



**A  
CHESTER  
COUNTY  
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 initiate 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 both understand the nature of the services available as well as 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 a significant number 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 U.S.

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.

### **I think my infant or toddler may have 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 Appendix A 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 five, you may want to first contact **Early Intervention Services**. Early Intervention Services will assess your child and screen for the signs of Autism to determine whether a referral for an evaluation by developmental specialists, such as CATCH (Childhood Autism Team Check), is indicated.

If your child qualifies for Early Intervention Services, he or she may receive in-home services, or services in the community based in a specialized preschool setting.

If your child is under the age of 3, contact the county at 610-344-5948, and indicate that you want to have your child evaluated. A Supports Coordinator will come to your home to do an intake interview and arrange for an evaluation of your child. If it is recommended that your child receive services, these services will be provided in your home. The early intervention team will also complete an Individual Family Service Plan (IFSP). This service is of no cost to you.

If your child is between the ages of 3 and 5, contact the Chester County Intermediate Unit Early Intervention division at 484-237-5150 or [Eireferral@cciu.org](mailto:Eireferral@cciu.org). A case manager and school psychologist will evaluate your child and determine his or her need for services. If it is recommended that your child is in need of services, these services will take place in the community in a specialized preschool setting. The early intervention team will also complete an Individualized Education Plan (IEP) that will be forwarded to the school when your child is ready to begin school. These services are also of no cost to you.

The Early Intervention Team may recommend that the CATCH team evaluate your child further if they feel that your child exhibits signs or symptoms of Autism.

## What is the CATCH team?

The Childhood Autism Team Check (CATCH) team — an early diagnostic team that includes a developmental pediatrician, school psychologists, social workers and other mental health professionals — can also diagnose your child. The team will assess your child and determine whether he or she has a diagnosis of Autism and/or another diagnosis. The team may also recommend other services including medical, educational and behavioral health services. The CATCH team can be reached at 484-237- 5140.



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

## ANSWERS TO YOUR QUESTIONS

### 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 IEP that notes 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 funding that is available through the state 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 about MA. What is it?**

Pennsylvania has a unique system in which parents of a disabled child can qualify for Medical Assistance regardless of his or her parent's 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.



*"Reality to an autistic person is a confusing, interacting mass of events, people, places, sounds and sights. There seems to be no clear boundaries, order or meaning to anything. A large part of my life is spent just trying to work out the pattern behind everything."*

-- A person with Autism

## **How do I qualify for Medical Assistance?**

In order to be eligible for Medical Assistance your child must 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>.

## **How do I go about obtaining Medical Assistance?**

In order to qualify for Medical Assistance you must obtain an assessment (if you have not done so already) that provides a diagnosis that qualifies for Medical Assistance. Such diagnoses include but aren't limited to Autism, Pervasive Developmental Disorder or 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 the application form, PA 600CH. The quickest way to obtain an application form is to call your local County Assistance Office at (610) 466-1100. You can also use the regular application form (PA 600) but you are not required to do so. You can also apply on-line using the COMPASS application. Families, however, are not encouraged to use the on-line version when applying given that there have been difficulties using the on-line form. PA600 CH-L is NOT to be used at this time for either applications or renewals.

## **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.



Give the people around you time to accept your child's diagnosis of autism... and once they seem receptive... give them information. Your focus has to remain on giving your child the help and support that is needed.

## ANSWERS TO YOUR QUESTIONS



Behavioral therapies, diet, vitamin and mineral supplementation, 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 the child is covered under any medical insurance, this should be noted on the application. A copy of the front and back 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 disabled child?**

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

- Be receiving Social Security Disability (SSD) benefits.
- Be 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 child's disability to the County Assistance Office. If rejected, the County Assistance Office must send a notice to close.
- Child received SSD/SSI and was certified disabled. SSA terminated for reasons other than disability – no need to recertify if 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 \$3000.00 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 \$3000-\$5000. 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. The parents will be sent a form to update their child's case and must complete and return the form, 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, they 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 HMO?**

Children receiving MA will be enrolled in an HMO. There are 3 HMOs available to MA clients in Chester County. These HMOs provide benefits for the physical health of your child. Community Care manages all behavioral health services.

### **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 in adulthood.

### 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 the parents to provide documentation of 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 on educational issues.

Psychologists, certified by the Pennsylvania Department of Education or licensed, 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’s 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, Scoutmaster, 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 BHRIS services? (continued)

**Therapeutic Staff Support (TSS)**—TSS provides direct services to clients with Autism Spectrum Disorders 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 in time 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 BHRIS or wraparound services?

In order to obtain BHRIS in Chester County, you can have your child evaluated at one of the Core Mental Health Providers in the county. An evaluation will be offered within seven days of the initial phone call.

### What will happen at an evaluation for BHRIS?

Before the evaluation, a master's level clinician will ask you questions about your child's developmental history, current and past behaviors including definitions of the behaviors, 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 BHRIS, another level of care that will address your child's needs, or may decide that he or she is uncertain whether BHRIS is the most appropriate care and that an Extended Assessment is needed.

### What is an Extended BHRIS Assessment?

An Extended Assessment is a more lengthy assessment that involves additional observation of your child in the settings in which he or she demonstrates the most difficulty. It also involves a Functional Behavioral Analysis (FBA). An FBA is used to determine the antecedents (triggers or causes) of your child's behavior as well as the consequences (or the results or outcome) of the behavior. The evaluator may also spend more time with the family and observe your child in the family home.

## **When is an Extended BHRS indicated?**

An Extended Assessment is not recommended for every child and is only indicated when:

- The intake staff is uncertain about the diagnosis.
- There are complex co-morbid medical issues.
- There is little available information and/or the family cannot provide adequate information.
- There is uncertainty regarding the most appropriate level of service for the child or family.

Upon completion of the Extended Assessment, the intake staff will determine if BHRS or some other service is the correct level of care for your child.

## **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 (included in Appendix G).



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

Though kids with Autism are affected in different ways, in all cases their capacity to communicate and interact with others is impaired.

## 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 BHRIS look like and what does it mean?**

Following the evaluation, the evaluator will summarize his or her findings and make specific recommendations that include the 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 Community Care Behavioral Health care manager, 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 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 for review for authorization. Community Care (a managed care organization) manages behavioral health services in Chester County

## 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.

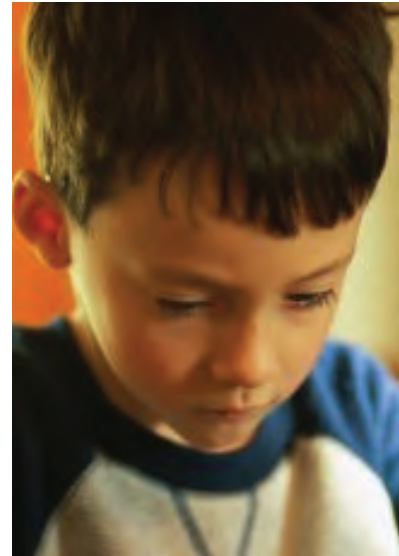
If Community Care’s care manager is uncertain about whether the packet meets medical necessity criteria or is missing required information necessary to make a decision, the evaluation will be further reviewed. In this case, Community Care may request in a letter more information from the provider or from the person who did the evaluation. The parents are not required to do anything further at this point. This letter in no way indicates 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 two days.

## What happens next if recommended services are approved?

If Community Care approves services and a provider has been identified, the provider will then begin to provide services. If a provider is unable to accept the member for treatment, the member is placed on a waiting list. The waiting list is reviewed every week with Community Care and all BHRS providers. 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 their 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. These services should be provided over the length of the authorization period. Please see Appendix F for a list of BHRS providers including the Core Providers (Core Providers conduct the initial assessment for services but may not actually provide the services).

## How do I keep getting these services?

Towards 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



### **What do I do if some or all of the recommended services are denied by Community Care Behavioral Health? 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 Community Care at 1-866-622-4228 and tell us your grievance. Or, write down your grievance and send it to:

Community Care  
1 East Uwchlan Avenue, Suite 311  
Exton, PA 19341  
Attention: Complaints and Grievances Department

Your provider can file a grievance for you if you give him or her 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.

Adults with Autism say that finding a suitable job would improve their lives more than anything else.

## **What happens after I file a First Level Grievance?**

Community Care will send you a letter to let you know we received your grievance. The letter will tell you about the First 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 assistance with your grievance by calling Community Care at 1-800-553-7499.

If you want to be included in the First Level grievance review, you must call us within 10 days of the date on the letter we sent you to let you know we received your grievance. 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.

A committee of one or more Community Care staff, including a doctor or licensed psychologist, who have 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 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 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 is not autistic, 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 Community Care at 1-800-553-7499.

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 our decision.

The Second Level grievance review committee will have three or more people on it. There be will be no Community Care doctor or psychologist on the committee. 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 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 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. We 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. Parents are typically the ones who provide continuity in daily living and stability across the life span.

## ANSWERS TO YOUR QUESTIONS



Autism occurs in all countries and within all socioeconomic classes.

Presently, there is no cure for Autism. However, 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 Community Care at 1-866-622-4228 and ask that your complaint or grievance be decided faster.

You will need to have a letter from your doctor or psychologist faxed to Community Care 1-888-589-6559 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 and at least one Community Care member, 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 (by a doctor who does not work for Community Care) review, you must contact Community Care within 2 business days from the date you get the expedited complaint or grievance decision letter. A decision will be issued within 5 business days from when we receive your request.

### **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. 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 we can reach him or her.

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 1-866-622-4228

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

Community Care will provide persons with disabilities with the following help in presenting complaints or grievances at no cost, if needed.

- Providing sign language interpreters
- Providing 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
- Providing someone to help copy and present information

NOTE: For some issues 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. In some cases you can request a Fair Hearing at any time.



*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.*

-- Singer, Red Grammer

## 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 AND 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 and send it 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 for 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 will be 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 to you) any records, reports and other information we have that is relevant to what you requested your fair hearing about.



Common Characteristics of Autism Include...

Disturbances in communicating with others

Repetitive or ritualistic behavior

May be extremely sensitive (hypersensitivity) to one of the senses (e.g., sound, touch, taste, sight) or extremely non-responsive (hyposensitive) to one of the senses

Selective hearing and may act as deaf

## ANSWERS TO YOUR QUESTIONS



### **When will the Fair Hearing be decided?**

A decision will be made between 60 and 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 reasons for the decision. It will tell you what to do if you don't like the decision.

### **How do I keep getting these services?**

If you want to ask for an expedited External complaint (by the Department of Health) or grievance (by a doctor who does not work for Community Care) review, you must contact Community Care within 2 business days from the date you get the expedited complaint or grievance decision letter. A decision will be issued within 5 business days from when we receive your request.

### **How can Community Care help with the Complaint and Grievance processes?**

If you have been receiving services that are being reduced, changed or stopped and your request for a Fair Hearing is hand-delivered or postmarked within 10 days of the date on the letter telling you that Community Care has reduced, changed, or stopped your services, or telling you Community Care's decision about your First or Second Level complaint or grievance, your services will continue until a decision is made.

### **Who 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.

Common Characteristics of Autism Include...

Resists change in routine

No eye contact, appears to "look through" people

Resists normal teaching methods

Uneven gross/fine motor skills

Marked physical over activity or extreme passivity

### **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 3 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 to 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 3 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

NOTE: An additional review of the grievance process written specifically for parents by a parent is included in Appendix H.

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

Call Community Care at 1-866-622-4228.



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. They have individual tastes and enjoy different activities, just like you do.

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

## APPENDIX A: DIAGNOSTIC CRITERIA

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 6 (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; or
  - (3) symbolic or imaginative play.

## APPENDIX B: DIAGNOSTIC CRITERIA

### 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 potential.

## APPENDIX C: DIAGNOSTIC CRITERIA

Give the people around you time to accept your child's diagnosis ... and once they seem receptive... give them information. Your focus has to remain on giving your child the help and support that is needed.

### 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.

**CATCH/Childhood Autism Team Check:** An early diagnostic team in Chester County that includes a developmental pediatrician, school psychologists, social workers and other mental health professionals.

**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 - a behavior - a 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 that is completed by 3-5 services and forwarded to the school district upon the start of school to formulate the IEP.

**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, or to 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 child comfortable and secure.

In addition to verbal praise, find other ways to reinforce good behaviors and promote self-esteem. After your child has successfully completed a task, for example, 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:** Refers to 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 that consists of a set of systematic observations, which are obtained under standardized conditions. The psychoeducational evaluation 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 (i.e., calming, adding concentration, shutting out an overwhelming sound). Other examples: hand-flapping, toe-walking, spinning, 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 their environment.

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

**STAP/Summer Therapeutic Activities Program:** An intensive Summer treatment program for children with exceptionalities, 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 the presentation of 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: AVAILABLE 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

- Pennsylvania Department of Education Consult Line, [www.pde.state.pa.us/special\\_edu/cwp/view.asp?a=177&Q=61680](http://www.pde.state.pa.us/special_edu/cwp/view.asp?a=177&Q=61680)  
The ConsultLine is designed to assist parents and advocates of children with disabilities or children thought to be disabled. If you have any questions concerning your child's special education program or the laws relating to the provision of services in your child's IEP (Individualized Educational Program), the special education specialists at ConsultLine may be able to assist you.
- Parent Education Network (PEN), <http://www.parentednet.org/>  
PEN is Pennsylvania's statewide Parent Training and Information Center. Much of the information included in this site is designed to support Pennsylvania parents of children with special needs, but information and links are included on Federal Special Education, National Disability Issues and Resources, Special Education Legal Links, Transportation, and Travel that will also pertain to parents and individuals with disabilities in other states.
- Education Law Center, <http://www.elc-pa.org>  
The Education Law Center (ELC), a 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 (HLP), <http://www.phlp.org>  
HLP provides free legal services and advocacy to Pennsylvanians having trouble accessing publicly funded health care coverage or services.
- PA Autism Task Force, <http://www.dpw.state.pa.us/General/AboutDPW/SecretaryPublicWelfare/AutismTaskForce/>

### Behavioral Health

- Child Guidance Resource Center, [http://www.cgrc.org/child\\_bhrs.html](http://www.cgrc.org/child_bhrs.html)  
Multiple locations that provide a full range of therapy and support services.
- Holcomb Behavioral Health Service

### **Behavioral Health (Continued)**

- Chester County Intermediate Unit, <http://www.cciu.org/Departments/StudentServices/Assessment/homecommunityservices.html/view?searchterm=home%20and%20community%20services>  
Home and Community Services serves children diagnosed with mental/behavioral health disorders and allows them to remain in the least restrictive setting possible.
- Creative Health Services, [http://cstmont.com/creative\\_health.htm](http://cstmont.com/creative_health.htm)  
Creative Health Services are a Core provider for Chester County BHRS system. Families can have initial behavioral health assessments and intakes done at this location.
- Community Services of Devereux, [http://www.devereux.org/site/PageServer?pagename=ben\\_csd](http://www.devereux.org/site/PageServer?pagename=ben_csd)  
Community Services of Devereux (CSD) is dedicated to providing high quality, therapeutically intensive, coordinated and community based services to children, adolescents and adults. CSD's continuum is designed to serve the needs of the Philadelphia and Chester County community as well as to be integrated into and complement the over-all range of care and level of services provided by all Devereux Centers providing services to Philadelphia and Chester County residents. As a result, collaborative partnerships between CSD staff, community resources, referral sources and payors are inherent in all services provided. Services are also monitored and evaluated by oversight agencies and funding sources, and through internal on-going and planned performance improvement activities. CSD conducts client, teacher and employee satisfaction surveys proactively and monitors client outcomes through a variety of mechanisms, including the Devereux Scales of Mental Disorders.
- Institute for Behavioral Change, <http://www.ibr-pa.org/>  
We deliver in-home and/or in-school behavior support to address troublesome behavior of all sorts in children of all ages who receive Medical Assistance benefits and need these services, at absolutely no cost whatsoever regardless of family income.
- Integrated Behavior Solutions, <http://www.integratedbehaviorsolutions.net>  
Integrated Behavior Solutions strives to provide targeted rehabilitation services to persons from 2 to 30 years of age with behavior deficits and/or developmental delays. Utilizing the skills and styles of a vast network of professionals, we seek to provide and apply holistic approaches to resolve problems across the behavioral health spectrum.

### **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.

## APPENDIX E: AVAILABLE RESOURCES

### Communication Resources (Continued)

- Boardmaker-Mayer-Johnson, <http://www.mayer-johnson.com>  
Our mission is to enhance 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 each designed for specific needs: Boardmaker is symbol-based desktop publishing software used for the creation of printed materials.
- 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

### Dentists

- Dr. Sheldon Bernick, [http://www.childrens-dentistry.com/index\\_files/Page865.htm](http://www.childrens-dentistry.com/index_files/Page865.htm)

### Developmental Optometry

- Dr. Chaya Herzberg, <http://www.optometrists.org/herzberg/index.html>  
Visual Rehabilitation for Special Populations, including Patients with Traumatic Brain Injuries, Stroke, Whiplash, Developmental Delays, Cerebral Palsy, Multiple Sclerosis, etc.
- Dr. Mitchell Scheimann, <http://www.visiontherapy-online.com/index.html>

### Developmental Pediatricians

- CHOP- Child Development Center, <http://www.chop.edu/consumer/jsp/division/service.sp?id=26666>  
34th St. and Civic Center Blvd.  
Philadelphia, PA 19104  
215-590-7500
- Dr. James Coplan, [www.ndepeds.com](http://www.ndepeds.com)  
919 Conestoga Rd.  
Building 1, Suite 100  
Rosemont, PA 19010  
610-520-2130
- Dr. Thomas Casey  
937 E. Haverford Rd. Suite 103  
Bryn Mawr, PA 19010  
610-527-0147

### **Developmental Pediatricians (Continued)**

- Dr. Beth Parrish and Dr. Maureen Fee, <http://www.stchristophershospital.com/CWSContent/stchristophershospital/ourServices/medicalServices/deptpeds.htm#developmental>  
St. Christopher's Hospital  
E. Erie Avenue and N. Front Street  
Philadelphia, PA 19134  
215-427-5531
- Shyamali Godboli, MD  
Crozer Keystone Health Network  
1 Medical Center Blvd # 326  
Chester, Pennsylvania 19013  
610-876-6898
- Dr. Scott Meyer and Dr. Thomas Challman, <http://www1.geisinger.org/patients/findadoc/docsearchresults.cfm>  
Geisinger Medical Center-Pediatric Subspecialties  
100 N. Academy Ave.  
Danville, PA 17822  
570-271-6440

### **Early Intervention**

- First Signs, <http://www.firstsigns.org>  
First Signs organization aim to educate parents, healthcare providers, early childhood educators, and other professionals in order to ensure the best developmental outcome for every child. Goals are to improve screening and referral practices and to lower the age at which young children are identified with autism and other developmental disorders. The First Signs Web site provides a wealth of vital resources, covering a range of issues: from healthy development, to concerns about a child; from the screening and referral process, to treatments for autism spectrum disorders.
- Checklist for growing children, <http://www.dpw.state.pa.us/Child/EarlyIntervention/003670018.htm>  
Find out what developmental milestones are appropriate for your child between the ages of 1 month to 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>  
Contact numbers to inquire about an intake/assessment with early intervention. This list is broken down by County.

## APPENDIX E: AVAILABLE RESOURCES

### Early Intervention (Continued)

- A Family's Introduction to Early Intervention in Pennsylvania, <http://www.pattan.k12.pa.us/regsforms/Resources2.aspx>  
This booklet explains how to request early intervention services; eligibility criteria; rights and responsibilities; individualized family service planning for ages birth to three; and individualized education planning for ages three to school age.

### Early Intervention Transitions

- Transitions for you and your child, <http://www.dpw.state.pa.us/Child/EarlyIntervention/003670022.htm>  
Transitions occur in our lives all the time in many different ways. Changes in our jobs or homes are examples. While receiving early intervention services, you and your child may experience transitions as well. This site discusses how you can plan for and manage transitions.
- Early Intervention Transition, <http://www.pattan.k12.pa.us/teachlead/EarlyInterventionTransition.aspx>  
Information contained here relates to both the transition from the infant or toddler programs to Preschool programs and the transition from Preschool programs to the school age district programs.

### General Pediatrics

- Dr. Brad Dyer  
Allstar Pediatrics  
400 North Gordon Drive, Suite 702  
Lionville, PA 19341  
610-363-1330
- Reading Pediatrics, <http://www.readingpediatrics.com/>  
All children with special health care needs (such as Down Syndrome, autism, cystic fibrosis) are encouraged to participate in Reading Pediatrics' Star program. Children enrolled in the Star Program will have an updated list of medications, allergies, and specialty care they receive kept in the computer and on their chart, ensuring their specific medical information will be known even in cases of an emergency visit, when their paper chart may not be immediately available.

### Interventions

- Applied Behavior Analysis
  - o Discrete Trial Therapy [http://kathyandcalvin.com/manuals/aba\\_train.htm](http://kathyandcalvin.com/manuals/aba_train.htm)  
Good overview of DTT with examples
  - o Lovaas Therapy [www.lovass.com](http://www.lovass.com)
  - o Verbal Behavior <http://www.autismusaba.de/lovaasvsvb.html>  
Discusses the differences between Lovaas and Verbal Behavior. While 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.

## **Interventions (Continued)**

- o Fluency Training, <http://www.autismteachingtools.com/page/bbbbfz/bbbbfz>  
A brief overview of fluency concepts is provided here for informational purposes, as well as some fluency charts and examples of how we use them. As with all interventions, we suggest you refer to the original source material before choosing how to apply these teaching technologies with your learners.
  - o Precision Teaching, <http://psych.athabascau.ca/html/387/OpenModules/Lindsay/introa1.shtml>  
A brief overview of fluency concepts is provided here for informational purposes, as well as some fluency charts and examples of how we use them. As with all interventions, we suggest you refer to the original source material before choosing how to apply these teaching technologies with your learners.
  - o 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.
  - o Positive behavior supports
  - o 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.
  - o 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. Although the goal of a Story™ should never be to change the individual's behavior, that individual's improved understanding of events and expectations may lead to more effective responses.
  - Picture Exchange Communication System (PECS), <http://www.pecs.com>  
The Picture Exchange Communication System (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: 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/>

## APPENDIX E: AVAILABLE RESOURCES

### Interventions (Continued)

- Other treatment approaches:
  - o Gluten/Casien free diet, <http://www.gfcfdiet.com>
  - o Complimentary approaches <http://www.autism-society.org/site/PageServer?pagename=ComplementaryApproaches> (Discusses art, music, animal therapies)
  - o 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

### Medical Assistance in Pennsylvania

- Take a screening test to see if eligible, apply on line, check benefits  
<https://www.humanservices.state.pa.us/compass/PGM/ASP/SC001.asp>

### For Medical Professionals

- American Academy of Pediatrics, <http://www.aap.org/healthtopics/autism.cfm>
- First Signs, <http://www.firstsigns.org>  
First Signs organization aim to educate parents, healthcare providers, early childhood educators, and other professionals in order to ensure the best developmental outcome for every child. Goals are to improve screening and referral practices and to lower the age at which young children are identified with autism and other developmental disorders. The First Signs Web site provides a wealth of vital resources, covering a range of issues: from healthy development, to concerns about a child; from the screening and referral process, to 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.

## APPENDIX E: AVAILABLE RESOURCES

### Miscellaneous

- Riverside Professional Development, <http://www.riversidepd.com/>  
Riverside Professional Development, LLC improves the performance of your professionals through interactive, classroom style training and one-on-one consultations. Riverside facilitators have over 200 years combined experience. Our history of success with clients in private sector, academic, and human service organizations along with State and City Government provide us a unique ability to assess your specific needs and create customized training. We provide a monthly schedule of open registration events at our training facility, The Riverside Center, while providing tailored workshops, either in-house or on-location, for our contracting clients. Created in 1989 by G. David Smith, Ph.D., B.C.B.A. and incorporated in 2005 under majority owner, Erin E. Smith, Riverside Professional Development is a woman owned and operated business headquartered in Harrisburg, PA.
- Cognitive Learning Systems, <http://www.coglearn.com/Default.aspx>  
Headquartered in Harrisburg, Pennsylvania, CLS is committed to the mission of developing and marketing research-based student and teacher educational programs and content designed to facilitate comprehension and enjoyment of learning. Cognitive Learning Systems believes this mission can be best achieved by integrating proven, research-based learning methods with curriculum and training.
- Traci DiFrancesco, M.Ed, ABA Consultant, [TraciDiFran@comcast.net](mailto:TraciDiFran@comcast.net)  
For 14 years, Ms. DiFrancesco has worked with children and adolescents with autism. She has been trained in ABA and consults in homes and schools. She uses functional behavior assessments. Once strengths and needs are recognized, goals are set. Some of the goals that she addresses are: activities of daily living, academic, communication, social skills, community skills, fine and gross motor skills, play skills and compliance issues. Data will be recorded daily, summarized and graphed. Interventions are clear and consistent. Modifications to the child's program are adjusted according to the data collected. The skills mastered are generalized to different people, items, and environments. Ms. DiFrancesco's goal is to teach children with developmental disabilities to function and learn according to their true potential.
- Residential Living Options, <http://www.residentiallivingoptions.org/>  
RLO is a non-profit organization that assists people with disabilities and their families with their individual housing needs. Throughout the southeastern region of Pennsylvania, there are hundreds of people with disabilities interested in developing housing of their choice. There is, however, limited funding to support them in realizing their dreams. RLO is committed to doing something about it!
- The Second Mile, <http://www.thesecondmile.org/welcome.php>  
The Second Mile is a nonprofit organization serving the youth of Pennsylvania. At The Second Mile, staff are committed to helping young people achieve their potential as individuals and as community members, and providing education and support for parents and youth service professionals.

## APPENDIX E: AVAILABLE RESOURCES

### National Organizations

- Autism Speaks, <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 our concerns and take action to address this urgent global health crisis. It is our firm belief that, working together, we will find the missing pieces of the puzzle.
- Autism Society of America, <http://www.autism-society.org>  
ASA is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families and the professionals with whom they interact. The Society and its chapters share a common mission of providing information and education, and supporting research and advocating for programs and services for the autism community.
- Cure Autism Now, <http://www.cureautismnow.org>  
Cure Autism Now (CAN) is an organization of parents, clinicians and leading scientists committed to accelerating the pace of biomedical research in autism through raising money for research projects, education and outreach.
- Autism National Committee, [www.autcom.org](http://www.autcom.org)  
This is the only autism advocacy organization dedicated to “Social Justice for All Citizens with Autism” through a shared vision and a commitment to positive approaches. Our organization was founded in 1990 to protect and advance the human rights and civil rights of all persons with autism, Pervasive Developmental Disorder, and related differences of communication and behavior.
- Center for Excellence in Autism Research, (CeFAR) <http://www.wpic.pitt.edu/research/CeFAR/default.htm>  
The Pittsburgh-based Center of Excellence, under the direction of Nancy J. Minshew, MD, an internationally recognized expert in autism, is among the top three CPEA's in the country. Dr. Minshew is working with a team of scientists from Carnegie Mellon University as well as the University of Illinois at Chicago, to search for the genetic, cognitive, and neurological basis for autism.
- Centers for Disease Control -Autism Information, <http://www.cdc.gov/ncbddd/autism/>
- OASIS, [www.aspergersyndrome.org](http://www.aspergersyndrome.org)  
As parents of children who are diagnosed with AS, we understand how essential is it that families of children diagnosed with Asperger Syndrome and related disorders, educators who teach children with AS, professionals working with individuals diagnosed with AS, and individuals with AS who are seeking support have access to information.
- Organization for Autism Research, <http://www.researchautism.org/index.asp>  
Putting research to work providing answers to questions for those confronted directly and indirectly by autism.

### Newly Diagnosed

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

### Occupational Therapy

- **A Total Approach**, <http://www.atotalapproach.com/default.asp>  
In order for the child to develop higher order thinking and learning performance, the child has to develop certain neuro-developmental pathways. Sensory Integration is mostly a “bottom up” approach, where we attempt to assist the child in developing more efficient coping strategies inside his / her nervous system, while also working at changing nervous system circuitry to develop a more functional adaptive response to the environment in the child.
- **Jody Seligson-Totally Sense-Sational**, <http://www.totalysensesational.com/id1.html>
- **Fitz-All**, [http://www.fitz-all.com/services/occupational\\_therapy/index.html](http://www.fitz-all.com/services/occupational_therapy/index.html)  
The occupational therapists at Fitz-All are very experienced in working with children with mild to moderate developmental delays, learning differences/disabilities, sensory processing disorders and children on the Autistic Spectrum.
- **Collage**, <http://www.collage-otp.org/>  
OTP serves individuals with social skills deficits that intrude in day-to-day interactions in work, school, family and leisure by providing regularly scheduled, social-skill-enhancing group activities supplemented with therapeutic individual and group interventions and educational outreach.

### Opportunities for Financial Giving/Support

- **The Hearts and Smiles Foundation**  
PO Box 1253  
Southampton, PA 18966  
215-669-4221; Fax 215-997-7987; [heartsandsmiles@comcast.net](mailto:heartsandsmiles@comcast.net)

### Psycho-Educational Testing

- **Bryn Mawr Child Study Institute**, <http://www.brynmawr.edu/csi/>  
The Child Study Institute of Bryn Mawr College provides a multidisciplinary approach to academic and interpersonal difficulties experienced by children, adolescents, adults and families. Highly qualified specialists in psychological assessment, educational support services, speech-language therapy, and psychotherapy work together as a team, collaborate closely with parents, and consult with teachers to help foster adjustment and competence in school, at home and in the community.

## APPENDIX E: AVAILABLE RESOURCES

### Psycho-Educational Testing (Continued)

- Margaret Kay, <http://www.margaretkay.com>
- Neurodevelopmental Psychology Center at Widener University, [http://www.widener.edu/Academics/Schools\\_amp\\_Colleges/School\\_of\\_Human\\_Service\\_Professions\\_/Institute\\_for\\_Graduate\\_Clinical\\_Psychology/Neuropsychology\\_Assessment\\_Center/5338/](http://www.widener.edu/Academics/Schools_amp_Colleges/School_of_Human_Service_Professions_/Institute_for_Graduate_Clinical_Psychology/Neuropsychology_Assessment_Center/5338/)  
The Neuropsychology Assessment Center (NAC) specializes in neuropsychological evaluations for the investigation of a variety of psychological conditions. These include conditions pertaining to learning disabilities, brain injuries, epilepsy, autistic spectrum disorders, speech and language delays, and social interaction problems. The center also provides personality assessments and intellectual evaluations.
- Main Line Clinical Associates, <http://www.mainlineclinical.com/Testing.html>

### Psychologists

- CHOP Department of Psychology, <http://www.chop.edu/consumer/jsp/division/service.jsp?id=26704>  
The Department of Psychology at The Children's Hospital of Philadelphia provides comprehensive inpatient and outpatient psychological services for infants, children and adolescents with pediatric conditions and their families.
- Main Line Clinical Associates, <http://www.mainlineclinical.com/index.html>
- Autism Spectrum Resource Center, <http://www.autismsrc.org>  
The center's mission is to provide therapeutic services and educational resources to individuals within the autism spectrum and their families. The staff recognize the special challenges that they confront in everyday living and respect their unique approach to life. The center's goal is to provide an environment where they will find a sense of belonging with like-minded individuals. They seek to promote a positive self-image that reflects their strengths, potential for growth, and unique contribution to our world.

### Psychiatrists

- CHOP Department of Psychiatry, <http://www.chop.edu/consumer/jsp/division/service.jsp?id=27690>  
The Department of Child and Adolescent Psychiatry offers an array of outpatient and emergency services. They provide comprehensive evaluation and treatment of children and adolescents with psychiatric conditions and behavioral or emotional difficulties. Specialty clinics include the Attention Deficit Hyperactivity Disorders program, the Mood and Anxiety Disorders clinic and the Pediatric Psychopharmacology program. The department is actively engaged in clinical research to support state of the art patient care.

## **Recreation**

- Island Dolphin Care, <http://www.islanddolphinscare.org/>  
Island Dolphin Care is a 501(c)3 not for profit organization that provides dolphin therapy to children with critical illnesses, disabilities and special needs from all over the world. They invite you to meet their therapy staff, learn about dolphin assisted therapy, explore great resources for families, and meet their dolphins.
- Cub Scout Pack 64-Chester County, <http://www.cubscoutpack64.com/>  
This is a Cub Scout Pack in the Chester County, PA Council, run by parents of boys on the autism spectrum. They are a group of about 20 boys that are having fun and enjoying activities that would be hard to involve them in without their own special pack.
- Upper Main Line YMCA-Open Doors, <http://www.umly.org/UMLY/displayInfo.asp?branchID=1&progID=7504>  
Open Doors is a unique program at the heart of the YMCA mission for persons who are differently-abled. It is ability, not disability that counts, and it is the possibilities that are most important!
- Camp Joy, [www.campjoy.com](http://www.campjoy.com)  
Weekend Getaways occur throughout the fall and spring. Beginning Friday evenings and winding down Sunday mornings, the sleep-over Getaway programs feature lots of camp fun: sing-alongs, storytelling, pizza parties, talent shows, and occasional excursions. Most of the Getaway staff members are selected from the Summer Camp counselor team.

## **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 an emergent situation requiring law enforcement.
- Police and Autism, <http://policeandautism.cjb.net/avoiding.html>  
Information on how parent and law enforcement can work together to provide a quick response in the event that a child elopes or runs from the caregivers.
- Medic Alert, <http://www.medicalert.org/Home/HomeEmblemCatalogs.aspx>  
MedicAlert 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

## APPENDIX E: AVAILABLE RESOURCES

### Safety (Continued)

- Safety Harnesses, <http://www.the-baby-boutique.com/tottether.html>, <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 allows for exploration.
- IonKids, <http://www.ion-kids.com/>  
The ionKids system allows you to monitor up to four tagged objects at once. Children, seniors, pets or anything you might lose and want to keep safe. The system consists of a base unit, a handheld device that allows parents to monitor up to four tags simultaneously and a Wristag. Tag holders can be purchased separately and can be clipped onto belt loops or lanyards; Wristags can be locked on children's wrists. ionKids lets you set a variable zone around the base unit so you will know when your child wanders too far. If you can't find them, use the locating device and let it show you where to go to find them.

### School Age to Adult Transition

- Living beyond high school, <http://www.autism-society.org/site/PageServer?pagename=livinghighschool>  
Discusses the importance of transition planning and need to consider when a child is nearing graduation from high school.
- Transition from Special Education to adult life, <http://www.transitionmap.org/>  
A Roadmap from school to the future for students ages 14 to 21 with developmental delay residing in Pennsylvania and receiving special education services.
- Transition Health Care Checklist, <http://www.dsf.health.state.pa.us/health/cwp/view.asp?q=243876>  
The Pennsylvania Department of Health Southwest Regional staff and their community partners recognized a gap in health services for youth with special health care needs. When these youth leave school, they transition from having different or no insurance coverage, from seeing pediatric specialists to searching for adult medical specialists, and from good coverage for medications to having to understand new systems for obtaining medicines.
- Secondary Transitions, <http://www.pattan.k12.pa.us/teachlead/SecondaryTransition.aspx>  
Secondary transition is the process of preparing students for life after they leave high school, including participation in post-secondary education or training, employment, and community living.

### Sibling Issues

- Autism Society article on sibling issues, <http://www.autism-society.org/site/PageServer?pagename=livingsiblings>  
Discusses some strategies on addressing the needs of the siblings of children who have autism.

### **Sibling Issues (Continued)**

- Sibling groups
  - o Second Sat/month. 8:45-10am for 4-6 yr olds and 10-12pm for 7-11 year olds. Cost \$35 Wayne at 987 Old Eagle School Rd., Suite 712, Wayne, PA 19087. Facilitators: Dale Fisher, LCSW , Deirdre Miller, MA. 610-668-8890; dalefish2000@aol.com
- Sibshops, <http://www.thearc.org/siblingsupport/sibshops-about#>  
Support groups for siblings of children with have special needs. Provides a listing by state of available groups. Website also has a listserv for siblings as well as a pen-pal program
  - o SIBSHOPS, for 8-to-13-year-old brothers and sisters of children with emotional/behavioral disorders. Mixture of new games, discussion and guest speakers. Info/Regis. 610-917-3010 x223; rkbrenneman@zoominternet.net
  - o SIBSHOPS - Pottstown. 2nd Sat of month (Sept thru May) Info: Jaime, Creative Health Services, 610-326-2767; jtyson@creativehs.org

### **Social Skills Groups**

- Prompt and Play, <http://www.promptandplay.com/>  
Prompt & Play is a center designed for children ages 3 through 18 who are in need of social skills, life skills, or individual counseling. The various groups at this center are designed to promote social and developmental growth within children.
- Autism Spectrum Resource Center, <http://www.autismsrc.org/>  
The center's mission is to provide therapeutic services and educational resources to individuals within the autism spectrum and their families. The staff recognize the special challenges that they confront in everyday living and respect their unique approach to life. The center's goal is to provide an environment where they will find a sense of belonging with like-minded individuals. They seek to promote a positive self-image that reflects their strengths, potential for growth, and unique contribution to our world.
- Bryn Mawr Child Study Institute, <http://www.brynmawr.edu/csi/>  
The Child Study Institute of Bryn Mawr College provides a multidisciplinary approach to academic and interpersonal difficulties experienced by children, adolescents, adults and families. Highly qualified specialists in psychological assessment, educational support services, speech-language therapy, and psychotherapy work together as a team, collaborate closely with parents, and consult with teachers to help foster adjustment and competence in school, at home and in the community.
- Center for Psychological Services, <http://www.centerpsych.com/>  
The Center for Psychological Services proudly offers a range of art therapy groups designed to help children, teenagers and young adults develop social skills and awareness. Existing strengths are reinforced and new skills are taught to build self-esteem in a relaxed and fun environment. No art talent is necessary to obtain maximum benefit from this program!

## APPENDIX E: AVAILABLE RESOURCES

### Social Skills Groups (Continued)

- Fitz-All, [http://www.fitz-all.com/services/therapeutic\\_support/social\\_thinking/index.html](http://www.fitz-all.com/services/therapeutic_support/social_thinking/index.html)  
Fitz-All has developed a range of groups for children pre-school through middle school who have a need to develop and/or improve social interaction skills. Small groups provide children the opportunity to integrate their skills in a small, more typical play group. All children are screened to determine their particular area of need and the best group and approach for them. Several approaches are used including the cognitive approach based on the I LAUGH model, by Michelle Garcia Winner, to facilitate communication skills for the development of social interactions.
- Collage, <http://www.collage-otp.org/>  
OTP serves individuals with social skills deficits that intrude in day to day interactions in work, school, family and leisure by providing regularly scheduled, social-skill-enhancing group activities supplemented with therapeutic individual and group interventions and educational outreach.
- Main Line Clinical Associates, <http://www.mainlineclinical.com/index.html>
- Theraplay, <http://www.theraplayinc.com/>
- Wanna Play, <http://www.wannaplayprogram.com/>  
Wanna Play offers small social groups aimed at children of all ages and abilities, to help develop their interactive social skills, using fun games and activities in both group and one-on-one settings.

### Spanish

- NFORMACION GENERAL SOBRE EL AUTISMO, <http://www.autism-society.org/site/PageServer?pagename=autismo>

### Speech Therapy

- CHOP-Center for Childhood Communications, <http://www.chop.edu/consumer/jsp/division/generic.jsp?id=77649>  
The Department of Speech-Language Pathology evaluates and treats children from birth to 21 years who have difficulties with communication and swallowing. Services are provided across the continuum of care from CHOP's intensive care units, acute care units, rehabilitation programs, multiple specialty clinics, and outpatient programs. Speech-language pathologists also teach families and professionals to work with children with various communication and swallowing difficulties and participate in research to advance the field of speech-language pathology.
- Jody Seligson-Totally Sense-Sational, <http://www.totalysensesational.com/id17.html>  
The Therapists from Communication Imaging are dedicated to providing individualized communication strategies and treatment plans for children of all ages. By emphasizing upon each child's strengths, treatment techniques and goals will focus on facilitating communication and maximizing each individual's potential. Speech Therapists will use such treatment techniques as PECS, oral motor exercises, sign-langage, Floortime/ DIR, etc. to help increase communication skills while in a therapeutic naturalistic setting.

### **Speech Therapy (Continued)**

- A Total Approach, <http://www.atotalapproach.com/default.asp>  
A trained masters level therapy program that works on specifically speech and communication through a variety of methods, including oral-motor, speech, articulation, assistive technology, as well as work on social and peer relationships.
- Bryn Mawr Child Study Institute, <http://www.brynmawr.edu/csi/>  
The Child Study Institute of Bryn Mawr College provides a multidisciplinary approach to academic and interpersonal difficulties experienced by children, adolescents, adults and families. Highly qualified specialists in psychological assessment, educational support services, speech-language therapy, and psychotherapy work together as a team, collaborate closely with parents, and consult with teachers to help foster adjustment and competence in school, at home and in the community.
- Theraplay, <http://www.theraplayinc.com/>
- Fitz-All, [http://www.fitz-all.com/services/speech\\_therapy/index.html](http://www.fitz-all.com/services/speech_therapy/index.html)  
Speech and Language therapy helps people to develop specific communication skills and/or to compensate for weaknesses in a specific area of ability. Speech/Language Pathologists serve all age ranges and a variety of disorders: speech, language, hearing, voice, fluency and swallowing.

### **Summer Programs/Camps**

- Aaron's Acres, <http://www.udservices.org/aaronsAcres.asp>  
Aaron's Acres was founded as a day camp in 1998 by a group of parents who had children with special needs. The purpose of Aaron's Acres is to provide ongoing supportive, educational and recreational services to children with special needs and their families.
- A Total Approach, <http://www.atotalapproach.com/default.asp>  
5 to 6-week camps are offered every summer to children with developmental delays, including spectrum disorders, and consists of heavy amounts of sensory integration work, DIR/Floortime, as well as educational activities.
- Camp Joy, [www.campjoy.com](http://www.campjoy.com)  
A special needs camp for kids and adults with developmental disabilities: mental retardation, autism, brain injury, and neurological disorders.
- Camp LeMar, [www.leemar.com](http://www.leemar.com)  
Camp Lee Mar is a private residential special needs camp for children and young adults with mild to moderate learning and developmental challenges, including but not limited to the following: mental retardation, developmental disabilities, down syndrome, autism, learning disabilities, Williams Syndrome, Asperger Syndrome, ADD, Prader Willi, and ADHD.

## APPENDIX E: AVAILABLE RESOURCES

### Summer Programs/Camps (Continued)

- Keystone Pocono Camp, [www.campkey.com](http://www.campkey.com)  
Committed to offering novel as well as proven and meaningful programming to individuals with various disabilities, ranging from developmental delays, ADHD, autism, and other related impairments. Ensuring the proper degree of structure, supervision, and most importantly fun.
- Summit Camp and Travel, [www.summitcamp.com](http://www.summitcamp.com)  
Camping for boys and girls with attention, social, or learning issues at Honesdale, Pennsylvania.
- Camp Jaycee, <http://www.campjaycee.org>  
New Jersey Camp Jaycee is a collaborative effort between the New Jersey Jaycees and the Arc of New Jersey with a mission of providing quality camping experiences to persons with developmental disabilities.

### Support Systems/Resources

- Grandparents
  - o <http://www.udel.edu/bkirby/asperger/grandparents.html>  
Answers common questions grandparents of children who have autism may have. The OASIS (online Aspergers Syndrome information and support)
- Religion and Autism
  - o [http://www.autism-society.org/site/PageServer?pagename=Religion\\_and\\_Autism](http://www.autism-society.org/site/PageServer?pagename=Religion_and_Autism)  
Provides both a Christian and Jewish perspective on children with ASD and how the church can provide an inclusive environment
  - o <http://gbgm-umc.org/disc/autism.stm>  
Information on autism for religious educators
  - o Autism Information, [www.autismlink.com](http://www.autismlink.com)
  - o Accessible PA [www.accessiblepa.state.pa.us](http://www.accessiblepa.state.pa.us)
  - o Children's Education and Resource Center <http://www.frs-inc.com/>
- Family Village, [www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)  
The Family Village is a global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services and support.
- ARC of Chester County, <http://www.arcofchestercounty.org/>  
Since 1952, The Arc of Chester County has been there, helping to meet challenges and empowering individuals to reach toward their full potential; successfully weaving their everyday experiences into the rich fabric of Chester County.

**Support Systems/Resources (Continued)**

- Access Services, <http://www.accessservices.org/index.php>  
Mission is to empower and serve persons with cognitive, emotional and behavioral disabilities through innovative services which enable them to live rich and fulfilling lives with positive family and community relationships.
- Autism Spectrum Resource Center, <http://www.autismsrc.org>  
The center's mission is to provide therapeutic services and educational resources to individuals within the autism spectrum and their families. The staff recognize the special challenges that they confront in everyday living and respect their unique approach to life. The center's goal is to provide an environment where they will find a sense of belonging with like-minded individuals. They seek to promote a positive self-image that reflects their strengths, potential for growth, and unique contribution to our world.
- Child and Family Focus, <http://www.childandfamilyfocus.org/>  
It is the mission of Child and Family Focus to provide a continuum of mental health services that will enhance the quality of physical, emotional, intellectual, spiritual, and relational well being of youth and their families. Through our commitment to excellence, we endeavor to provide and advocate for least-restrictive, family- and community-based settings as the most conducive for effective growth and positive change. CFF Autism Family Based Services offer a unique approach to helping the child and the family of the child, who has been diagnosed with a developmental disability within the Autism Spectrum Disorder (ASD).
- Parents Involved Network, [www.pinofpa.org](http://www.pinofpa.org)  
Parents Involved Network of Pennsylvania (PIN) is an organization that assists parents or caregivers of children and adolescents with emotional and behavioral disorders. PIN provides information, helps parents find services and will advocate on their behalf with any of the public systems that serve children. These include the mental health system, education, and other state and local child-serving agencies.
- National Alliance for the Mentally Ill, <http://namipa.nami.org>  
NAMI PA offers the Family to Family Education course for members who have adult children and an educational program specific to the needs of families of children and adolescents. The NAMI-CAN, for young families, and NAMI-CARE, for consumers, models of support are also available.
- Pa Training and Technical Assistance Network, [www.pattan.k12.pa.us](http://www.pattan.k12.pa.us)
- Special Kids Network, <http://www.dsf.health.state.pa.us/health/cwp/browse.asp?A=179&BMDRN=2000&BCOB=0&C=35825>  
It is information and referral to services that children with special health care needs and their families may need. It is available Monday through Friday from 8:00 a.m. to 8:00 p.m. and Saturdays 8:00 a.m. to 6:00 p.m.

## APPENDIX E: AVAILABLE RESOURCES

### Support Systems/Resources (Continued)

- Parent to Parent of Pennsylvania, <http://www.parenttoparent.org/>  
Parent to Parent of Pennsylvania 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.
- Local support groups
  - o ASCEND – West Chester - third Wednesday each month. Grove United Methodist Church, West Chester. Networking and Support. Info: Barbara at 610-701-0466, Barb.Sullivan@comcast.net
  - o ASCEND – West Grove - 3rd Tues of every other month. 11/21- 7pm at Avon Grove Charter School, Info: Jane 610-345-1156, JaneLeeT@aol.com
  - o ASCEND – Delaware County - 10/10, 7:30pm - HANDLING BULLIES 101 with Brad Norford, PhD. at Grace Chapel, Darby and Eagle Roads, Havertown  
Info: Deirdre 610-449-6776, or dcwright@ascendgroup.org or [www.ascendgroup.org](http://www.ascendgroup.org)
  - o Autism Alliance Meeting - Monthly at the CCIU, Boot Road, Downingtown. Call for date/time: Brenda Eaton, Autism Network Coordinator, [brendae@cciu.org](mailto:brendae@cciu.org) 484-237-5354

### For Teachers/Educators

- Autism Education Network, <http://www.autismeducation.net>  
The Autism Education Network's mission is to improve public special education programs and to influence public policy that affects individuals with autism. We use new technology and the Internet to connect and empower people in order to affect change. We provide free information about special education rights and programs and our outreach efforts include seminars about special education law and conferences regarding best practices in autism treatment and methodologies.
- PaTTAN, <http://www.pattan.k12.pa.us/teachlead/Autism.aspx>  
Offers 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 are highlighted. Can also find publications such as Introduction to Early Interventions, Providers 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.
- 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.

**For Teachers/Educators (Continued)**

- IDEA Regulations
  - a. <http://www.wrightslaw.com/idea/art.htm>
  - b. [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)
  
- Wrightslaw, <http://www.wrightslaw.com/>  
Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law and advocacy for children with disabilities. Wrightslaw includes thousands of articles, cases, and free resources on dozens of special education topics.
  
- Different Roads to Learning, <http://www.difflearn.com/>  
For 10 years, Different Roads to Learning has been striving to meet the needs of families and professionals working with children diagnosed with autism spectrum disorders. Product line contains over 250 products, including books, flashcards, and videos, along with other materials critical to Applied Behavior Analysis and Verbal Behavior programs. Have always sought out products that meet the unique learning style and educational needs of the children in the community.
  
- HandRighting, Ink, <http://www.handrightingink.com/index.html>  
Specializes in teaching handwriting to children and adults of all ages. Provide seminars for teachers and parents, and are happy to provide school-based intervention. Do not hesitate to contact for further information.

## APPENDIX F: CHESTER COUNTY BHRS PROVIDERS

Access, Inc.

Contact: Sandy West, Director  
500 Office Center Drive  
Fort Washington, PA 19034  
Phone: 215-540-2150 x247  
Fax: 215-540-2165  
Email: [swest@accessservices.org](mailto:swest@accessservices.org)

Assessment & Treatment Alternatives, (ATA)

Contact: Jordan Weisman, Psy.D,  
Contact : Kimberly Thomas, Dir. of BHRS  
1225 Vine Street  
3rd Floor  
Philadelphia, PA 19107  
Phone: 215-402-2100  
Fax: 215-405-2108  
Email: [www.atainc.org](http://www.atainc.org)

Chester County Intermediate Unit

Contact: Catherine Scanlon, Coordinator  
Contact: Jeanne Crysler, Asst. Coordinator  
455 Boot Road  
Downingtown, PA 19335  
Phone: 484-237-5000- Catherine  
Phone: 484-237-5241-Jeanne  
Direct: 484-237-5192  
Fax: 484-237-5167 and 484-237-5263  
Email: [catherines@cciu.org](mailto:catherines@cciu.org); [jeannec@cciu.org](mailto:jeannec@cciu.org)

Child Guidance Resource Center Media Office

Contact: Aimee Salas, AVP Specialized Services  
2000 Old West Chester Pike  
Havetown, PA 19083  
Phone: 484-454-8700  
Direct: Ext 1119  
Fax: 484-454-8813  
Email: [asalas@cgrc.org](mailto:asalas@cgrc.org)

Child Guidance Resource Center Coatesville Office

Contact: Teri Kelly  
31 South 10th Ave.  
Coatesville, PA 19320  
Phone: 610-383-5635 x311  
Fax: 610-383-6581  
Email: [tkelly@cgrc.org](mailto:tkelly@cgrc.org)

Community Services of Devereux, Beneto Center

Contact: Tarah Sellers, LPC, NCC  
1041 West Bridge Street  
Phoenixville, PA 19460  
Phone: 610-933-8110 x2841  
Fax: 610-933-7451  
Email: [tsellers@devereux.org](mailto:tsellers@devereux.org)

Creative Health Services

Contact: Morgan Crummy (attends BHRS staff mtg)  
Contact: Frank Pogash  
1 Mennonite Church Road  
Spring City, PA 19475  
Phone: 610-948-6490  
Fax: 610-474-00011  
Frank Email: [fpogash@creativehealthservices.org](mailto:fpogash@creativehealthservices.org)  
Morgan Email: [mcrummy@creativehealthservices.org](mailto:mcrummy@creativehealthservices.org)

Devereux Whitlock Center

Contact: Alicia Kolber, LSW, Program Director  
Contact: Chrissy Book  
139 Leopard Road  
Berwyn, PA 19312  
Alicia Direct: 610-251-2082  
Chrissy Direct: 610-699-9905  
Fax: 610-251-2059  
Alicia Email: [akolber@devereux.org](mailto:akolber@devereux.org)  
Crissy Email: [cbook@devereux.org](mailto:cbook@devereux.org)

Elwyn

Contact: Ellen Chung-Finnegan, Dir. of Clinical Operations  
111 Elwyn Road  
Elwyn, PA 19063  
Phone: 610-891-2000  
Direct: 610-558-8100 x118  
Fax: 610-558-8155  
Email: [Ellen.chung@elwyn.org](mailto:Ellen.chung@elwyn.org)

## APPENDIX F: CHESTER COUNTY BHRS PROVIDERS

Foundations Behavioral Health  
Contact: Monica Figueroa, Coordinator  
833 East Butler Avenue  
Doylestown, PA 18901  
Phone: 215-340-1500 x282  
Fax: 215-489-3020  
Email: monica.figueroa@fbh.com

Holcomb Behavioral Health  
Exton Office  
Vance Hamill 610-363-1488  
930 East Lancaster Avenue, Suite 220  
Exton, PA 19341  
Phone: 610-363-1488  
Fax: 610-363-8273  
Email: vhamill@holcombbhs.org

Holcomb Kennet Square office  
Susan Carter  
920 East Baltimore Pike  
Kennet Square, PA 19348  
Ph# (610) 388-7400  
Fax# (610) 388-7407  
Email: scarter@holcomb.org

Human Services, Inc.  
Contact: Delphine Miller (for evaluation only)  
Contact: Tom Ernst (for MT or BSC; no TSS)  
520 East Lancaster Avenue  
Downingtown, PA 19335  
Delphine Phone: 610-430-6141 x508  
Tom Phone 610-873-1005 x273 or 873-1010 x273  
Delphine: Fax 610-430-7708 / Tom: 610-873-9307

Milestone Community Healthcare, Inc.  
Contact: Elaine Gilbert, Director  
844 Centre Avenue  
Reading, PA 19601  
Phone: 610-655-9845  
Email: egilbert@salisb.com (prefers email only)

North East Treatment Centers (NET)  
Contact: Judith Stone, Director of CYF, MH Svcs.  
PA-BHCYFS Division  
Suburban Counties, Springfield Counseling Services  
1260 Woodland Road, Suite 100  
Springfield, PA 19064  
Phone: 610-328-7196 x26  
Fax: 610-328-6264  
Email: jstone@net-centers.org

Progressions Behavioral Health Systems  
Contact: Susan Bubb, Director  
513 King Street  
Pottstown, PA 19464  
Phone: 610-970-5000 x109  
Fax: 610-970-3331  
Email: ptownwrap@aol.com

The Network for Behavior Change  
Contact: John Cappo x15  
1850 E. Lincoln Highway  
Coatesville, PA 19320  
Phone: 610-383-1432  
Fax: same as phone number above  
Email: sakossor@ibc-pa.org  
jcappo@ibc-pa.org

TW Ponessa Exton office  
Contact: Stacy Mason  
403 W. Lincoln Highway  
Exton Center Suite 206  
Exton, PA 19341  
Phone: 610-363-5500  
Fax: 610-363-6499  
Email: smason@twponessa.com  
TW Ponessa Assoc. Lancaster office  
Cathy DeGuire / Email: cdeguire@twponessa.com  
2141 Oregon Pike  
Lancaster, PA 17601  
Phone: 717-560-7917  
Fax: 717-735-1901

## APPENDIX G: OTHER SERVICES

### Other Levels of Care/Treatment Available to Children With Autism

**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., MR, D&A). 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.

**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 hr/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, 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)** — See further description below.

**Family Based Mental Health Services (FBMHS)** — FBMHS for children and adolescents are team-delivered services rendered in the home and community which are designed to integrate mental health treatment, family support services and case management, so that families may continue to care for their children and adolescents with serious mental illnesses or emotional disturbances at home. Family Based Mental Health Services 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 the delivery of acute care. It is often used to transition members out of acute care or serves as an alternative. The primary functions of partial hospitalization services include providing support to help the patient manage the safety of himself, others and property, to reduce acute and chronic symptoms, to evaluate and manage medication therapies, to help the child and family build a variety of skills that strengthen the child's ability to function independently, and to develop an aftercare plan for less restrictive, less intrusive services.

**Other 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 the District's 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, 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.

Case Management Services — This type of service (which is only available in some counties) assists members and families with service coordination, linkage to resources or other needed services and mental health advocacy. When receiving BHR services, a member can also receive case management services through their BHRS provider. The case manager in BHRS is responsible for coordination of care between providers, identification of community supports, help link members to alternative services, schedule appropriate ISPT meetings and organize/manage packet information required by the Managed Care Organizations.

Resource Coordinator — This individual helps to link families to services, identify appropriate supports/resources including both mental health and educational settings, can aid in transportation to and from medical/psychiatric appointments and identify 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, can aid in transportation to and from medical/psychiatric appointments and identify community supports as well as medication monitoring/compliance. Children involved with an ICM have access to 24-hour on-call ICMs to assist in a mental health crisis.

Crisis Services — These services may be accessed through a medical or psychiatric hospital emergency room, 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 H: DENIAL AND APPEAL PROCESS

**A Parents Guide to the Denial and Appeal Process** (\* a parent friendly version of the denial and grievance process written by a parent)

There are times when prescribed services for children with disabilities are denied by Behavioral Health Managed Care Organizations (BHMCOs). Parents often find themselves thrown into the process ill-prepared to advocate for the continued delivery of medically necessary services for their children. Recognizing that parents do not have the luxury of becoming legal and clinical experts in every aspect of the lives of their children, this short paper will not attempt to explain the somewhat ambiguous “Medical Necessity Criteria” used to determine a child’s eligibility for BHRS (or Wraparound services), nor will it attempt to define an “appropriate diagnostic,” as both concepts are beyond the author’s range of expertise.

The simple aim of this paper is to (1) familiarize families with the prescribed time lines to which HealthChoices BHMCOs (e.g., Community Care and CBHNP) are required to observe when resolving Grievances, and (2) to offer practical advice to parents on how to use these time lines to the child’s advantage.

NOTE: This paper is not a substitute for building a strong and convincing case for your child’s level of need and appropriate level of service necessary to meet that need, but is, rather, a companion to a substantive case – that is, a way to use procedure to strengthen your chances for successfully advocating for your child’s Wraparound service needs.

### Some Preemptive Steps

1. Request a copy of the Psychologists Evaluation (“Psych Eval”) before its submission to Community Care.

One of most common reasons for denial is that Psych Evals fail to paint an accurate picture of the child’s level of need. Prepare for the possibility that Community Care will either deny your request for services or request additional information before approving the prescribed services. One of the most common reasons for denial is that Psych Evals do not paint an accurate picture of the child’s level of need. Evaluators typically get to see a very small part of the child’s day and this can result in impressions that do not give the most accurate portrayal of the child’s needs. If you believe a evaluators report has omitted important information about your child, be sure to bring this to the evaluator’s attention.

Words of Advice: (1) Find a psychologist you can trust, and (2) if the psychologist believes more time is necessary to complete a thorough evaluation, contact Community Care immediately for approval of additional billable hours for the Psych Eval.

NOTE: Some evaluating psychologists may balk at a parent’s request to review the Psych Eval prior to submission to Community Care. Don’t let this deter you – BE PERSISTENT!

## APPENDIX H: DENIAL AND APPEAL PROCESS

2. Timing of Provider’s Submission of Prescription Packet to Community Care
  - a. Rule of Thumb: The best way to avoid a dispute is to prepare for a dispute.
  - b. Assume Community Care will either deny your request for services or approve a lesser amount than requested.
  - c. A Prescription Packet submitted to Community Care too early could undermine your ability to defeat a service denial.
  - d. Recommendation: Ask your wraparound provider to refrain from submitting the completed packet until approximately two (2) weeks prior the expiration of your current treatment period.
    - i. Community Care must issue a decision on recommended services within days of receiving the Prescription Packet
    - ii. While this may create a “time pinch,” the parent should consider the inconvenience an important preemptive step toward defeating a service denial.

### How to Beat a Denial in Three Easy Steps

At a glance, the tactics set forth below may appear to be an unfair use of the process. As advocates for our children, however, we cannot assume that the other side will play fair. In fact, representatives of other BHMCOs have admitted that they do not know how to reduce service intensity in a systematic, child-centered manner. Community Care is bound to specific time lines for resolving Complaints and Grievances. Service denials (and approvals for a lesser intensity of service than what was requested) are resolved through the Grievance process. Each treatment period for wraparound services is 120 days in length. As you can see on Table No. 1 below, a “simple” Grievance could take 150 days to resolve.

NOTE: Grievances that are not resolved by the end of the Treatment Period in dispute become moot, and provided the family requests each Grievance Level within 10 days of each denial, the child will continue to receive the intensity of services received prior to the denial.

TABLE NO. 1

<sup>1</sup> A complaint is filed when you are unhappy with Community Care or your provider or you do not agree with a decision made by Community Care (for example, 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, or you are unhappy that you have not received services that you have been approved to get).	
<sup>2</sup> A grievance is filed 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 denies a service, approves less than what was asked for, or approves a different service from the one that was asked for.	
STEP	DAYS
Time to Request 1st Level Grievance from Time of Denial	10
1st Level Grievance Must Be Decided	30
Time to Request 2nd Level Grievance from Time of 1st Level Decision	10
2nd Level Grievance Must Be Decided	30
Time to Request External Grievance Review (Fair Hearing)	10
External Grievance Review Must Be Decided	60
<b>TOTAL POTENTIAL NUMBER OF DAYS IN PROCESS</b>	<b>150</b>

## APPENDIX H: DENIAL AND APPEAL PROCESS

1. Step One: Requesting the 1st Level Grievance
  - a. Within ten (10) days of the date of your denial letter, request a 1st Level Grievance.
    - i. You have forty-five (45) days to request a Grievance, BUT in order to ensure your child continues to receive the level of service he or she received prior to the denial, a Grievance must be requested within 10 days of the date of the denial letter.
    - ii. Suggestion: Remember to begin using the time line to your advantage now. Using a calendar, begin counting the days, and make your request 8 or 9 days after the date of the denial letter.
  - b. Ask to be included in the 1st Level Grievance Meeting, and request the latest date possible (preferably 20+ days following your 1st Level Grievance request).
2. Step Two: Requesting the 2nd Level Grievance
  - a. Within ten (10) days of the date of your 1st Level Grievance decision, request a 2nd Level Grievance. Suggestion: Remember to continue using the time line to your advantage. Using a calendar, count the days, and make your request 8 or 9 days after the date of the denial letter.
  - b. Contact the Pennsylvania Health Law Project for consultative assistance on how to build your case before the 2nd Level Grievance Panel.
  - c. Request the latest date possible for conducting the 2nd Level Grievance Panel Review (preferably 20+ days).
3. Step Three: Requesting the External Grievance Review
  - a. Within ten (10) days of the date of your 2nd Level Grievance decision, request an External Grievance Review.
  - b. Contact the Pennsylvania Health Law Project for possible free legal representation at the External Grievance Review.
  - c. Request the latest date possible for conducting the External Grievance Review (preferably 40-50+ days).

### Hints and Other Possible Tactics

- If the BHMCO argues that the Psychologist's Evaluation fails to support the prescribed hours, request the 1st Level Grievance as mentioned above and coordinate the filing of an "Addendum" to the Evaluation with your Psychologist. The BHMCO must consider the Evaluation as amended and issue a new decision. If they continue to deny services as prescribed the clock starts over and you can request a 1st Level Grievance again, further running down the clock.
- Under certain circumstances, you may request as many as 15 additional days to resolve a 1st Level Grievance.
- Upon receiving a service denial, contact an experienced advocate as soon as possible to discuss "next steps."

### Conclusion

Wraparound denials can be disheartening, but with a small amount of thought and planning, your child can continue receiving medically necessary services throughout the grievance process, and the odds of beating a service denial can be greatly improved.

## **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, you can call Community Care at 1-866-622-4228. Tell us your complaint and we will help you. Or write down your complaint and mail it to us at:

Community Care  
1 East Uwchlan Avenue, Suite 311  
Exton, PA 19341  
Attention: Complaints and Grievances Department

## **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.

## **APPENDIX H: COMPLAINT PROCESS**

### **What Happens After I File A First Level Complaint? (Continued)**

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 also ask for assistance with your complaint by calling Community Care at 1-800-553-7499.

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 has 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.

### **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 our 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.

## APPENDIX H: COMPLAINT PROCESS

### 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.

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

Pennsylvania Department of Health  
Bureau of Managed Care  
Health and Welfare Building, Rm 912  
7th and Foster Streets  
Harrisburg, PA 17120  
Telephone Number: 1-888-466-2787  
Fax: 1-717-705-0947  
Relay Service: 1-800-654-5984

OR

Pennsylvania Insurance Department  
Bureau of Consumer Services  
1321 Strawberry Square  
Harrisburg, PA 17120  
Telephone Number: 1-877-881-6388

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

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

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

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

### What to Do to Continue Getting Services:

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

Community Care, a non-profit behavioral health managed care organization established to serve the needs of the publicly funded health system, manages behavioral health benefits for nearly one million people. Over the past decade, Community Care has improved the quality of life for its members through a commitment to expanding access to services, the development and use of a clinically-focused care management model, and supporting community-based recovery-oriented services. Staff members work with members and their families to create an environment that provides hope, empowerment, choice and opportunities that facilitate recovery.





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