



**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, 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 receiving services. It was written from a parent's perspective and was designed to provide parents with a guide that provides basic information about behavioral health services available to their child and how to access these services.

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

*“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



Many kids with Autism Spectrum Disorders are making enormous strides and some are now indistinguishable from their peers.



## ANSWERS TO YOUR QUESTIONS



Autism is no longer seen as a rare condition. The disorder currently affects over 400,000 people in the United States.

### **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 or 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/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 specific contact information for each county.

**Note: The services mentioned above are county-based services. Please call your local Community Care Customer Service Representative (See Appendix G) for assistance.**



Autism occurs in 1 in every 150 births and at a rate of 5 boys to every girl.

## 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 your child’s school psychologist conduct a psychoeducational evaluation to diagnose your child and to create an Individualized Education Plan (IEP) with 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 from your employer). 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 (MA) often covers these services. MA is state funding that is available if your child has a disabling diagnosis. Autism, Pervasive Developmental Disorder NOS, and Asperger’s (as well as numerous other diagnoses) are considered “disabilities.”

### **I have heard of Medical Assistance (MA). 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 to 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 Web at <http://www.ssa.gov/disability/professionals/bluebook>. Such diagnoses include, but aren't 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 complete the application form?**

It helps to write "MA 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 (MA) 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 income (SSI/SSD) for the child through the Social Security Office.



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

## ANSWERS TO YOUR QUESTIONS



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

### **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). MRT sends 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 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 MA 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 MA 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 (MA) 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 MA 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 MA?**

Eligibility for a child receiving MA must be reviewed at yearly intervals. The new 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 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



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.

### 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 “MA 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 PA (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 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.

## 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)**—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)**—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, including the child’s home, school, church, community center, a neighbor or extended family member’s home, and other community settings. They provide child-centered, family-focused individual and family psychotherapy, as defined in the treatment plan and agreed upon by the therapist and 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, guidance counselor, principal, or subsystems of any of the above, such as sibling groups, as clinically indicated, agreed upon, and identified in the treatment plan.



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

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.

## ANSWERS TO YOUR QUESTIONS



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.

### Which types of professionals deliver BHRS services? (continued)

**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.

### 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 happens next 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)**.



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

## 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 the 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 5 business days to submit the requested information. After receiving the additional information, Community Care will make a decision within 2 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 Functional Behavioral Assessment (FBA), a process that attempts to understand from different views the variables surrounding the reason for the occurring behavior(s). 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 for you. 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 Service 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.

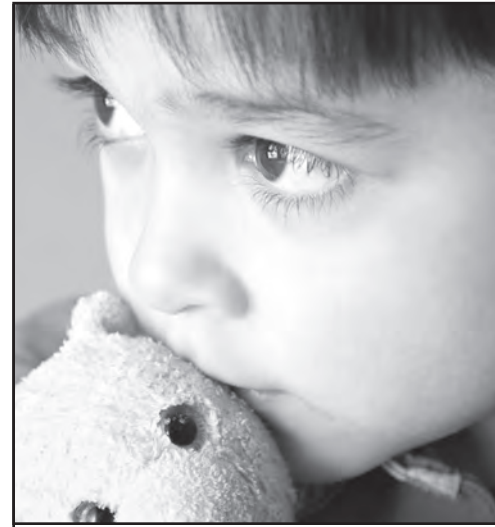
A committee of one or more Community Care staff, including a doctor or licensed psychologist who has not been involved in the issue you filed your grievance about, will make a decision about your First Level grievance. Your grievance will be decided no more than 30 days after it is received. A letter will be mailed to you no more than 5 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 these services?**

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 these services?**

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 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 these services?**

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 health is at immediate risk?

If your doctor or psychologist believes that the usual time frame for deciding your complaint or grievance will harm your health, you, your doctor, or your 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 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 health. If your doctor or psychologist does not fax Community Care this letter, 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 their decision within 48 hours of receiving your doctor or psychologist's letter explaining how the usual time frame of 30 days for deciding your complaint or grievance will harm your 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	<b>within 30 days</b> of getting a letter from Community Care telling you of this decision <b>OR within 30 days</b> 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 <b>AND</b> the provider can bill you for the service	<b>within 30 days</b> of getting a letter from Community Care telling you of this decision <b>OR within 30 days</b> 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	<b>within 30 days</b> 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	<b>within 30 days</b> of getting a letter from Community Care telling you of this decision <b>OR within 30 days</b> 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	<b>within 30 days</b> from the date you should have received the service <b>OR within 30 days</b> 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:

- Member's name.
- Member's Social Security number and date of birth.
- A telephone 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 we made the decision or explain what happened. If you ask, Community Care will help you file for a Fair Hearing. Community Care will give you (at no cost) any records, reports, and other information we have that is 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 health is at immediate risk?**

If your doctor or psychologist believes that using the usual time frames to decide your Fair Hearing will harm your health, you or your 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 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 health.

If your doctor or psychologist does not fax a letter, your doctor or psychologist may testify at the Fair Hearing to explain why using the usual time frames to decide your Fair Hearing will harm your 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 telephone within three business days after you ask for the Fair Hearing.

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

If your 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 doctor or psychologist sends a written letter or testifies at the Fair Hearing?**

If your doctor or psychologist sends a written statement or testifies at the Expedited Fair Hearing, the 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 provider or Community Care? How do I do this?**

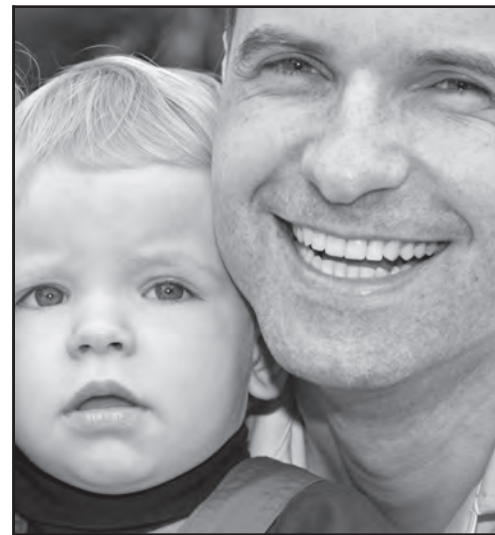
A complaint is when you tell us you are unhappy with Community Care or your provider, or you do not agree with a decision made by Community Care.

Some reasons why you might file a complaint include:

- You are unhappy with the care you are getting.
- You are unhappy that you cannot get the service you want because it is not a covered service.
- You are unhappy that you have not received services that you have 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 Service 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.
- The disturbance causes clinically significant impairment in social, occupational and/or other important areas of functioning.
- 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 Autism 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 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 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, grooming, etc. 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.

**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 interact 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 nurturing from a 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., Mental Retardation and drug and alcohol). Such acute care requires coordinated, intensive, and comprehensive treatment, tailored to the individual consumer'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 Facilities (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 as 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 and returns to his or her primary residence daily.



**Levels of Care/Treatment Available to Children With Autism (Continued)**

**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** — 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** — 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 your 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 are getting.
- You are unhappy that you cannot get the service you want because it is not a covered service.
- You are unhappy that you have not received services that you have been approved to get.\*

\* Community Care providers of service must provide services within 1 hour for emergencies, within 24 hours for urgent situations, and within 7 days for routine appointments and specialty referrals. When a treatment plan is approved, you 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 you cannot get a service you want because it is not a covered service.
- Community Care will not pay a provider for a service you received.
- Community Care did not decide a First Level complaint or grievance you filed earlier 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 any information we have 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 Service 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 you have not received services that you have been approved to get.
- You are unhappy that Community Care has decided you cannot get a service you want because it is not a covered service.
- You are unhappy that Community Care will not pay a provider for a service you 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 our offices or be included by phone. You are not required to attend this meeting. If you do not attend, it will not affect our 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 we received it.

A letter will be mailed to you no more than 5 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 to continue getting services:**

If you have been receiving services that are being reduced, changed, or stopped because they are not covered services for you, 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 you have been receiving are not covered services for you, 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 we received your complaint. The letter will tell you about the Second Level complaint process.

- You may ask Community Care to see any information we have 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 5 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 you have been receiving services that are being reduced, changed, or stopped because they are not covered services for you 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 G:  
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 PO Box 1266 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





**Community Care Behavioral Health Organization**  
**One Chatham Center, Suite 700**  
**112 Washington Place**  
**Pittsburgh, PA 15219**  
**[www.ccbh.com](http://www.ccbh.com)**

## APPENDIX H: ACCESSING EARLY INTERVENTION

The Alliance For Infants and Toddlers, Inc., was established in 1988 by a Federal grant to assist families of low birth weight infants. In 1992, the Alliance was chosen by Allegheny County as the Early Intervention Service Coordination Agency for families of children, ages birth to three years, who have developmental concerns.

The Alliance For Infants and Toddlers, Inc. is the service coordination unit for families of children receiving Early Intervention services (birth to three years of age) in Allegheny County.

### How to Get Started:

Families with concerns about their child's (age birth to 3) development or who would like to know more about Early Intervention services should contact The Alliance For Infants and Toddlers, Inc., at 412-885-6000.

Families with a child between the ages of 3 and 5 should contact the Allegheny County/City of Pittsburgh, Early Childhood Education Program at 1-866-214-KIDS (5437).



## APPENDIX I: BHRS PROVIDERS

Allegheny Children's Initiative  
2304 Jane Street  
Pittsburgh, PA 15203  
412-431-8006; Fax: 412-431-8124

Allegheny Psychological Services  
Medical Center East  
211 N. Whitfield Street, Suite 500  
Pittsburgh, PA 15206  
412-361-1575; Fax: 412-361-7156

Alliance Health Wraparound, Inc.  
634 Brown Avenue  
Turtle Creek, PA 15145  
412-823-5293; Fax: 412-823-5294

Community Alternatives, Inc.  
2100 Wharton Street, Suite 319  
Pittsburgh, PA 15203  
412-381-5040; Fax: 412-381-5138

Community Psychiatric Centers  
John E. Carosso, PsyD  
Parkway Building  
339 Haymaker Road, Suite 1104  
Monroeville, PA 15146  
412-372-8000; Fax: 412-372-4117

Community Psychiatric Centers  
Robert Lowenstein, MD  
Professional Building  
701 5th Avenue  
New Kensington, PA 15068  
724-335-7200; Fax: 724-850-7214

Community Psychiatric Centers  
Robert Lowenstein, MD  
814 East Pittsburgh Street  
Greensburg, PA 15601  
724-850-7200; Fax: 724-850-7214

Community Psychiatric Centers  
Robert Lowenstein, MD  
Medical Center East  
211 N. Whitfield Street, Suite 475  
Pittsburgh, PA 15206  
412-661-5437; Fax: 412-681- 5438

Community Psychiatric Centers  
Robert Lowenstein, MD  
Monessen Business Center, Suite 320  
435 Donner Avenue  
Monessen, PA 15062  
724-684-4710; Fax: 724-684-4710

Community Psychiatric Centers  
Robert Lowenstein, MD  
814 East Pittsburgh Street  
Greensburg, PA 15601  
724-850-7200; Fax: 724-850-7214

Family Behavioral Resources  
4156 Kenneth Drive  
Gibsonia, PA 15044  
724-449-9222; Fax: 724-449-9221

Family Behavioral Resources  
2526 Monroeville Boulevard, Suite 200 - A  
Monroeville, PA 15146  
412-824-4005; Fax: 412-824-4006

Family Behavioral Resources  
101 Towne Square Way, Suite 239  
Brentwood Towne Square  
Pittsburgh, PA 15227  
412-881-2400; Fax: 412-881-6400

Family Behavioral Resources  
8962 Hill Drive  
North Huntingdon, PA 15642  
724-861-9200; Fax: 724-861-5926

Family Behavioral Resources  
Park West One  
1000 Cliff Mine Road, Suite 100  
Pittsburgh, PA 15275  
412-788-4224; Fax: 412-788-4487

Family Behavioral Resources  
943 4th Avenue  
New Kensington, PA 15068  
724-335-9733; Fax: 724-335-9734

Family Behavioral Resources  
75 East Maiden Street, Suite 103  
Washington, PA 15301  
724-229-0311; Fax: 724-229-3277

Family Links  
2644 Banksville Road  
Pittsburgh, PA 15216  
412-942-0549; Fax: 412-343-8249

Family Psychological Associates  
365 Franklin Hill Road  
Kittanning, PA 16201  
412-421-2773; Fax: 412-421-2797

Glade Run Lutheran Services  
5701 Center Avenue, Suite L -12  
Pittsburgh, PA 15206  
412-661-1827; Fax: 412-661-1867

Glade Run Lutheran Services  
PO Box 70, Beaver Road  
Zelienople, PA 16063  
724-283-9436; Fax: 724-282-9759

Mercy Behavioral Health  
1200 Reedsdale Street  
Pittsburgh, PA 15233  
412-697-0707; Fax: 412-697-4730

Milestone Centers, Inc.  
(formerly Allegheny East MH/MR)  
10 Duff Road, Suite 301  
Pittsburgh, PA 15235  
412-731-9707; Fax: 412-731-9834

Nisar Health and Human Services, Inc.  
560 Beatty Road  
Monroeville, PA 15146  
412-374-8275; Fax: 412-374-0708  
www.nisarinc.com

Northwestern Human Services  
10700 Frankstown Road, Suite 501  
Pittsburgh, PA 15235  
412-371-6108; Fax: 412-371-6276

Paula Teacher and Associates  
10700 Frankstown Road, Suite 310  
Penn Hills, PA 15235  
412-371-4090; Fax: 412-371-4182

PLEA  
733 South Avenue  
Pittsburgh, PA 15221  
412-243-3464; Fax: 412-243-5649

Pressley Ridge  
Autism & Developmental Disabilities Program  
1450 Ingram Street  
Pittsburgh, PA 15212  
1-888-777-0820; Fax: 412-321-0508

SharpVisions, Inc.  
1425 Forbes Avenue  
Pittsburgh, PA 15219  
412-456-2144; Fax: 412-456-2145

Southwestern Human Services  
110 Fort Couch Road, 2nd Floor  
Pittsburgh, PA 15241  
412-831-8211; Fax: 412-831-8225

SPHS Behavioral Health  
301 East Donner Ave, Suite 102  
Monessen, PA 15062  
1-888-733-6906; Fax: 724-684-9196

Turtle Creek Valley MH/MR  
1705 Maple Street  
Homestead, PA 15120  
412-461-1122; Fax: 412-464-1531

Watson Institute  
301 Camp Meeting Road  
Sewickley, PA 15143  
412-749-2889; Fax: 412-741-0855

Wesley Spectrum Services (North)  
5465 William Flynn Highway, 3rd Floor  
Gibsonia, PA 15044  
724-443-4888; Fax: 724-443-4889

Wesley Spectrum Services (South)  
5 Mayview Road  
Canonsburg, PA 15317  
724-820-1590

Wesley Spectrum Services (East)  
121 Erhardt Drive  
Penn Hills, PA 15235  
412- 573-0141

WJS Psychological Services  
633 Long Run Road  
McKeesport, PA 15132  
412-751-5280; Fax: 412-751-5530

WPIC - Conroy Merck  
412-488-4151

WPIC Intensive Wraparound Program (Early  
Intensive Autism Services: 2-5 years of age)  
1011 Bingham Street  
Franklin Building, 4th Floor  
Pittsburgh, PA 15203  
412-235-5300; Fax: 412-235-5387

WPIC - Mathilda Theiss Therapeutic Nursery  
373 Burrows Street  
Pittsburgh, PA 15219  
412-383-1570; Fax: 412-682-4640

Youth Advocate Program  
26 Terminal Way  
Pittsburgh, PA 15219  
412-381-5563; Fax: 412-381-5584



NOTE: The following list represents a broad sampling of available services. This list is not exhaustive of all available resources. Inclusion does not constitute endorsement. Resources may or may not be funded through the Pennsylvania Medicaid HealthChoices program. Contact Community Care with questions.

## APPENDIX J: 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](http://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](http://www.thearcpa.org)  
Local ARC chapters offer information about advocacy, community resources, outpatient therapists, and support groups.

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

ARC of Armstrong County  
309 Market Street, Suite 2, Kittanning, PA 16201, 724-545-3426

ARC of Beaver County  
500 Market Street, Suite 200A, Bridgewater, PA 15009, 724-775-1602

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

ARC of Fayette County  
80 Old New Salem Road, Uniontown, PA 15401, 724-438-8416

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

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



## **Advocacy (continued)**

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

ARC of Westmoreland County  
RD 12, Box 227, Donohue Road, Greensburg, PA 15601, 724-837-8159

AutismLink, [www.AutismLink.com](http://www.AutismLink.com)

National non-profit organization, founded in Pittsburgh, offering a comprehensive website that provides an array of information about Autism support, resources, and links to national and local organizations across the state of Pennsylvania. The AutismLink listserv gives members up-to-the minute information about Autism news on national, regional, and local levels. Online chat rooms, discussion groups, and forums connect families directly affected by Autism with professionals, presenting the opportunity for collaboration on formal and informal levels. Mentoring program for parents of newly diagnosed children.  
135 Cumberland Road, Suite 105, Pittsburgh, PA 15237, 1-866-PUZZLE-2

Autism Society of Pittsburgh, [www.autismsocietyppgh.org](http://www.autismsocietyppgh.org)

A local chapter of the Autism Society of America (ASA), the ASA of Pittsburgh offers information, a library with a variety of legal, medical, nutritional, educational and psychological materials (the Danny Cope Autism Library) information and support, newsletters, workshops, a referral system, legal information, parent support, and more. Founders of the first Spectrum Charter School providing vocational training as well as a unique educational experience for individuals with Autism aged 14 to 21, S.P.E.A.K. (Summer Program for the Education of Autistic Kids), and an ESY (Extended School Year) program that teaches basic living skills, recreation, community training, and IEP objectives.  
4371 Northern Pike, Monroeville, PA 15146, 412-856-7223 (or 7224)

Autism Speaks (NAAR and Autism Speaks Working Together), [www.autismspeaks.org](http://www.autismspeaks.org) and [www.autismwalk.org/pittsburgh](http://www.autismwalk.org/pittsburgh)

Bob and Suzanne Wright formed Autism Speaks to help raise awareness, much needed funding, and to support the thousands of families across the nation who are affected by Autism Spectrum Disorders. In February 2006, the National Alliance for Autism Research merged with Autism Speaks to unite forces in the fight against Autism.

Beth Whitehouse – Pittsburgh Regional Director, [bwhitehouse@autismspeaks.org](mailto:bwhitehouse@autismspeaks.org)  
4068 Mt. Royal Boulevard, Allison Park, PA 15101, 412-487-6851

Fighting Autism, [www.fightingautism.org](http://www.fightingautism.org)

Mission is to improve the quality of life for children with Autism through research, education, advocacy and treatment. Fighting Autism hosts an annual conference where scientists and physicians present the most current innovative research and biomedical treatment options for those with Autism and hold monthly biomedical support group meetings.

351 Ivy Drive, Gibsonia, PA 15044, 412-641-7383

KIDS TOGETHER INC, [www.kidstogether.org](http://www.kidstogether.org)

Advocates, volunteer non-profit provides information on inclusive communities, schools, list serve, e-mail newsletter, website.

PO Box 45, Quakertown, PA 18951, [staff@kidstogether.org](mailto:staff@kidstogether.org)

## **Autism Organizations and Websites**

DPW Bureau of Autism Services, [http://www.dpw.state.pa.us/ServicesPrograms/Autism Resources](http://www.dpw.state.pa.us/ServicesPrograms/AutismResources), trainings, and general information.

Autism Society of America, [www.autismweb.com/resources](http://www.autismweb.com/resources)

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

Autism Information, [www.autisminfo.com](http://www.autisminfo.com)

Education, resources, and advocacy.

Autism Network for Dietary Intervention (ANDI), [www.autismndi.com](http://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](http://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](http://www.autismtoday.com)

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

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

Autism Research Network, [www.autismresearchnetwork.org](http://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](http://www.autism-society.org)

Education, resources, and advocacy.

Applied Behavior Analysis Resources (Richard Saffran's Website), [rsaffran.tripod.com](http://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](http://www.autism-connection.org)

Nonprofit, providing information and resources about Autism and other developmental disabilities.

Dr. Carbone (Verbal Behavior), [www.dr-carbone.net](http://www.dr-carbone.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.

## **Autism Organizations and Websites (continued)**

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

Christina Burk, [www.christinaburkaba.com](http://www.christinaburkaba.com)  
Applied Verbal Behavior

Cure Autism Now, [www.canfoundation.org](http://www.canfoundation.org)  
An Autism Speaks website.

Dana's View from the Inside, [www.danasview.net](http://www.danasview.net)  
Message board links and stories of recovery.

Dan Marino's Childnettv  
[www.childnet.tv](http://www.childnet.tv)

Dan Marino's Foundation  
[www.danmarinofoundation.org](http://www.danmarinofoundation.org)

Defeat Autism Now, [www.autism.com/ari](http://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](http://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](http://www.do2learn.com)  
Offers ASD information and picture schedules.

Exploring Autism, [www.exploringautism.org](http://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](http://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](http://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.

## **Autism Organizations and Websites (continued)**

Generation Rescue, [www.generationrescue.org](http://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](http://www.pachildren.state.pa.us)

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

Monarch Educational Materials [www.monarchmaterials.com](http://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](http://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/](http://www.udel.edu/bkirby/asperger/)

Online Asperger Syndrome information and support.

Relationship Development Intervention (Dr. Steven Gutstein) – [www.connectionscenter.com](http://www.connectionscenter.com)

Details Dr. Steven Gutstein's intervention.

Talk About Curing Autism, [www.tacanow.org](http://www.tacanow.org)

Provides information and resources and support to families affected by Autism.

Unlocking Autism, [www.unlockingautism.org](http://www.unlockingautism.org)

Founded to increase awareness about Autism.

Yahoo! Groups – [www.yahoo.com](http://www.yahoo.com)

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

## **Autism Publications**

The Advocate, [www.autism-society.org](http://www.autism-society.org)

Available through the Autism Society of America.

Autism/Asperger's Digest Magazine, [www.autismdigest.com](http://www.autismdigest.com)

Monthly magazine offering information about Autism, Asperger's Syndrome, and Pervasive Developmental Disorder.

Exceptional Parent, [www.eparent.org](http://www.eparent.org)

Monthly magazine for parents of children with special needs.

Future Horizons, [www.futurehorizons-autism.com](http://www.futurehorizons-autism.com)

Catalogs, newsletters, books, audiotapes, videos, and a list of conferences.

## **Autism Publications (continued)**

Mothering Magazine, [www.mothering.com](http://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?pagenam e=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](http://home.sprynet.com/~schafer)

Daily email report, perhaps the most comprehensive publication on the latest news about everything related to Autism.

## **Allergist**

Dr. David Skoner

Allegheny General Hospital, 320 East North Avenue, 7th Floor South Tower, Pittsburgh, PA 15212  
412-359-6640

## **Behavioral Health Managed Care Organizations**

Community Care Behavioral Health Organization, [www.ccbh.com](http://www.ccbh.com)

One Chatham Center, Suite 700, 12 Washington Place, Pittsburgh, PA 15219  
(Allegheny County only) 1-888-251-CCBH (2224)

Community Care Behavioral Health Organization, [www.ccbh.com](http://www.ccbh.com)

480 Jeffers Street, Developac Business Park, Building #2, Dubois, PA 15801

Value Behavioral Health, [www.valueoptions.com](http://www.valueoptions.com)

520 Pleasant Valley Road, Trafford, PA 15085

Armstrong 1-877-688-5969

Beaver 1-877-688-5970

Butler 1-877-688-5971

Fayette 1-877-688-5972

Greene 1-877-688-5973

Indiana 1-877-688-5974

Lawrence 1-877-688-5975

Washington 1-877-688-5976

Westmoreland 1-877-688-5977

## **Chiropractor**

Dr. Viola Agostino-Valletta

2026 Logans Ferry, New Kensington, PA 15068, 724-335-3696

Dr. Julie Bertoline

201 Penn Center Boulevard, Pittsburgh, PA 15235, 412-823-2180



## **Chiropractor (conitnued)**

Dr. Dina LiVolsi

4290 Old William Penn Highway, Monroeville, PA 15146, 412-372-8598

Dr. Daniel Pompa

Pompa Health Solutions, 145 Lake Drive, Suite 104, Wexford, PA 15090, 724-940-7733

Dr. Richard Rafferty

2475 Rochester Road, Sewickley, PA 15143, 412-369-4282

## **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.

## **Compounding Pharmacies**

Healthy Kids RX Wexford

Offers Kirkman Labs products and mercury-free vaccines  
10441 Perry Highway, Wexford, PA 15090, 724-934-5439

Ranier's Compounding

1107 Lowry Avenue, Suite A, Jeannette, PA15644, 724-527-5533

Yakim's Compounding

PO Box 173, 412 Broadway, Pitcairn, PA 15140, 1-800-368-3112

## **Dentists**

Academy of Dentistry for the Handicapped  
5808 Eva Street, Pittsburgh, PA 15206, 412-661-2222

Dentistry For Kids, [www.dentistry-for-kids.com](http://www.dentistry-for-kids.com)

Dr. Deborah H. Brandes  
500 Lewis Run Road, Suite 128, West Mifflin, PA 15122, 412-469-9400

Dr. Barry Bupp  
101 Clay Pike, North Huntingdon, PA 15642, 724-863-4720

Children's Hospital  
3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-5440

Dr. Chiniwalla  
501 Smith Drive, Suite 2, Cranberry, PA 16066, 724-776-9033

Dr. Howard Elson  
332 5th Avenue, #309, McKeesport, PA 15132, 412-672-4077

Family Dental Butler  
222 W. Cunningham Street, Butler, PA 16001, 724-285-6853

Dr. Julie Ford  
144 Forest Hills Plaza, Pittsburgh, PA 15221, 412-824-7511

Dr. James Geshay, Jr.  
634 Pittsburgh Road, Uniontown, PA 15401, 724-439-1576

Dr. James Goldsmith  
330 Morganza Road, Canonsburg, PA 15137, 724-916-0111

Dr. David Hajel  
1590 North Center Avenue, Suite A, Somerset, PA 15501, 724-444-0850

Dr. Michael Hanna  
1229 Silver Lane, #2, McKees Rocks, PA 15316, 412-859-3199

Dr. Jeffrey Klink  
6525 Mars Road, Cranberry, PA 16066, 724-776-0011

Small Smiles Dental Center  
5198 Penn Avenue, Pittsburgh, PA 15206, 412-361-5437

Dr. Christa Tappert  
20421 Route #19, Suite 320, Cranberry, PA 16066, 724-776-1228

## **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

## **Developmental Pediatricians**

Dr. Scott Faber  
The Children's Institute, 1405 Shady Avenue, Pittsburgh, PA 15217, 412-420-2400

Dr. Sara Hamel  
Children's Hospital, 3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-5560

## **Early Intervention/Intermediate Units**

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

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

Alliance for Infants and Toddlers (Allegheny County), [www.ait.org](http://www.ait.org)  
The Hough Building, 2801 Custer Avenue, Pittsburgh, PA 15227, 412-885-6000

ARIN Intermediate Unit 28 (Armstrong and Indiana counties), [www.iu28.org](http://www.iu28.org)  
2895 W Pike, Indiana, PA 15701, 724-463-5300

Beaver Valley Intermediate Unit (Beaver County), [www.bviu.org](http://www.bviu.org)  
225 Center Grange Road, Aliquippa, PA 15001, 724-774-7800

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

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

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

## **Early Intervention Resources**

First Signs, <http://www.firstsigns.org>

Educates parents, health care 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>

## **Educational Advocate**

Cindy Duch  
3016 Greenridge Drive, Verona, PA 15147, 412-798-2217

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

Mary White and Joy Lascik  
114 Allison Drive, Pittsburgh, PA 15238  
412-767-4004, 412-782-0463

Catherine Scott  
215 Sieaforth Avenue, Pittsburgh, PA 15216, 412-561-1279

Pennsylvania Protection and Advocacy  
Ellen Mancuso, [emancuso@ppainc.org](mailto:emancuso@ppainc.org)  
Coalition of PA 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](mailto:00sedir@psupen.psu.edu)  
717-783-6913; TTY: 1-800-879-2301

## **Endocrinologist**

Dr. Deborah Rosenstein  
Locust Street, Suite 306, Pittsburgh, PA 15219, 412-371-3000

Dr. Selma Witchel  
Children's Hospital, 3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-5325

## **Gastrointestinal**

Dr. Moises Arriaga  
420 E North Avenue, East Wing, Pittsburgh, PA 15222, 412-321-2480

Dr. Ram Chandra  
Liberty Avenue, Suite 204, Pittsburgh, PA 15212, 412-391-2216

Dr. Maria Clavell  
Children's Hospital, 3705 Fifth Avenue, Suite 204, Pittsburgh, PA 15213, 412-692-5180

Dr. Mark Lowe  
Children's Hospital, 3705 Fifth Avenue, Suite 204, Pittsburgh, PA 15213, 412-692-5180

## **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](http://kathyandcalvin.com/manuals/aba_train.htm)  
Good overview of DTT with examples

Lovass Therapy, [www.lovass.com](http://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/bbbbfz/bbbbfz>  
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.



## **Interventions (continued)**

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](http://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](http://www.phlp.org)

Toll-free help line, 1-800-274-3258

## **Medical Professionals**

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

First Signs, <http://www.firstsigns.org>

Educates parents, health care 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 Association**

Mental Health Association - Pittsburgh

Works on behalf of mental health through advocacy, education, and public policy.

Brenda Lee, 1945 Fifth Avenue, 3rd Floor, Pittsburgh, PA 15219, 412-391-3820

Mental Health Association of Pennsylvania, [www.mhapa.org](http://www.mhapa.org)

Wendy Luckenbill, Family/Child Policy Coordinator, [Wluckenbill@mhapa.org](mailto:Wluckenbill@mhapa.org), 1-800-692-7443

## **Occupational Therapy, Physical Therapy, Speech and Language Therapy**

Aspire Pediatric Therapy

OT and SLT

West: 890 Beaver Grade Road, Moon Township, PA 15108, 412-474-3566

South: 666 Washington Road, Pittsburgh, PA 15228, 412-572-6761

North: 135 Cumberland Road, Pittsburgh, PA 15237, 412-367-7652

## **Occupational Therapy, Physical Therapy, Speech and Language Therapy (continued)**

AVID Learning Center, [www.avidlearning.org](http://www.avidlearning.org)

OT, SLT, Advocacy, and more.

2120 Freeport Road, New Kensington, PA 15068, 724-594-1090 or 724-594-1091

Barclay Rehab Pediatric Therapy Center

PT, OT, and SLT

540 North 4th Street, Youngwood, PA 15617, 724-925-6700

Bollman Behavior and Speech Services, Inc.

SLT

Bellevue/Emsworth, 412-366-6236

The Children's Institute of Pittsburgh, [www.amazingkids.org](http://www.amazingkids.org)

PT, OT, SLT, and Functional Feeding Clinic.

1405 Shady Avenue, Pittsburgh, PA 15217, 412-420-2400

Children's Therapy Center

PT, OT, and SLT

1000 Waterdam Plaza, Suite 120, McMurray, PA 15317

724-537-1490 (SLT)

724-527-1263 (OT)

Crossroads Speech and Hearing

3240 Washington Road, Suite 200, McMurray, PA 15317, 724-941-4434

Nathan Speech Services

SLT, Advocacy, Social Skills Groups

Wightman School Community Center, 5604 Solvay Street, Pittsburgh, PA 15217, 412-363-8388

Neurological Therapy Specialists, [www.neurological-therapy-specialists.com](http://www.neurological-therapy-specialists.com)

PT, OT, and SLT

143 Hartman Rd. Suite #12, Oakley Park, Greensburg, PA 15601, 1-800-945-0023

Pediatric Therapy Specialists, Inc.

PT, OT, and SLT

100 Hightower Boulevard, Suite 201, Pittsburgh, PA 15205, 412-787-1180

Positive Steps Therapy, [www.positivestepstherapy.org](http://www.positivestepstherapy.org)

PT, OT, and SLT

5465 Route 8, Gibsonia, PA 15044, 724-444-5333

Rehabilitation Specialists, [www.rehabspecialists.net](http://www.rehabspecialists.net)

SLT; Therapy provided at locations throughout Allegheny, Butler, and Beaver Counties

35 N. Balph Avenue, Bellevue, PA 15202, 412-761-6062

RSI of Pennsylvania, [www.rehabspecialistsinc.com](http://www.rehabspecialistsinc.com)

PT, OT, and SLT

112 Third Avenue, Carnegie, PA 15106, 412-429-7760

## **Occupational Therapy, Physical Therapy, Speech and Language Therapy (continued)**

Therapeutic Specialists, Inc., [www.tsiot.com](http://www.tsiot.com)  
PT and OT in School Settings  
110 Fort Couch Road, Pittsburgh, PA 15241, 412-833-6663

### **Oral Surgeon**

Children's Hospital  
3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-5440

Dr. Michael Grimes  
2250 Mosside Blvd, Suite 213, Monroeville, PA 15146, 412-856-8002

### **Orthodontists**

Dr.'s John Grady and Dan Kastner  
1000 Brooktree Road, #200, Wexford, PA 15090, 724-935-9222

### **Orthopedic Surgeons**

Dr. Alexander Bell  
St. Francis Hospital, 2 St. Francis Way, Suite 211, Cranberry, PA 16066, 724-772-5445

Dr. Jon Grudziak  
1300 Oxford Drive, Bethel Park, PA 15102, 412-642-6088

Dr. Stephen Mendleson  
Children's Hospital, 3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-5325

Dr. Mary Louise Russell  
Children's Hospital/Cerebral Palsy Clinic, 3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-5097

Dr. Peter Sotos  
1 Nolte Drive, Kittanning, PA 16201, 724-543-9087

### **Parent Mentor/Consultant**

Pamela Shrank  
1221 Holy Cross Drive, Monroeville, PA 15146, 412-373-4056

### **PARENT-TO-PARENT**

Helps parents find others familiar with the struggles of raising special needs children.  
1-800-986-4550

Roberta Waltenbaugh  
109 Trenton Place, Mt Vernon, PA 15135, 412-751-7118

## **Parent Mentor/Consultant (continued)**

Terri Davis  
119 Video Drive, Munhall, PA 15120, 412-461-8618

Vicki Morris  
2217 Mt. Pleasant Drive, Monroeville, PA 15146, 412-823-0857

## **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 PA. Organization provides disability information and information about special education process and parent's rights. Parent Advisors provide information 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 Efke, 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](http://www.pattan.k12.pa.us/about/PaTTANPittsburgh.aspx)  
3190 William Pitt Way, Pittsburgh, PA 15238, 412-826-2336; 1-800-446-5607

## **Pediatric Cardiology**

Dr. Lee Beerman  
Children's Hospital – Department of Cardiology  
3705 Fifth Avenue, 2nd Floor, Pittsburgh, PA 15213, 412-692-5540

## **Pediatric Neurology**

Dr. Gulay Alper  
Children's Hospital, 3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-5520

Dr. Amy Goldstein  
Children's Hospital, 3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-5520

Dr. Robert Safier  
Children's Hospital, 3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-3413

## **Pediatric Ophthalmologist/Optomertist**

Dr. Merrill Bowan  
1720 Washington Road, Pittsburgh, PA 15241, 412-831-5255

Dr. Alexander Cheng, Ophthalmologist  
210 Greentree Road, Suite 105, Pittsburgh, PA 15220, 724-934-3333

Everett and Hurite Ophthalmologists  
125 Emeryville Drive, Cranberry, PA 16066, 724-776-1233

Kieffer Optical (Specializes in fitting glasses for kids with special needs)  
405 Loop Street, Aspinwall, PA 15215, 412-781-1535

Dr. Hans Lessmann  
1789 South Braddock Avenue, Suite 130, Pittsburgh, PA 15218, 412-731-5007

Dr. Joseph Paviglianiti  
20397 Route #19, 2 Landmark Drive, Cranberry, PA 16066, 724-772-3388

Dr. Robert Prazer  
110 VIP Drive, #301, Wexford, PA 15090, 724-935-9999

## **Pediatricians**

Bass Wolfson Pediatrics  
The Wilkins Building, Suite 202, 5608 Wilkins Avenue, Pittsburgh, PA 15217  
412-422-3590 or 724-776-4433

Bellevue Pediatrics  
446 Lincoln Avenue, Pittsburgh, PA 15202, 724-761-1190

Dr. Debra Bogen (Supportive of DAN! Autism protocol)  
Children's Hospital, 3705 Fifth Avenue, Pittsburgh, PA 15213, 412-692-6000

Dr. Claire Budd  
6530 Route 22, Delmont, PA 15626, 724-468-5500

Caring Hands Pediatrics  
105 Braunlich Drive, Pittsburgh, PA 15237, 412-369-7720

Children's Community Pediatrics  
300 Halket Street, Suite 4710, Pittsburgh, PA 15213, 412-681-2200

Children's Community Pediatrics  
1925 Route 51, South, Jefferson Hills, PA 15025, 412-384-9030

Children's Community Pediatrics  
3907 Old William Penn Highway, Murrysville, PA 15668, 724-327-5210



## **Pediatricians (continued)**

Dr. Kenneth Keppel  
RR 8 Box 573, Kittanning, PA 16210, 724-548-7430

Dr. Margaret Lagnese  
2585 Freeport Road, Pittsburgh, PA 15238, 412-828-4940

Dr. James Mortimer  
602 Evans City Road, Suite 204, Butler, PA 16001, 724-482-2220

Dr. Michele Sredy  
Somerset Pediatrics, 426 Main Street, Berlin, PA 15530, 724-443-2888

Dr. Todd Wolynn  
850 Clariton Boulevard, Suite 3300, Pittsburgh, PA 15236, 412-521-6544

Dr. Mark Yaros  
Somerset Family Practice, 329 South Pleasant Avenue, Somerset, PA 15561, 724-445-3575

Pediatric Alliance Offices, [www.pediatricalliance.com](http://www.pediatricalliance.com)  
Locations throughout the Greater Pittsburgh area, 412-278-5100

## **Psychiatrists**

Dr. Tiberiu Bodea  
John Merck Program, 1011 Bingham Street, Pittsburgh, PA 15203, 412-235-5445

Dr. Lisa Jamnback  
Allegheny General Hospital, East Commons Professional Building, 8th Floor  
4 Allegheny Center, Pittsburgh, PA 15212, 412-330-4215

Dr. Gary Swanson  
Allegheny General Hospital, East Commons Professional Building  
4 Allegheny Center, Pittsburgh, PA 15212, 412-330-4320

## **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.

## **Safety (continued)**

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=livin gsiblings>

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 information 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](mailto:info@equalemployment.org)

Department of Public Welfare – Office of Mental Health and Substance Abuse [www.dpw.state.pa.us/omhsas/dpwmh.asp](http://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](http://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](mailto:ppa@ppainc.org)

## **State Departments/Agencies/Programs and Other Resources (continued)**

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 Departments/Agencies/Programs and Other Resources (continued)**

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**

ABOARD, [www.aboard.org](http://www.aboard.org)

Support for parents of children with Autism/Autism Spectrum, website etc.

Howard Carpenter, 35 Wilson Street, Suite 100, Pittsburgh, PA 15223, 1-800-827-9385

[info@aboard.org](mailto:info@aboard.org)

ABOARD: African American Support Group

Tina Simpson, 233 Edgewood Avenue, Apt 7A, Pittsburgh, PA 15218, 412-242-5596

ABOARD: Allegheny Teen High Functioning Support Group (AUTISM/ASPERGERS)

Teresa Jamison, 37 Barton Drive, Freedom, PA, 724-775-1484; [tlj@access995.com](mailto:tlj@access995.com)

ABOARD: Children's Hospital of Pittsburgh Autism Spectrum Support Group

Nicole Speshok, 315 Oakland Avenue, Pittsburgh, PA 15213, 412-687-7283

ABOARD: For parents of children with Aspergers or High Functioning Autism Support Group

Support group for parents of teenagers and school-age children.

Rebecca Klaw, [rebeccaklaw@aol.com](mailto:rebeccaklaw@aol.com), 412-247-0599

ABOARD: North Hills Support Group

Support group for parents of children with Autism Spectrum.

Jennifer Fulton, 1831 President Drive, Glenshaw, PA 15116, 412-486-1743

ABOARD: South Hills Support Group

Deborah Dorsey, 1719 Hathaway Lane, Upper St. Clair, PA 15241, 412-831-0892

ABOARD: Special Needs Support Group

Eliot Frank, Temple Ohav Shalom, 8400 Thompson Run Road, Allison Park, PA 15101, 724-933-5595

## Support Groups (continued)

ABOARD: Support Group Specializing in Autism and Law Enforcement  
Community Resource for Western Pennsylvania Search and Rescue  
Lenore Wossidlo, 7457 McClure Avenue, Pittsburgh, PA 15218, 412-241-4370

ASCEND PA (Asperger's Syndrome Coalition for Education, Networking, and Development),  
[www.ascendgroup.org](http://www.ascendgroup.org)

ASCEND Group Inc., the Asperger and Autism Alliance for Greater Philadelphia, a nonprofit organization, was founded in 2001 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.

Autism and Other Neurobiological Disorders Online Support Group, [http://health.groups.yahoo.com/group/Autism\\_and\\_Other\\_Neurobiological\\_Disorders/](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](mailto:Info@autismlink.com)

### Autism Society of Pittsburgh

Ann Fuger, 4371 Northern Pike, Monroeville, PA 15146, 412-856-7223

### Family Behavioral Resources

Dr. Heather Madray, Brentwood Towns Square, Suite 239, Pittsburgh, PA 15227, 412-881-2400

### Murrysville Asbergers Parents (MAPS) Support Group

Betty Rauscher, 1002 Arlington Avenue, Export, PA 15632, 724-327-5151

### NAMI Borderline Group

Support group for those who have children with borderline personality issues.

Rose Schmitt, 114 Lederer Avenue, Pittsburgh, PA 15209, 412-487-2036

### NAMI McKeesport Support Group

Cindy McHolme, 301 Oberdick Drive, McKeesport, PA 15135, 412-754-0998

### NAMI Minority Families Support Group

Wilma Sirmons, PO Box 59367, Pittsburgh, PA 15210, 412-327-4890

### NAMI Mon Valley Support Group

Support for those whose loved ones are dealing with mental health issues.

Harriet Hetrick, 99 Voyager Estates, West Newton, PA 15089, 724-872-2186

## **Support Groups (continued)**

### **NAMI Pittsburgh East Support Group**

Anne Handler, 5802 Northumberland Street, Pittsburgh, PA 15217, 412-421-3656

### **NAMI Pittsburgh North Support Group**

Mildred Benitz, 2244 Reise Run Road, Pittsburgh, PA 15237, 412-366-5907

### **NAMI Pittsburgh South Support Group**

Support for those whose loved ones have mental health issues.

Eileen Lovell, 220 Outlook Drive, Pittsburgh, PA 15228, 412-561-2388

### **Northwestern Human Services Autism Support Group**

Devon Lewis, 10700 Frankstown Road, Suite 200, Pittsburgh, PA 15235, 412-247-1091, Ext. 18

### **PENNSYLVANIA FAMILY SUPPORT ALLIANCE AFFILIATE**

(formerly Parents Anonymous) Support group for parents/caregivers of children who feel overwhelmed and need a safe place to talk.

Marcia Warren, Family Resources, 134 South Highland Ave, Pittsburgh, PA 15206, 412-363-1702 Ext. 1422

### **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

### **Southminster Presbyterian Church Caregivers Group**

Support for those dealing with children with disabilities.

Robbi Bruesewitz, 766 Lebanon Avenue, Pittsburgh, PA 15228, 412-344-1135

### **Steel Valley Family Centers Parents Support Group**

Dr. Elena Runko, 1800 West Street, Rear Building, Homestead, PA 15120, 412-461-8012

### **The Watson Institute**

Offers support groups for parents of children with Autism, parents of children who are neurologically impaired, and people with a disabled sibling.

301 Camp Meeting Road, Sewickley, PA 15143

Sal Schlieper, sals@thewatsoninstitute.org, 412-749-2828

Lorie Turian, loriet@thewatsoninstitute.org, 412-749-2824

## **Support Groups or Forums – Online (Local)**

[groups.yahoo.com/group/pittsburgh\\_autism](http://groups.yahoo.com/group/pittsburgh_autism)

[groups.yahoo.com/group/pittsburgh\\_autism\\_friends](http://groups.yahoo.com/group/pittsburgh_autism_friends)

[groups.yahoo.com/group/butler\\_autism](http://groups.yahoo.com/group/butler_autism)

[groups.yahoo.com/group/The\\_Alle-Kiski\\_Valley\\_Autism\\_ABOARD\\_Support\\_Group](http://groups.yahoo.com/group/The_Alle-Kiski_Valley_Autism_ABOARD_Support_Group)



## **Support Groups or Forums – Online (Local) (continued)**

[www.autismlink.com/chat.shtml](http://www.autismlink.com/chat.shtml)

Offers many new discussion boards regarding ASDs, parental and marital stresses, biomedical, traditional therapies, Autism in girls, and boards for every state including Pennsylvania.

## **Support Groups or Forums – Online (National)**

[groups.yahoo.com/group/children\\_with\\_autism](http://groups.yahoo.com/group/children_with_autism)

[groups.yahoo.com/group/autism\\_in\\_girls](http://groups.yahoo.com/group/autism_in_girls)

[groups.yahoo.com/group/autism-aspergers](http://groups.yahoo.com/group/autism-aspergers)

[groups.yahoo.com/group/parenting\\_Autism](http://groups.yahoo.com/group/parenting_Autism)

[groups.yahoo.com/group/AspergersSupport](http://groups.yahoo.com/group/AspergersSupport)

[groups.yahoo.com/group/P2ParentsChat](http://groups.yahoo.com/group/P2ParentsChat)

[www.udel.edu/bkirby/asperger/messageboards.html](http://www.udel.edu/bkirby/asperger/messageboards.html)

## **Support Groups or Forums – Online (National) - Related Disorders and Treatment Approaches**

[groups.yahoo.com/group/abmd](http://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](http://groups.yahoo.com/group/DTT-NET)

Parents and professionals discuss behavioral interventions for Autism such as Applied Behavioral Analysis, Verbal Behavior, Natural Environment Training, and Discrete Trial Training.

[groups.yahoo.com/group/GFCFKids](http://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](http://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](http://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](http://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](http://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](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](http://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](http://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

## **Teachers/Educators (continued)**

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

[http://www.pde.state.pa.us/special\\_edu/cwp/view.asp?Q=111436&A=177](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|](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 PA schools are defined and addressed. Links to other reference materials on standard practices and procedures.

Wrights law, <http://www.wrights law.com/>

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

## **Therapeutic Play Groups**

Dr. Rebecca Wieggers

East Suburban Psychological Association (Separate groups for boys and girls)  
2550 Mosside Boulevard, Suite 304, Monroeville, PA 15146, 412-373-3471

The Hope Learning Center

155 Lake Drive, Wexford, PA 15090, 724-933-HOPE, [info@thehopelearningcenter.com](mailto:info@thehopelearningcenter.com)

## **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-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 road map 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](mailto: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



