental health crisis.

Crisis Services — These services may be accessed through a medical or psychiatric hospital emergency room or crisis center or via a mobile crisis team. A mobile crisis team provides individual or team-delivered intervention in the member's home, school, work, or community to address the crisis situation. Regardless of the method of crisis intervention, the main goal of crisis services is to establish safety, provide stabilization, and divert hospitalization when possible.

APPENDIX F: COMPLAINT PROCESS

What is a complaint?

A complaint is when you tell us you are unhappy with Community Care or a provider, or you do not agree with a decision made by Community Care.

These are some examples of a complaint:

- You are unhappy with the care you or your child are receiving.
- You are unhappy that your child cannot get the service that you want for him or her because it is not a covered service.
- You are unhappy that your child has not received services that have been approved for him or her.*

* Community Care providers of service must provide services within one hour for emergencies, within 24 hours for urgent situations, and within seven days for routine appointments and specialty referrals. When a treatment plan is approved, your child should expect to receive services according to that treatment plan.

What should I do if I have a complaint?

First Level Complaint

To file a complaint, call your Community Care Customer Service Representative and ask to speak to the Complaints and Grievances Department. Tell us your complaint and assistance will be provided. Or write down your complaint and mail it to the Community Care office in your area (**See Appendix G**).

When should I file a First Level complaint?

You must file a complaint within 45 days of getting a letter telling you that:

- Community Care has decided that your child cannot get a service because it is not a covered service.
- Community Care will not pay a provider for a service that your child received.
- Community Care did not decide a First Level complaint or grievance that you filed within 30 days of when you filed it.

You must file a complaint within 45 days of the date you should have received a service if your provider did not give you the service. You may file all other complaints at any time.

What happens after I file a First Level Complaint?

Community Care will send you a letter to let you know we received your complaint. The letter will tell you about the First Level complaint process.

You may ask Community Care to see the information it has about your complaint. You may also send information that may help with your complaint to the Community Care office in your area. You can also ask for assistance with your complaint by calling your customer services representative (**See Appendix G**).

APPENDIX F: COMPLAINT PROCESS

If you filed a complaint because of one of the reasons listed below, you can be included in the First Level complaint review. (You must call Community Care within 10 days of the date on the letter to tell us that you want to be included.)

- You are unhappy that your child has not received services that were approved for him or her.
- You are unhappy that Community Care has decided that your child cannot get a service that you want for him or her because it is not a covered service.
- You are unhappy that Community Care will not pay a provider for a service that your child received.
- You are unhappy that Community Care did not make a decision about your First Level complaint or grievance within 30 days of when you filed it.

You can come to a Community Care office or be included by phone. You are not required to attend this meeting. If you do not attend, it will not affect the decision. One or more Community Care staff who have not been involved in the issue you filed your complaint about will make a decision on your complaint. Your complaint will be decided no more than 30 days after it was received by Community Care.

A letter will be mailed to you no more than five business days after Community Care makes its decision. This letter will tell you the reason(s) for the decision. It will also tell you how to file a Second Level complaint if you don't like the decision.

What to do so that your child will continue getting services:

If your child has been receiving services that are being reduced, changed, or stopped because they are not covered services, and you file a complaint that is hand-delivered or postmarked within 10 days of the date on the letter (notice) telling you that the services your child has been receiving are not covered services, the services will continue until a decision is made.

What if I do not like Community Care's First Level complaint decision?

Second Level Complaint

If you are not happy with Community Care's First Level complaint decision, you may file a Second Level complaint with Community Care.

When should I file a Second Level complaint?

You must file your Second Level complaint within 45 days of the date you get the First Level complaint decision letter. Use the same address or phone number you used to file your First Level complaint.

APPENDIX F: COMPLAINT PROCESS

What happens after I file a Second Level complaint?

Community Care will send you a letter to let you know that your complaint was received. The letter will tell you about the Second Level complaint process.

- You may ask Community Care to see any information it has about your complaint. You may also send information that may help with your complaint to Community Care.
- You can come to a meeting of the Second Level complaint committee or be included by phone. Community Care will contact you to ask if you want to come to the meeting. You don't have to attend if you do not want to. If you do not attend, it will not affect the decision.
- The Second Level complaint review committee will have three or more people on it. At least one Community Care member will be on the committee. The members of the committee will not have been involved in the issue you filed your complaint about.
- The committee will make a decision no more than 30 days from the date Community Care received your Second Level complaint. A letter will be mailed to you within five business days after the committee makes its decision. This letter will tell you the reason for the decision. It will also tell you how to ask for an external complaint review if you don't like the decision.

What to do to continue getting services:

If your child has been receiving services that are being reduced, changed, or stopped because they are not covered services and you file a Second Level complaint that is hand-delivered or postmarked within 10 days of the date on the First Level complaint decision letter, the services will continue until a decision is made.

What if I still don't like the decision?

External Complaint Review

If you are not happy with the Second Level complaint decision, you may ask for a review of your complaint by the Department of Health or the Insurance Department. The Department of Health handles complaints that involve the way a provider gives care or services. The Insurance Department reviews complaints that involve Community Care's policies and procedures.

You must ask for an External complaint review within 15 days of the date you receive the Second Level complaint decision letter. If you ask, Community Care will help you put your complaint in writing.

APPENDIX F: COMPLAINT PROCESS

You must send your request for External review in writing to either:

Pennsylvania Department of Health

Bureau of Managed Care

Health and Welfare Building, Room 912

7th and Forster Streets

Harrisburg, PA 17120

Telephone Number: 1-888-466-2787

Fax: 1-717-705-0947

Relay Service: 1-800-654-5984

OR

Pennsylvania Insurance Department

Bureau of Consumer Services

1321 Strawberry Square

Harrisburg, PA 17120

Telephone Number: 1-877-881-6388

If you send your request for an External complaint review to the wrong department, it will be sent to the correct department.

The Department of Health or the Insurance Department will get your complaint information from Community Care. You may also send them any other information that may help with the external review of your complaint.

An attorney, or another person of your choice, may represent you during the External complaint review.

A decision letter will be sent to you after the decision is made. This letter will tell you the reason(s) for the decision and what you can do if you don't like the decision.

What to do to continue getting services:

If your child has been receiving services that are being reduced, changed, or stopped because they are not covered services and you file a request for an External Complaint review that is hand-delivered or postmarked within 10 days of the date on the Second Level complaint decision letter, the services will continue until a decision is made.

APPENDIX G: BUREAU OF AUTISM SERVICES

The Bureau of Autism Services (BAS) provides a wealth of information and services for individuals and families who are struggling with Autism. In 2003, in response to a significant increase in the number of individuals diagnosed with Autism Spectrum Disorder (ASD), former Pennsylvania Secretary of Public Welfare Estelle B. Richman created the Autism Task Force, which included service providers, educators, administrators, researchers, and over 250 family members struggling with Autism.

The goal of the task force was to develop a system that would “make Pennsylvania a national model of excellence in Autism service delivery” for individuals living with Autism and their families. The creation of the Office of Autism Affairs, which in early 2007 was transformed into the Bureau of Autism Services within the Office of Developmental Programs, has helped the Department of Public Welfare (DPW) take great strides towards this goal.

Nina Wall-Cote is the Director of the Bureau of Autism Services for the Pennsylvania DPW. She earned a master's degree from Bryn Mawr College's Graduate School of Social Work and Social Research. A licensed social worker who has worked in private practice with families and adolescents, she specialized as a private consultant for children with serious behavioral and emotional health challenges. Ms. Wall-Cote has also trained and supervised clinicians in southeastern Pennsylvania who work with children living with Autism Spectrum Disorder (ASD) and behavioral health challenges.

Ms. Wall-Cote was a founding member and President of the Pennsylvania Action Coalition for Autism Services (PACAS), a statewide board of autism advocacy chairs and directors representing various regions of Pennsylvania. Ms. Wall-Cote also served as a board member of Pennsylvania Protection and Advocacy (PP&A), where she represented the perspective of the autism advocacy community and challenges faced by families living with Autism throughout the Commonwealth.

According to their website, the Bureau's goals include:

- Ensuring open communication between departments.
- Expanding adult services to serve more individuals and families.
- Expanding training opportunities and establishing BAS Training certification.
- Addressing gaps in housing, transition, employment, training, and family support.
- Ensuring sustainability of BAS and its services.
- Promoting community collaboration.

The Bureau of Autism Services is a great resource for all families who are struggling with the challenges of Autism. For more information, visit www.autisminpa.org or call 1-866-539-7689.

Source: www.dpw.state.pa.us

APPENDIX H:
COMMUNITY CARE
CONTACT INFORMATION

Counties Served	Community Care Office	Customer Service
Allegheny (Main Office)	One Chatham Center Suite 700 112 Washington Place Pittsburgh, PA 15219	1-800-553-7499
Adams, Berks, York	1200 Camp Hill Bypass Suite 100 Camp Hill, PA 17011	1-866-738-9849 (Adams) 1-866-292-7886 (Berks) 1-866-542-0299 (York)
Chester	One E. Uwchlan Avenue Suite 311 Exton, PA 19341	1-866-622-4228
Carbon, Monroe, Pike	Courtyard Professional Art Bldg 300 Community Drive Suite F Tobyhanna, PA 18466	1-866-473-5862
Bradford, Columbia, Montour, Northumberland, Schuylkill, Sullivan, Snyder, Tioga, Union, Wayne	72 Glenmaura National Blvd 2nd Floor Moosic, PA 18507	1-866-878-6046
Lackawanna, Luzerne, Susquehanna, and Wyoming	72 Glenmaura National Blvd 2nd Floor Moosic, PA 18507	1-866-668-4696
Centre, Huntingdon, Mifflin, Juniata	2505 Green Tech Drive Suite F State College, PA 16803	1-866-878-6046
Cameron, Clarion, Clearfield, Elk, Forest, Jefferson, McKean, Potter, Warren	480 Jeffers Street Developac Business Park Building #2 DuBois, PA 15801	1-866-878-6046
Erie	1314 Griswold Plaza Erie, PA 16501	1-855-224-1777



COMMUNITY CARE
Behavioral Health Organization

Community Care Behavioral Health Organization
One Chatham Center, Suite 700
112 Washington Place
Pittsburgh, PA 15219
www.ccbh.com

YAB Autism Resources

BHRS Resources

Alternative Consulting Enterprises, Inc.
527 East Lancaster Avenue
Shillington, PA 19607
610-796-8110

Child & Family Support Services
4 S. 4th Street
Reading, PA 19602
610-376-8558
515 Old Swede Road, Suite B8
Old Swede Office Complex
Douglassville, PA 19518
610-385-0653

Concern Professional Services
22-24 Franklin Street
Fleetwood, PA 19522
610-944-0445

Familicare Counseling
501 Washington Street, 7th Floor
Reading, PA 19601

Holcomb Behavioral Health Systems
1940 N. 13th, Suite 248
Reading, PA 19604

Milestones Achievement Center
Integrated supports under one roof for children with serious and/or complex educational and behavioral challenges who cannot be supported optimally in their home school, at least for a period of time. Supports offered include: Applied Behavior Analysis; Occupational Therapy; nursing services; Physical Therapy; Special Education; Speech Therapy; Therapeutic Camping; and whatever a child needs.

345 N. Wyomissing Boulevard
Reading, PA 19610
610-396-3672; Email: info@macamerica.net

Milestones Achievement Center – York County
555 Ryan Run Road, Suite 201
York, PA 17404
717-848-1623; Email: info@macamerica.net
NHS Human Services
149 East College Avenue
Spring Grove, PA 17362
717-764-2559

Pennsylvania Comprehensive Behavioral Health Services
1651 Mount Zion Road
York, PA 17402
717-600-0900

Pennsylvania Counseling Services
128 N. George Street
York, PA 17401
717-848-6116

Pennsylvania Counseling Services
1733 Penn Avenue
Reading, PA 19609
610-670-9924

Progressions (Eugenia Hospital)
144 N. 6th Street
Reading, PA 19601
610-375-7454

Viaquest Behavioral Health of PA
555 Raymond Street
Reading, PA 19609
610-929-7570

Youth Advocate Program
1220 Centre Avenue
Reading, PA
610-478-7561

Youth Advocate Program
127 W. Market Street
York, PA 17401
717-843-9555

EI Resources

To access Early Intervention (EI) services for your child ages birth to 3, please contact your local Mental Health/Mental Retardation (MH/MR) office. To access Early Intervention services for your child ages 3-5, please contact your local Intermediate Unit (IU).

MH/MR Offices

Berks County Services Center
633 Court Street, 15th Floor, Reading, PA 19601, 610-478-3271 or 610-478-4980

York/Adams Mental Health/Mental Retardation Program, www.york-county.org
Steven A. Warren, Director, sawarren@york-county.org
100 West Market Street, Suite 301, York, PA 17401
717-771-9618 or 1-800-441-2025, Ext. 9618; Fax: 717-771-9826

Intermediate Units (For referral to Early Intervention ages 3-5)

Capital Area Intermediate Unit
55 Miller Street, Summerdale, PA 17093-0489, 717-732-8400
Email: info@caiu.org

Intermediate Unit - Berks County
1111 Commons Boulevard, PO Box 16050, Reading, PA 19612, 610-987-2248

Lincoln Intermediate Unit

Offers a variety of services through the Autistic Support Program, including autistic support classrooms, support for children within a regular education setting, in-service and training programs and a pre-referral assessment procedure. A team of professionals work together and employ various techniques and methodologies in helping each child to reach his or her fullest potential.

Mrs. Brenda Hartman, Program Supervisor, bahartman@iu12.org

Ms. Dawn Dull, Program Secretary, dmdull@iu12.org

Lincoln Intermediate Unit No. 12

65 Billerbeck Street, PO Box 70, New Oxford, PA 17350, 717-624-6466; Fax: 717-624-6519

Capital Area Intermediate Unit

55 Miller Street, Summerdale, PA 17093-0489, 717-732-8400

Email: info@caiu.org

Autistic Unit (provides specific case management to children with a diagnosis of Autism ages 5 -18)

100 West Market Street, York, PA 17401, 717-771-9618

Early Intervention

120 West Market Street, York, PA 17401, 717-771-9618

Early intervention services. They will assess and refer for whatever services are deemed necessary for the child, which could include case management, referral to Easter Seals, etc.

Community Support Resources

Adult Issues

Planning for the future, <http://www.autism-society.org/site/PageServer?pagename=livingplanning>

Autism Living and Working, <http://www.autismlivingworking.org/>

ALAW is demonstrating, through the Autism Pilot Program developed jointly with the Pennsylvania Department of Public Welfare's Office of Social Programs that adults with Autism/Pervasive Developmental Disorder can be accommodated in order to live as valued neighbors, workers, and full citizens of our Commonwealth.

Advocacy

ABOARD (Advisory Board on Autism and Related Disorders), www.aboard.org

Committed to “maximizing potential, maximizing possibilities” for children, adolescents, and adults with Autism. ABOARD offers information dissemination, a lending library, support groups across the state, and media communications.

35 Wilson Street, Suite 100, Pittsburgh, PA 15233, 412-781-4116

Advocacy and Resources for Citizens (ARC) with Cognitive, Intellectual, and Developmental Disabilities, www.thearcpa.org

Local ARC chapters offer information about advocacy, community resources, outpatient therapists, and support groups.

The Arc of Adams County, PO Box 551, Biglerville, PA 17307, 717-677-8487

The Arc of Montgomery, Berks, and Bucks, 3075 Ridge Pike, Eagleville, PA 19403, 610-265-4700

The Arc of York County, 497 Hill Street, York, PA 17403, 717-846-6589

Asperger Advocates, <http://www.orgsites.com/pa/aspergeradvocates/index.html>

A support group for families of children with Asperger's Syndrome. This group serves York County, Pennsylvania. They support one another to learn more about the challenges of raising a child with Asperger's through speakers, shared experiences, and information.

A.S.P.I.R.E. (Asperger's Syndrome Parents Interested in Resources and Education)

A family support group in the Reading/Berks County Area for parents and caregivers of adolescents and young adults with Asperger's Syndrome or High Functioning Autism, seeking empowerment through an exchange of information, support, and fellowship.

Meetings are free and open to the public. Lending library available.

The Reading Hospital and Medical Center, Education Room D

Sixth Avenue and Spruce Street, West Reading, PA 19611

Mara or Randy Winn, 610-670-1053

Anne Rubright, Alr1030@aol.com

Autism Organizations and Websites

DPW Bureau of Autism Services, <http://www.dpw.state.pa.us/ServicesPrograms/Autism>
Resources, trainings, and general information.

Autism Society of America, www.autismweb.com/resources

Includes information on Applied Behavior Analysis and the diagnostic criteria for Autism and other Pervasive Developmental Disorders.

Autism Society of America, York, PA Chapter, info@autismyork.org

Provides support to parents, family, and friends of individuals on the Autism Spectrum.

The group promotes understanding and respect of all families and the choices they make regarding therapies and interventions. They offer opportunities for families to learn, grow, and develop relationships as they guide one another through the journey of Autism Spectrum Disorders. To stay connected, the group hosts 2 message boards on Google Groups. The first, <http://groups.google.com/group/AutismYork>, is for announcements regarding upcoming events only. The second,

<http://groups.google.com/group/AutismYorkChat>, is used by families to ask questions, provide support, share knowledge, voice frustrations, and to keep everyone updated on future events.

PO Box 6683, Wyomissing, PA 19610, 610-736-3739 or 717-801-1272

Autism Society of Berks County

PO Box 6613, Wyomissing, PA 19610, 610-736-3739

Autism Information, www.autisminfo.com

Education, resources, and advocacy.

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

Provides help and support for families using casein and gluten free diet in the treatment of Autism and related disorders.

Autism Speaks, www.autismspeaks.org

Autism Speaks aims to bring the Autism community together as one strong voice to urge the government and private sector to listen to concerns and take action.

Autism Today, www.autismtoday.com

Autism directory, forum, events, and information about interventions.

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

Autism Research Network, www.autismresearchnetwork.org

Provides information about the networks supported by the National Institute of Health and the research they conduct.

Autism Society of America, www.autism-society.org
Education, resources, and advocacy.

Applied Behavior Analysis Resources (Richard Saffran's Website), rsaffran.tripod.com
Information on treatment and therapy (including applied behavior analysis, behavioral intervention, behaviors modification, and discrete trial training), special education, early intervention, and child disability resources.

Autism Connection, www.autism-connection.org
Nonprofit, providing information and resources about Autism and other developmental disabilities.

Dr. Carbone (Verbal Behavior), www.drcarbone.net
Verbal behavioral therapy.

Center for Excellence in Autism Research (CeFAR),
<http://www.wpic.pitt.edu/research/CeFAR/default.htm>
This Pittsburgh based Center of Excellence under the direction of Nancy J Minshew, MD, an internationally recognized expert in Autism, is among the top three CPEA's in the country. Dr. Minshew is working with a team of scientists from Carnegie Mellon University as well as the University of Illinois at Chicago, to search for the genetic, cognitive and neurological basis for Autism.

Centers for Disease Control, <http://www.cdc.gov/ncbddd/autism/>
Autism information.

Christina Burk, www.christinaburkaba.com
Applied Verbal Behavior

Cure Autism Now, www.canfoundation.org
An Autism Speaks website.

Dana's View from the Inside, www.danasview.net
Message board links and stories of recovery.

Dan Marino's Childnettv, www.childnet.tv

Dan Marino's Foundation, www.danmarinofoundation.org

Defeat Autism Now, www.autism.com/ari

ARI, a non-profit organization, publishes the Autism Research Review International, a quarterly newsletter covering biomedical and educational advances in Autism research.

Developmental Delay Resources, www.devdelay.org

A nonprofit organization dedicated to meeting the needs of those working with children who have developmental delays in sensory motor, language, social, and emotional areas. DDR publicizes research into determining identifiable factors that would put a child at risk and maintains a registry, tracking possible trends. DDR also provides a network for parents and professionals and current information after the diagnosis to support children with special needs.

Do 2 Learn, www.do2learn.com

Offers ASD information and picture schedules.

Exploring Autism, www.exploringautism.org

Helps families who are living with the challenges of Autism stay informed about breakthroughs involving the genetics of Autism. Explains genetic principles as they relate to Autism and provides the latest research news.

Families for Early Autism Treatment, www.feat.org

A non-profit organization of parents, family members, and treatment professionals dedicated to providing best outcome education, advocacy, and support for the Autism community.

First Signs, www.firstsigns.org

A national non-profit organization dedicated to educating parents and pediatric professionals about the early warning signs of Autism and other developmental disorders.

Generation Rescue, www.generationrescue.org

Formed by parents of children who have been diagnosed with childhood neurological disorders (NDs). Provides scientific and medical literature in support of the position that environmental illnesses can be treated through biomedical intervention.

Governor's Commission for Children and Families, www.pachildren.state.pa.us

Health and Human Services, advocacy resources, and guides for parents and families.

Monarch Educational Materials www.monarchmaterials.com
Dedicated to helping individuals diagnosed with Autism, PDD, Asperger's Syndrome, ADHD, Reactive Attachment Disorder, and developmental delays, by creating tools that promote identification, generalization, social skills, conversational skills, and recall ability.

National Autism Association, www.nationalautismassociation.org
Educating and empowering families affected by Autism and other neurological disorders, while advocating on behalf of those who cannot fight for their own rights.

OASIS (Asperger's Support), www.udel.edu/bkirby/asperger/
Online Asperger Syndrome information and support.

Relationship Development Intervention (Dr. Steven Gutstein) –
www.connectionscenter.com
Details Dr. Steven Gutstein's intervention.

Talk About Curing Autism, www.tacanow.org
Provides information and resources and support to families affected by Autism.

Unlocking Autism, www.unlockingautism.org
Founded to increase awareness about Autism.

Yahoo! Groups – www.yahoo.com
Over 700 chat rooms and message boards related to Autism can be found be 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
Available through the Autism Society of America.

Autism/Asperger's Digest Magazine, www.autismdigest.com
Monthly magazine offering information about Autism, Asperger's Syndrome, and Pervasive Developmental Disorder.

Exceptional Parent, www.eparent.org
Monthly magazine for parents of children with special needs.

Future Horizons, www.futurehorizons-autism.com
Catalogs, newsletters, books, audiotapes, videos, and a list of conferences.

Mothering Magazine, www.mothering.com
A natural family living magazine often featuring columns and stories about families affected by Autism Spectrum Disorders.

Newly diagnosed information: Familial Stress, <http://www.autism-society.org/site/PageServer?pagename=livingfamily>.

An article from the Autism Society of America; discusses and outlines the unique stressors experienced by families who have recently received a diagnosis of Autism for one of their children.

Schafer Autism Report, home.sprynet.com/~schafer
Daily email report, perhaps the most comprehensive publication on the latest news about everything related to Autism.

Autism Schools

NHS Autism Schools, <http://www.nhsonline.org/AutismSchools.htm>
Licensed private academic schools for children and youth with Autism Spectrum Disorders.

Contact: Susan Campbell.

Reading (Berks County), 641 Gregg Avenue, Reading, PA 19611, 610-208-0466; Fax: 617-208-0774
Corlene Ocker, Director

York (York County), 3151 W. Market Street, York, PA 17404, 717-792-2304; Fax: 717-792-2907
George Severns, Director

The Vista School, <http://www.thevistaschool.org/>
1801 Oberlin Road, Middletown, PA, 717-985-9655

Blindness

PA Blindness Association

Covers an initial visit to optometrists for children with Autism if their primary health insurance does not. Home and community-based assistance.

866-695-7673; 800-757-5042

Communication Resources

Do 2 Learn, <http://www.dotolearn.com/>

A web site providing activities to promote independence in children and adults with special learning needs. Free teacher and parent materials.

Picture Exchange Communication System (PECS), <http://www.pecs.com/>

Lori Frost and Andy Bondy pioneered the development of The Picture Exchange Communication System (PECS) beginning in 1985 within the state of Delaware. It is a unique augmentative/ alternative training package that allows children and adults with Autism and other communication deficits to initiate and develop functional communication.

Boardmaker-Mayer-Johnson, <http://www.mayer-johnson.com>

Enhances learning and human expression for individuals with special needs through symbol-based products, training and services. To facilitate the creation of symbol-based communication and educational tools, Mayer-Johnson offers a family of powerful, yet easy-to-use Boardmaker software products designed for specific needs.

Assistive Communication Links, <http://prekese.dadeschools.net/PRIMETIME/PTlinks.htm>

Adapted Books,

<http://schools.nycenet.edu/D75/academics/literacy/adaptedbooks/catalog.htm>

Complete catalog of books with pictures files in order to adapt and make them more interactive. Uses boardmaker and Adobe PDF.

Community Resources

All About Children Pediatric Partners

Specializing in Pediatrics; caring for children and young adults to age 18, and persons with special challenges. Affiliated with the Reading Hospital Medical Center and St. Joseph's Medical Center.

655 Walnut Street, West Reading, PA 19611, 610-372-9222

Amazing Kids Club of Adams Hanover Counseling Services

33 Frederick Street, Hanover, PA 17331, 717-646-2953

Autism Society of Berks County

PO Box 6683, Reading, PA 19612, 610-736-8739

Easter Seals Central Pennsylvania (York)

Therapeutic Recreation

2201 South Queen Street, York, PA 17402, 717-741-3891 or 1-888-372-7280; Fax: 717-741-5359

Mental Health/Mental Retardation - Berks County

Berks County Service Center

633 Court Street, 15th Floor, Reading, PA 19601, 610-478-3271

Milestones Achievement Center

Integrated supports under one roof for children with serious and/or complex educational and behavioral challenges who cannot be supported optimally in their home school, at least for a period of time. Supports offered include: Applied Behavior Analysis; Occupational Therapy; nursing services; Physical Therapy; Special Education; Speech Therapy; Therapeutic Camping; and whatever a child needs.

345 N. Wyomissing Boulevard, Reading, PA 19610, 610-396-3672; Email: info@macamerica.net

Milestones Achievement Center – York County

555 Ryan Run Road, Suite 201, York, PA 17404, 717-848-1623; Email: info@macamerica.net

Service Access and Management – Adams County

334 York Street, Gettysburg, PA 17325, 717-848-8744 or 1-888-245-8744

Service Access and Management – Berks County
19 N. 6th Street, Suite 300, Reading, PA 19601, 610-236-0530 or 1-877-236-4894

NHS Human Services
651 Albright Avenue, York, PA 17404, 717-843-0064

NHS Human Services
210 N. Park Road, Wyomissing, PA 19610, 610-396-9600

United Way of Berks (Easter Seals)
Provides quality, comprehensive programs and services to people with disabilities and other special needs in the community by creating solutions that promote dignity and change lives by maximizing each individual's potential.

James Reece, Vice President, 1040 Liggett Avenue, Reading, PA 19611
610-775-1431 or 610-685-4550

Developmental Disabilities Planning

Graham Mulholland, Executive Director, Developmental Disabilities Council
569 Forum Building, Commonwealth Avenue, Harrisburg, PA 17120
717-787-6057; 1-877-685-4452; Fax: 717-772-0738; paddpc@aol.com

Diagnosis/Developmental Pediatricians

Albert Einstein Healthcare Network
Behavioral Pediatrics/Developmental Medicine
Einstein Center One, Suite 220, 9880 Bustleton Avenue, Philadelphia PA 19115, 215-827-1500

Children's Hospital of Philadelphia
34th Street and Civic Center Boulevard, Philadelphia, PA 19104, 215-590-1000

Geisinger Medical Center
Pediatric Neurodevelopment, 100 N Academy Avenue, Danville, PA 17822, 570-214-9361

Good Shepherd Rehabilitation Hospital
Pediatric Services, 850 South Fifth Street, Allentown, PA 18103, 1-888-44-REHAB

Penn State Hershey Autism Center
Penn State Milton S. Hershey Medical Center
500 University Drive, PO Box 850, HP16, Hershey, PA 17033, 717-531-8338

St. Christopher's Hospital for Children
Department of Pediatrics, Section of Developmental Pediatrics
Erie Avenue at Front Street, Philadelphia, PA 19134, 215-427-5531

Early Intervention

First Signs, <http://www.firstsigns.org>
Educates parents, healthcare providers, early childhood educators, and other professionals in order to ensure the best developmental outcome for every child. Goals are to improve screening and referral practices and to lower the age at which young children are identified with Autism and other developmental disorders. The First Signs website provides a vital resources, covering a range of issues including healthy development, concerns about a child, screening and referral processes, and treatments for Autism Spectrum Disorders.

Checklist for growing children,
<http://www.dpw.state.pa.us/Child/EarlyIntervention/003670018.htm>
Appropriate milestones for children ages 1 month - 3 years.

Planning for the IFSP, <http://www.dpw.state.pa.us/Child/EarlyIntervention/003670020.htm>
A family's introduction to Early Intervention program planning.

Early Intervention contact numbers,
<http://www.dpw.state.pa.us/Child/EarlyIntervention/003670016.htm>

Early Intervention/Intermediate Units

Capital Area Intermediate Unit
55 Miller Street, Summerdale, PA 17093, 717-732-8400, Email: info@caiu.org

Intermediate Unit - Berks County
1111 Commons Boulevard, PO Box 16050, Reading, PA 19612, 610-987-2248

Lincoln Intermediate Unit

Offers a variety of services through the Autistic Support Program, including autistic support classrooms, support for children within a regular education setting, in-service and training programs and a pre-referral assessment procedure. A team of professionals work together and employ various techniques and methodologies in helping each child reach his or her fullest potential.

Mrs. Brenda Hartman, Program Supervisor, bahartman@iu12.org

Ms. Dawn Dull, Program Secretary, dmdull@iu12.org

Lincoln Intermediate Unit No. 12, 65 Billerbeck Street, PO Box 70, New Oxford, PA 17350
717-624-6466; Fax: 717-624-6519

Capital Area Intermediate Unit

55 Miller Street, Summerdale, PA 17093, 717-732-8400, Email: info@caiu.org

Educational Advocate

Pennsylvania Education For All Coalition

Chapter meetings, on-line community, parent consultant network.

Diane Perry

The Partnership Institute on Disabilities

Temple University, 1301 Cecil B Moore Avenue, Room 423 Ritter Annex, Philadelphia,
PA 19122

215-204-3031; 610-522-0698

Pennsylvania Protection and Advocacy

Ellen Mancuso, emancuso@ppainc.org

Coalition of Pennsylvania advocacy groups for children with special needs.

Educational Resources

Bureau of Special Education, <http://www.pde.psu.edu>

Department of Education, 333 Market Street, 7th Floor, Harrisburg, PA 17126-0333

Dr. Frances Warkomski, State Director, 00sedir@psupen.psu.edu

717-783-6913; TTY: 1-800-879-2301

Employment

Office of Vocational Rehabilitation,
<http://www.dli.state.pa.us/landi/cwp/view.asp?A=128&Q=61197>
OVR provides a wide range of services to eligible applicants including: diagnostic services, vocational evaluation, counseling, training, restoration services, placement assistance, assistive technology and support services. Students in the eleventh and twelfth grades with Autism are eligible for services into adulthood.
1130 12th Avenue, Suite 500, Altoona, PA 16601, 814-946-7240 or 1-800-442-6364
(Serving Centre and Huntingdon Counties)
555 Walnut Street, 8th Floor, Harrisburg, PA 17101, 717-787-7836

Feeding

The Feeding Evaluation Clinic
Dr. Keith Williams, Director, Hershey Medical Center
PO Box 850, Hershey, PA 17033, 717-531-7117

Hospitals

Hershey Medical Center
PO Box 850, Hershey, PA 17033, 717-531-7117

Insurance Departments

Pennsylvania Insurance Department
Bureau of Consumer Services, 1321 Strawberry Square, Harrisburg, PA 17120
717-787-2317; 1-877-881-6388

Interventions

Applied Behavior Analysis(ABA) encompasses a spectrum of specific therapies:

Discrete Trial Therapy, http://kathyandcalvin.com/manuals/aba_train.htm
Good overview of DTT with examples.

Lovass Therapy, www.lovass.com

Verbal Behavior, <http://www.autismusaba.de/lovaasvb.html>

Discusses the differences between Lovaas and Verbal Behavior. The Lovaas-based approach uses ABA to teach language skills based on the premise that receptive language should be developed prior to expressive language. The Verbal Behavior approach focuses on teaching specific components of expressive language (mands, tacts, intraverbals among others) first.

Fluency Training, <http://www.autismteachingtools.com/page/bbbbfg/bbbbfbz>

A brief overview of fluency concepts, as well as fluency charts and examples of how to use them.

Precision Teaching,

<http://psych.athabascau.ca/html/387/OpenModules/Lindsley/introa1.shtml>

A brief overview of fluency concepts, as well as fluency charts and examples of how to use them.

Incidental Teaching, <http://www.spiesforparents.cpd.usu.edu/Modules/Module%203%20-%20Incidental%20Teaching/Introduction.htm>

Basic overview and explanation of incidental teaching and provides examples. Positive behavior supports.

DIR– Floortime, <http://www.floortime.org/faqs.php?faqid=3>

The DIR (Developmental, Individual-Difference, Relationship-Based)/Floortime approach provides a comprehensive framework for understanding and treating children challenged by Autism Spectrum and related disorders. It focuses on helping children master the building blocks of relating, communicating and thinking, rather than on symptoms alone.

TEACCH, <http://www.teacch.com/>

Social Stories, <http://www.thegraycenter.org/socialstories.cfm>

A Social Story™ describes a situation, skill, or concept in terms of relevant social cues, perspectives, and common responses in a specifically defined style and format. The goal of a Social Story™ is to share accurate social information in a patient and reassuring manner that is easily understood by its audience. Half of all Social Stories™ developed should affirm something that an individual does well.

Picture Exchange Communication System (PECS), <http://www.pecs.com/>
PECS is an augmentative communication system developed to help individuals quickly acquire a functional means of communication. PECS is appropriate for individuals who do not use speech or who may speak with limited effectiveness, e.g., those who have articulation or motor planning difficulties, limited communicative partners, lack of initiative in communication, etc.

American Sign Language (ASL), <http://www.lifeprint.com/asl101/>

Sensory Integration Therapies, <http://216.194.201.208/terrytown/sensoryintegration.org/>

Interventions/Other

Gluten/Casein free diet, <http://www.gfcfdiet.com>

Complementary approaches, <http://www.autism-society.org/site/PageServer?pagename=ComplementaryApproaches>
Discusses art, music, and animal therapies.

Biomedical and dietary approaches, <http://www.autism-society.org/site/PageServer?pagename=BiomedicalDietaryApproaches>

Kids

Just for Kids Autism Fact Sheet, <http://www.njcosac.org/cosacautism>
Article explaining Autism to kids in simple language with pictures.

Law

Education Law Center, www.elc-pa.org
Non-profit legal advocacy and educational organization dedicated to ensuring that all of Pennsylvania's children have access to a quality public education.

Pennsylvania Health Law Project, www.phlp.org
Toll-free help line, 1-800-274-3258

Pennsylvania Department of Education, www.pde.state.pa.us/
333 Market Street, Harrisburg, PA 17126, 717-783-6788

Pennsylvania Disability Law Project, dlp-pa.org
1-800-538-8070; 215-238-8070

Phil Drumheiser, Esq., pdrumheiser@epix.net
Attorney specializing in Autism rights.
717-245-2688

Medical Professionals

American Academy of Pediatrics, <http://www.aap.org/healthtopics/autism.cfm>

First Signs, <http://www.firstsigns.org>
Educates parents, healthcare providers, early childhood educators, and other professionals in order to ensure the best developmental outcome for every child. Goals are to improve screening and referral practices and to lower the age at which young children are identified with Autism and other developmental disorders. The First Signs website provides vital resources that cover a range of issues including healthy development, concerns about a child, screening and referral processes, and treatments for Autism Spectrum Disorders.

AAP-The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children,
<http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/5/e85>

Centers for Disease Control-Autism Information, <http://www.cdc.gov/ncbddd/autism/>

Autism toolkit for physicians,
<http://www.northshorelij.com/body.cfm?id=4726&oTopID=4725&PLinkID=2849>
Helpful informational topics for health care practitioners including special considerations for seeing patients with Autism, screening tools, research, and more.

National Institute of Mental Health,
<http://www.nimh.nih.gov/healthinformation/autismmenu.cfm>
Information on Autism from the National Institute of Mental Health.

Mental Health/Mental Retardation Program

Autistic Unit
141 West Market Street, York, PA 17401, 717-771-9618

Berks County Services Center
633 Court Street, 15th Floor, Reading, PA 19601, 610-478-3271 or 610-478-4980

Early Intervention
120 West Market Street, York, PA 17401, 717-771-9618

York/Adams Mental Health/Mental Retardation Program, www.york-county.org
Steven A. Warren, Director, sawarren@york-county.org
100 West Market Street, Suite 301, York, PA 17401
717-771-9618 or 1-800-441-2025, ext 9618; Fax: 717-771-9826

Occupational, Physical, and Speech Therapies

Memorial Hospital
325 South Belmont Street, PO Box 15118, York, PA 17405, 1-800-436-4326

Reading Hospital and Mental Health Center of Berks Co.
Sixth Avenue and Spruce Street, West Reading, PA 19611, 610-988-8000 or 866-988-4377

Parent Training Information

Parent Education Network, pen@parentednet.com; www.parentednet.org
333 East 7th Avenue, York, PA 17404, 717-845-9722; 1-800-522-5827

Parents Union for Public Schools, ParentsU@aol.com
Linda White
1315 Walnut Street, Suite 1124, Philadelphia, PA 19107, 215-546-1166; Fax: 215-731-1688

PEAL Center

Pennsylvania's Parents Training and Information Center serving Western and Central Pennsylvania. Organization provides disability information, information about special education process and parent's rights, Parent Advisors are available to provide info and resources to assist the family with problem-solving strategies and direct them to other community resources, trainings in understanding IEP's, IDEA'04, building continuity, etc.

Parent Education and Advocacy Leadership Center

1119 Penn Avenue, Suite 400, Pittsburgh, PA 15222, 412-422-1040; 1-866-950-1040

Debra Efekman, defkeman@pealcenter.org

Pennsylvania Training and Technical Assistance Network (PaTTAN),

<http://www.pattan.k12.pa.us>

6340 Flank Drive; Suite 600, Harrisburg, PA 17112, 717-541-4960; 1-800-360-7282

Janet Armstrong, jarmstrong@pattan.k12.pa.us

Pittsburgh Office, www.pattan.k12.pa.us/about/PaTTANPittsburgh.aspx

3190 William Pitt Way, Pittsburgh, PA 15238, 412-826-2336; 1-800-446-5607

Psychologists

CHOP Department of Psychology,

<http://www.chop.edu/consumer/jsp/division/service.jsp?id=26704>

The Department of Psychology at The Children's Hospital of Philadelphia provides comprehensive inpatient and outpatient psychological services for infants, children and adolescents with pediatric conditions and their families.

Psychiatrists

CHOP Department of Psychiatry,

<http://www.chop.edu/consumer/jsp/division/service.jsp?id=27690>

The Department of Child and Adolescent Psychiatry offers an array of outpatient and emergency services. Provide comprehensive evaluation and treatment of children and adolescents with psychiatric conditions and behavioral or emotional difficulties. Specialty clinics include the Attention Deficit Hyperactivity Disorders program, the Mood and Anxiety Disorders clinic and the Pediatric Psychopharmacology program. Actively engaged in clinical research to support state-of-the-art patient care.

Safety

Safety in the home, <http://www.autism-society.org/site/PageServer?pagename=livingsafety>

Resources and ideas for assuring the home is a safe environment for the child and family.

Safety ID cards to print, <http://www.leanonus.org/pages/11/index.htm>

ID cards to print and put relevant information that would assist first responders and police should there ever be emergent situation requiring law enforcement.

Police and Autism, <http://policeandautism.cjb.net/avoiding.html>

Information on how parent and law enforcement can work together to provide a quick response in the event that a child elopes or runs from the caregivers.

Medic Alert, <http://www.medicalert.org/Home/HomeEmblemCatalogs.aspx>

Provides comprehensive Kid Smart services that can safeguard and identify your child in an emergency. With a single phone call, emergency response personnel can access medical history and records, protecting your child against potentially adverse treatments or medication conflicts.

Child Locator (GPS watches for kids), <http://childlocator.com/>

Child friendly watches that serve as a GPS system.

Safety Harnesses, <http://www.the-baby-boutique.com/tottether.html> and <http://www.the-baby-boutique.com/harnessbuddy.html>

Harnesses that help protect your child from danger by allowing close access of your child, but still allowing for exploration.

Sibling Issues

Autism Society article on sibling issues, <http://www.autism-society.org/site/PageServer?pagename=livingsiblings>

Discusses some strategies on addressing the needs of the siblings of children who have Autism.

Sibshops, <http://www.thearc.org/siblingsupport/sibshops-about#>

Support groups for siblings of children with special needs. Provides a listing by state of available groups. Website also has a listserv for siblings as well as a pen-pal program.

State Departments/Agencies/Programs and Other Resources

(CAP) Pennsylvania Client Assistance Program

Advocacy program helps people who are seeking services from the OVR, Blindness, Visual Services, Centers for Independent Living, and other programs funded under federal law. Provides info and advice about rehab programs and legal rights/responsibilities and helps resolve problems that may arise while seeking services from rehab programs. There is no charge.

Steve Pennington, Statewide Director Center for Disability Law & Policy

1617 JFK Boulevard, Suite 800, Philadelphia, PA 19103

215-557-7112 (V/TTY), 1-888-745-CDLP; Harrisburg Office: 717-364-1733

info@equalemployment.org

Department of Public Welfare – Office of Mental Health and Substance Abuse,

www.dpw.state.pa.us/omhsas/dpwmh.asp

Health & Welfare Building, Room 502, PO Box 2675, Harrisburg, PA 17105, 717-787-

6443

Department of Public Welfare – Office of Mental Retardation,

www.dpw.state.pa.us/omr/dpwmr.asp

Health & Welfare Building Room 512, PO Box 2675, Harrisburg, PA 17105, 717-787-

3700

Pennsylvania Consumer Protection and Advocacy

1414 North Cameron Street, Suite C, Harrisburg, PA 17103, 1-800-692-7443, 1-877-375-

7139 (TDD)

ppa@ppainc.org

Programs for Children and Youth who are Deaf or Hard of Hearing

Debra Maltese, Director, Office for the Deaf and Hard of Hearing

1110 Labor & Industry Building, 7th and Forster Streets, Harrisburg, PA 17120

717-783-4912 (V/TTY), 1-800-233-3008 (V/TTY)

Programs for Children with Special Health Care Needs

C. Gail Stock, Director, Division of Special Health Care Programs

Department of Health, Room 724, PO Box 90, Harrisburg, PA 17108, 717-783-5436

Programs for Infants and Toddlers with Disabilities: Birth through 2 years
Jacqueline Epstein, Chief, Children's Services Division
Office of Mental Retardation, Department of Public Welfare
PO Box 2675, Harrisburg, PA 17105, 717-783-8302

Programs for Children with Disabilities: Ages 3 through 5
Richard Price, Chief, Division of Early Intervention
Bureau of Special Education, Department of Education
333 Market Street, 7th Floor, Harrisburg, PA 17126, 717-783-6879

Protection and Advocacy Agency
Kevin Casey, Executive Director, Pennsylvania Protection & Advocacy, Inc.
1414 N. Cameron Street, Suite C, Harrisburg, PA 17103, 717-236-8110; 1-800-692-7443
(V/TTY)

State Agency for the Visually Impaired
Douglass C. Boone, Director, Blindness & Visual Services, Dept. of Public Welfare
PO Box 2675, Harrisburg, PA 17105, 717-787-6176; 1-800-622-2842

State Coordinator of Vocational Education for Students with Disabilities
Marjorie Lowe Blaze, Supervisor, Special Populations Section, Department of Education
Bureau of Vocational-Technical Education, 333 Market Street, 6th Floor, Harrisburg, PA
17126
717-787-5293

State Department of Education: Special Education
Bureau of Special Education, Department of Education
333 Market Street, 7th Floor, Harrisburg, PA 17126, 717-783-2311

State Developmental Disabilities Planning Council
Graham Mulholland, Executive Director, DD Planning Council
568 Forum Building, Commonwealth Avenue, Harrisburg, PA 17120, 717-787-6057

State Education Agency Rural Representative
Thomas Winters, Division Chief, Advisory Service, Department of Education
333 Market Street, 6th Floor, Harrisburg, PA 17126, 717-787-8022

State Mental Health Agency
Charles Curie, Deputy Secretary for Mental Health
Office of Mental Health, Department of Public Welfare
Health & Welfare Building, Room 502, PO Box 2675, Harrisburg, PA 17105, 717-787-6443

State Mental Health Representative for Children and Youth
Anita K. Thiemann, Director, Bureau of Children's Services
Office of Mental Health Department of Public Welfare, PO Box 2675, Harrisburg, PA 17105, 717-772-2351

State Mental Retardation Program
Nancy R. Thaler, Deputy Secretary for Mental Retardation
Department of Public Welfare
Health & Welfare Building, Room 512, PO Box 2675, Harrisburg, PA 17105, 717-787-3700
E-mail: PADPWNT@aol.com

State Vocational Rehabilitation Agency
Gil Selders, Executive Director
Office of Vocational Rehabilitation, Department of Labor & Industry
1300 Labor & Industry Building, Seventh and Forster Streets, Harrisburg, PA 17120, 717-787-5244

WIC (Women-Infants-Children) Supplemental Nutrition Program
You are eligible if your child receives Medical Assistance regardless of your income.
1-800-942-9467

Support Groups

Asperger Advocates, <http://www.orgsites.com/pa/aspergeradvocates/index.html>
A support group for families of children with Asperger's Syndrome. This group serves York County, Pennsylvania. They support one another to learn more about the challenges of raising a child with Asperger's through speakers, shared experiences, and information.

A.S.P.I.R.E. (Asperger's Syndrome Parents Interested in Resources and Education)
A family support group in the Reading/Berks County Area for parents and caregivers of adolescents and young adults with Asperger's Syndrome or High Functioning Autism, seeking empowerment through information, support, and fellowship. Meetings are free and open to the public. Lending library available.

Autism and Other Neurobiological Disorders Online Support Group,
http://health.groups.yahoo.com/group/Autism_and_Other_Neurobiological_Disorders/

AUTISMLINK

Support groups, information, etc.

135 Cumberland Road, Suite 105, Pittsburgh, PA 15237, 1-866-PUZZLE-2

AUTISMLINK Special Education Support Group

Learn how to advocate for your children in their school setting, information, speakers, support. Children will be at the Center for Creative Play at no cost. TSS provided free of charge.

Contact: Cindy Waeltermann, Info@autismlink.com

Autism Society of America, York, PA Chapter, info@autismyork.org

Provides support to parents, family, and friends of individuals on the Autism Spectrum. The group promotes understanding and respect of all families and the choices they make regarding therapies and interventions. They offer opportunities for families to learn, grow, and develop relationships as they guide one another through the journey of Autism Spectrum Disorders. To stay connected, the group hosts 2 message boards on Google Groups. The first, <http://groups.google.com/group/AutismYork>, is for announcements regarding upcoming events only. The second, <http://groups.google.com/group/AutismYorkChat>, is used by families to ask questions, provide support, share knowledge, voice frustrations, and to keep everyone updated on future events.

PO Box 6683, Wyomissing, PA 19610, 610-736-3739 or 717-801-1272

Autism Society of Berks County

PO Box 6613, Wyomissing, PA 19610, 610-736-3739

The Reading Hospital and Medical Center, Education Room D

Sixth Avenue and Spruce Street, West Reading, PA 19611

Mara or Randy Winn, 610-670-1053, Anne Rubright, Alr1030@aol.com

Pennsylvania ASCEND (Asperger's Syndrome Coalition for Education, Networking, and Development), www.ascendgroup.org

ASCEND Group Inc., the Asperger and Autism Alliance for Greater Philadelphia, is a nonprofit organization that was founded in 2001. It was launched by parents of children with Asperger Syndrome (AS) as a means to create a community of people who are concerned about the many ways that AS and other Autism Spectrum disorders affect children and adults and their families in the home, at school, and in every area of their lives. In 2003, it was expanded to serve families of adults, as well. ASCEND refers adults on the Autism spectrum to regional and national resources.

Pennsylvania Parents and Caregivers Resource Network

Statewide cross-disability group that supports parents and caregivers. Helps families to form local groups and network with other parents.

PO Box 4336, Harrisburg, PA 17111, 1-888-890-5665; 1-888-572-7368; 717-561-0098;
info@ppcrn.org

Support Groups or Forums – Online (National) for Parents of Children with Autism

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

Support Groups or Forums – Online (National) - 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

Parents and professionals 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 considering or are already implementing a gluten-free, casein free diet for their children.

groups.yahoo.com/group/IEP_guide

For families with children with special needs (not Autism-specific). 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

Provides information, education, and support to families who have children affected by Sensory Integration Disorder (or Dysfunction), or sensory issues related to Autism.

groups.yahoo.com/group/VerbalBehavior

Parents and professionals discuss Verbal Behavior, an approach taught within an ABA program based on the book by B. F. Skinner.

Support Systems/Resources

For Grandparents, <http://www.udel.edu/bkirby/asperger/grandparents.html>

Answers common questions grandparents of children who have Autism may have.

Religion and Autism, http://www.autism-society.org/site/PageServer?pagename=Religion_and_Autism

Provides a Christian and Jewish perspective on children with ASD and how the church can provide an inclusive environment.

<http://gbgm-umc.org/disc/autism.stm>

Information on Autism for religious educators.

Family Village, www.familyvillage.wisc.edu

A global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, as well as for their families and those that provide them services and support.

Autism Spectrum Resource Center, <http://www.autismsrc.org>

Provides therapeutic services and educational resources to individuals within the Autism spectrum and their families in an environment where they will find a sense of belonging with like-minded individuals. Promotes positive self-image, potential for growth, and unique contribution to the world.

Parents Involved Network (PIN), www.pinofpa.org

Assists parents or caregivers of children and adolescents with emotional and behavioral disorders. PIN provides information, helps parents find services, and advocates with any of the public systems that serve children, including the mental health system, education and other state and local child-serving agencies.

Special Kids Network,

<http://www.dsf.health.state.pa.us/health/cwp/browse.asp?A=179&BMDRN=2000&BCOB=0&C=35825>

Information and referrals for children with special health care needs and their families.

Parent to Parent of Pennsylvania, <http://www.parenttoparent.org>

Matches parents and family members of children and adults with disabilities or special needs, on a one-on-one basis, according to condition or concerns.

Teachers/Educators

Adapted Books,

<http://schools.nycenet.edu/D75/academics/literacy/adaptedbooks/catalog.htm>

Provides PECS and other visual materials to adapt books for children. Requires Adobe Acrobat reader and/or Boardmaker.

Autism Education Network, <http://www.autismeducation.net>

Improves public special education programs and influences public policy that affects individuals with Autism. Connects and empowers people in order to affect change.

Provides free information about special education rights and programs. Outreach efforts include seminars about special education law and conferences regarding best practices in Autism treatment and methodologies.

IDEA Regulations, <http://www.wrightslaw.com/idea/art.htm>

http://www.pde.state.pa.us/special_edu/cwp/view.asp?Q=111436&A=177

PaTTAN, <http://www.pattan.k12.pa.us/teachlead/Autism.aspx>

Information regarding current PA standards, teaching practices, effective assessments, and instruction. Training and workshop information for educators, as well as publications relevant to Autism Spectrum Disorders. Publications such as Introduction to Early Interventions, Provider's Guide to Early Intervention.

PDE Special Education,

http://www.pde.state.pa.us/special_edu/site/default.asp?g=0&special_eduNav=|978|&k12Nav=|1141|

Mission, role, and function of special education in Pennsylvania schools are defined and addressed. Links to other reference materials on standard practices and procedures.

Wrightslaw, <http://www.wrightslaw.com/>

Information for parents, educators, and advocates about special education law and advocacy for children with disabilities. Includes articles, cases, and free resources on special education topics.

Transitioning

Transitions for you and your child,

<http://www.dpw.state.pa.us/Child/EarlyIntervention/003670022.htm>

Discusses how to plan for and manage the transitions that occur all the time in many different ways, such as changes in jobs or homes.

Living beyond high school, [http://www.autism-](http://www.autism-society.org/site/PageServer?pagename=livinghighschool)

[sociedad.org/site/PageServer?pagename=livinghighschool](http://www.autism-society.org/site/PageServer?pagename=livinghighschool)

Discusses the importance of transition planning and considerations when a child is nearing graduation from high school.

Transition from Special Education to adult life, <http://www.transitionmap.org/>

A Roadmap from school to the future for Pennsylvania students ages 14 to 21 with developmental delay and receiving special education services.

Vocational Rehabilitation Centers

Susan Aldrete, Executive Director, saldrete@dli.state.pa.us

Office of Vocational Rehabilitation, Department of Labor and Industry

1300 Labor and Industry Building, Seventh and Forster Streets, Harrisburg, PA 17120

717-787-5244; 1-800-442-6351