Next Step Guide



Improving the Lives of All Affected by Autism Northwestern Pennsylvania

Autism Society Options Policy

The Autism Society promotes the active and informed involvement of family members and the individual with autism in the planning of individualized, appropriate services and supports. The Board of the Autism Society believes that each person with autism is a unique individual. Each family and individual with autism should have the right to learn about and then select, the options that they feel are most appropriate for the individual with autism. To the maximum extent possible, we believe that the decisions should be made by both the parents and the individual with autism.

Services should enhance and strengthen natural family and community supports for the individual with autism and the family whenever possible. The service option designed for an individual with autism should result in improved quality of life. Abusive treatment of any kind is not an option.

We firmly believe that no single type of program or service will fill the needs of every individual with autism and that each person should have access to support services. Selection of a program, service or method of treatment should be on the basis of a full assessment of each person's abilities, needs and interests. We believe that services should be outcome based to insure that they meet the individualized needs of a person with autism.

With appropriate education, vocational training and community living options and support systems, individuals with autism can lead dignified, productive lives in their communities and strive to reach their fullest potential.

The Autism Society believes that all individuals with autism have the right to access appropriate services and supports based on their needs and desires.

⁻Adopted by the Autism Society Board of Directors 4/1/95; revised by the Autism Society Board of Directors, 12/12/2009

⁻Adopted by Autism Society Northwestern Pennsylvania, July 1, 2011

Table of Contents

| What is Autism? | . 1 |
|---|----------------|
| SignsDiagnosisDSM-V Diagnosis Criteria | . 4 |
| Evaluation options | . 9 |
| nsurance | |
| Medical Assistance (MA) Supplemental Security Income (SSI) HIPP Act 62 Medical Assistance Transportation Program (MATP) | 11 16 17 |
| BHRS Services | 19 |
| Through the Lifespan | 24 |
| Infants and Toddlers School-aged Transition What Happens at 18 Adulthood | 26 30 32 |
| Estate Planning | 43 |
| *Glossary | 47 |

What is Autism?

Definition

Autism is a severe developmental disorder that effects the brain's normal development and impacts social and communication skills. Children with autism look like other kids, but may display strange behaviors that are different from neuro-typical children. Some individuals with autism have cognitive challenges while some do not.

Prevalence

In the United States, Autism is estimated to occur in about one to every 68 children (CDC March 2014). In recent years there has been an increase in the rate of autism. This increase is mostly explained by the improvements in diagnostic methods. Research shows that boys are more likely to have autism than girls. The current estimate for boys in the United States is about one in every 45 boys and one in 189 girls is

diagnosed with Autism. Prevalence for males in Pennsylvania is about one in 75 (April 2012).

Causes

Scientists aren't certain about what causes ASD, but it's likely that both genetics and environment play a role.

Researchers have identified a number of genes associated with the disorder. Studies of people with ASD have identified irregularities in several regions of the brain. These abnormalities suggest that ASD could result from the disruption of normal brain growth early in fetal development. The disruption in normal brain growth affects how brain cells communicate with each other, possibly due to the influence of environment factors or gene function. While these findings are intriguing, they are preliminary and require further study. The theory that parental practices are responsible for ASD has long been disproved.

What role does heredity play?

Twin and family studies strongly suggest that some people have a genetic predisposition to autism. Identical twin studies show that if one twin is affected, there is up to a 90 percent chance the other twin will be affected. There are a number of studies in progress to determine the specific genetic factors associated with the development of ASD. In families with one child with ASD, the risk of having a second child with the disorder is approximately 5 percent, or one in 20. This is greater than the risk for the general population. Researchers are looking for clues about which genes contribute to this increased susceptibility. In some cases, parents and other relatives of a child with ASD show mild impairments in social and communicative skills or engage in repetitive behaviors. Evidence also suggests that some emotional disorders, such as bipolar disorder, occur more frequently than average in the families of people with ASD.

What are some common signs of autism?

The hallmark feature of ASD is impaired social interaction. As early as infancy, a baby with ASD may be unresponsive to people or focus intently on one item to the exclusion of others for long periods of time. A child with ASD may appear to develop normally and then withdraw and become indifferent to social engagement.

Children with an ASD may fail to respond to their names and often avoid eye contact with other people. They have difficulty interpreting what others are thinking or feeling because they can't understand social cues, such as tone of voice or facial expressions, and don't watch other people's faces for clues about appropriate behavior. Individuals with ASD may have difficulty putting themselves in other people's shoes which can appear as lack of empathy. These skills can be learned over time. Individuals with ASD often have a difficult time interpreting how others are thinking or feeling via tone of voice or body language.

Many children with an ASD engage in repetitive movements such as rocking and twirling, or in self-abusive behavior such as biting or head-

banging. They also tend to start speaking later than other children and may refer to themselves by name instead of "I" or "me." Many will echo words and phrases. Some children with an ASD don't know how to play interactively with other children. Some speak in a sing-song voice about a narrow range of favorite topics, with little regard for the interests of the person to whom they are speaking.

Children with characteristics of an ASD may have co-occurring conditions, including Fragile X syndrome (which causes intellectual disability), tuberous sclerosis, epileptic seizures, Tourette Syndrome, learning disabilities, and attention deficit disorder. About 20 to 30 percent of children with an ASD develop epilepsy by the time they reach adulthood

Signs

ASD varies widely in severity and symptoms and may go unrecognized, especially in mildly affected children or when it is masked by more debilitating handicaps. Very early indicators in the first years of life include:



Early Symptoms

- Does not show warm or joyful expressions by 6 months or thereafter
- No back-and-forth sharing of sounds, smiles, or other facial expressions by 9 months or thereafter
- Does not babble or coo by 12 months

- Does not gesture (point, wave, grasp) by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his/her own by 24 months

Later indicators include:

- impaired ability to make friends with peers
- impaired ability to initiate or sustain a conversation with others
- absence or impairment of imaginative and social play
- stereotyped, repetitive, or unusual use of language

- restricted patterns of interest that are abnormal in intensity or focus
- preoccupation with certain objects or subjects (Perseveration*)
- inflexible adherence to specific routines or rituals.

Do signs of autism change over time?

For many children, symptoms improve with treatment and with age. Early Intervention is very important in addressing symptoms and making lifelong improvements. Children whose language skills regress early in life—before the age of 3—appear to have a higher than normal risk of developing epilepsy or seizure-like brain activity. During adolescence, some children with an ASD may become depressed or experience behavioral problems, and their treatment may need some modification as they transition to adulthood. People with an ASD usually continue to need services and supports as they get older, but many are able to work successfully and live independently or within a supportive environment.

How do I get a diagnosis?

If you believe you or your loved one may have autism or any other developmental disability you need to seek a diagnosis from an professional in the autism field. Your first step should be to consult with your own pediatrician or doctor. Because there is no medical test to diagnose autism, you may hear from your pediatrician that you're worrying too much, that all kids develop at a different rate, and that he's doing fine. Your pediatrician may be absolutely correct, but it's always possible that he or she is mistaken.

If you still have concerns, ask your pediatrician or doctor for a referral to a clinic, hospital program or developmental pediatrician or neurologist who has significant experience in diagnosing developmental disorders.

Health care providers will often use a questionnaire or other screening instrument (Autism Diagnostic Observation Schedule (ADOS))* to gather information about a child's development and behavior. Some screening instruments rely solely on parent observations, while others rely on a combination of parent and doctor observations. If screening instruments indicate the possibility of an ASD, a more comprehensive evaluation is usually indicated.

A comprehensive evaluation requires a multidisciplinary team, including a psychologist, neurologist, psychiatrist, speech therapist, and other professionals who diagnose children with ASDs. The team members will conduct a thorough neurological assessment and in-depth cognitive and language testing. Because hearing problems can cause behaviors that could be mistaken for an ASD, children with delayed speech development should also have their hearing tested.

If diagnosed before the age of 3, your child should be referred to the early intervention program (page 24) which will offer a help to children who may display developmental delays in one or more of the following areas: Speech and Language, Gross or Fine Motor, Cognition, Self-Help or Social/Emotional Development. The program is responsible for Intake, Screening and Service Coordination and is free of charge. In Erie County the agency is Erie County Care Management located at 1601 Sassafras Street, Erie, PA 16502. Tel (814) 528-0600.

After the Age of 3, children will be directed to their school districts (page 26) for follow up on the services provided through early intervention, or an evaluation by the School district's own multi-disciplinary team of specialists.

If your child is diagnosed with an intellectual disability as well as autism you should contact Erie County Care Management (814) 528-0600. Erie County Care Management will do an evaluation and provide you with a case worker to coordinator your services. A child with an intellectual disability is also eligible for FSS (Family Support Service*) funding.

Autism Spectrum Disorder (ASD) diagnosing Criteria ~ DSM-V

The doctor evaluating you or your child will refer to the DSM-V as a reference that listed the criteria for every diagnosis.

Previous to the newly revised DSM-V (May 2012), Autism spectrum disorder consisted of Autism, Asperger's syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified. Research from the Neurodevelopmental Work Group has led to these disorders being classified as one that is known as *Autism Spectrum Disorder*. All disorders in this category represent a continuum from mild to severe.

American Psychiatric Association has listed the following as criteria for Autism Spectrum Disorder. An individual must meet criteria A, B, C, and D for diagnosis.

A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:

- 1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,
- 2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and bodylanguage, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
- 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people

- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
 - 1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypes, echolalia*, repetitive use of objects, or idiosyncratic phrases*).
 - 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
 - 3. Highly restricted, fixated interests that happen to be abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or preservative interests).
 - 4. Hyper-or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).
- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)



D. Symptoms together limit and impair everyday functioning.

| Severity Level for ASD | Social Communication | Restricted Interest and Repetitive Behaviors |
|---|---|---|
| Level 3: Requiring very substantial support | Severe deficits in verbal and nonverbal communication skills causing sever impairments in functioning; very limited initiation of social interactions and minimal response to social overtures from others. | Preoccupations, fixated rituals and/or repetitive behaviors markedly interfere with functioning in all spheres. Marked distress when rituals or routines are interrupted; very difficult to redirect from fixated interest or returns to it quickly. |
| Level 2: Requiring substantial support | Marked deficits in verbal and nonverbal social communication skills; social impairments apparent even with supports in place; limited initiation of social interactions and reduced or abnormal response to social overtures from others. | RRB's and/or preoccupations or fixated interests appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts. Distress or frustration is apparent when RRB's are interrupted; difficult to redirect from fixated interest. |
| Level 1: Requiring support | Without support in place, deficits in social communication cause noticeable impairments. Has difficulty initiating social interactions and demonstrates clear examples of atypical or unsuccessful responses to social overtures of others. May appear to have decreased interest in social interactions. | Rituals and repetitive behaviors (RRB's) cause significant interference with functioning in one or more contexts. Resists attempts by others to interrupt RRB's or to be redirected from fixated interest. |

Evaluation Options

Psychoeducational Evaluation

If your child is school-aged (has started kindergarten), you can request an evaluation from your child's school psychologist or principal. The school may conduct a psychoeducational evaluation to diagnose your child. Your child may qualify for special education and the school will create an Individualized Education Plan (IEP) or a 504 plan. The plan can be modified in order for your child to have the appropriate education.

Outpatient Provider Evaluation

A community health provider or a private psychiatrist, psychologist, or neuropsychologist can provide a diagnosis for your child. A licensed psychologists or psychiatrist will meet with your child and complete an assessment that includes a diagnosis and recommendations for services.

Private Physician or Pediatrician

Assessment can be made by your private pediatrician, physician, neurologist, or other qualified licensed physicians. This cost is often covered by your insurance company. There may be some instances where private pay is required. It's recommended that you talk with your physician with any concerns.

Treatments

Treatments for autism aren't a cure but more of an intervention services to help promote the quality of life for the child and their family.

Treatments are based on an individual basis and should accommodate the child's specific needs as well as the family's needs.



The American Academy of Pediatrics (AAP) recommends the following strategies for helping a child to improve overall function and reach his or her potential:

- Behavioral training and management. Behavioral training and management uses positive reinforcement, self-help, and social skills training to improve behavior and communication. Many types of treatments have been developed, including Applied Behavioral Analysis (ABA*), Floor time*, Verbal behavior therapy*, Pivotal Response Therapy (PRT*) and sensory integration*.
- Specialized therapies. These include speech, occupational, and physical therapy. These therapies are important components of managing autism and should all be included in various aspects of the child's treatment program. Speech therapy can help a child with autism improve language and social skills to communicate more effectively. Occupational and physical therapy can help improve any deficiencies in coordination and motor skills. Occupational therapy may also help a child with autism to learn to process information from the senses (sight, sound, hearing, touch, and smell) in more manageable ways.
- Medicines are most commonly used to treat related conditions and problem behaviors, including depression, anxiety, hyperactivity, and obsessive-compulsive behaviors.
- Community support and parent training. Talk to your doctor or contact an advocacy group for support and training. As you gain knowledge and try to make sense of this disorder, please know that many people have probably experience some or all of the emotions you may be going through at this time. The Autism Society NWPA (814-455-3540) wants to help! Often times, just talking to someone who has "been there" can really help.

It is best to only change one (1) approach at a time so you know what is working and which one isn't the best match for your child or young adult.

Many people with autism have sleep problems. These are usually treated by staying on a routine, including a set bedtime and time to get up. Your doctor may try medicines as a last resort.

Costs

Caring for an individual with autism can range from \$3.5 to \$5 million. Annual costs in the U.S. totals about \$90 million, but costs can be reduced to about two-thirds with early diagnosis and intervention.

Medical Assistance (MA) and Supplemental Security Income (SSI)

Medical Assistance has a broad coverage of medical and mental health services for persons under 18. If your child has a social security approved disability, he/she may be eligible for Medical Assistance under PH-95 or "loophole." PH-95 or "loophole" only uses your child's income to determine eligibility. If your child is eligible, they remain eligible until the end of the month of his/her 18th birthday. To maintain coverage, you must complete an annual reapplication, and keep the County Assistance Office notified of any address change. This is Pennsylvania's system of health care services for children with severe disabilities. Like private insurance, not all providers accept Medical Assistance. Always check with your provider to ensure that your Medical Assistance HMO will be accepted.

What does MA cover?

MA covers services rarely covered by employer provided insurance such as Behavioral Health Rehabilitation Services ("wraparound")*, in-home personal care services, diapers, nutritional supplements, prescriptions and transportation (page 18) to and from medical appointments. It also covers services, like in-home nursing, physical, speech or occupational therapy, without annual or lifetime caps often imposed by other insurance plans. Medical Assistance can be a child's only insurance or it can be secondary to other coverage, covering those services or equipment not covered by the child's primary insurance.

Will my child qualify for PH-95 "loophole"?

There is a common misconception that all children with a disability, or all children with an IEP (Individual Education Plan), or all children with a particular diagnosis qualify for Medical Assistance. That is not the case. The rules are just not that simple. However, many children with severe disabilities will qualify for Medical Assistance, regardless of their parent's income.

Here are some basic rules:

- A child can qualify for Medical Assistance even if she or he has other health insurance (although the other insurance needs to be billed first)
- Age: Under 18.
- Disability: Child must meet the Social Security disability guidelines.
- Resources (assets): Not considered (neither the parent's nor the child's).
- Income: Income of the parents or other caregivers is NOT counted. However, income which is legally considered to be the child's IS counted, with some exceptions.

Having countable income does not disqualify a child from Medical Assistance, so long as the amount of the income does not exceed the income maximum. The maximum amount of countable income a child

with severe disabilities can have



and still get Medical
Assistance is \$931 a month
for the year 2012 (it goes
up some each year).
However, not all income
is counted and
significant deductions
are also taken.

The application process for PH-95 (loophole) for MA and SSI

Things you will need:

- 1. Child's birth certificate
- 2. Child's Social Security card
- Assemble documentation of the child's disability or condition. (While Social Security will do this for families applying for SSI, it is the parent/guardian's responsibility to do this when applying for Medical Assistance under the disabled child (loophole) provision.)
- Bank Account with the child or young adult's name (page 15).
 May be a joint account
- 5. If age 16 or older state photo identification

How to Apply

You can apply either by filling out a paper application or by applying online. You can obtain a paper application form- PA600CH- by calling the Healthy Kids Hotline 1-800-986-5437. You can also apply online at http://www.compass.state.pa.us. When filling out the application it is helpful to put "MA for disabled Child" at the top of the application. After you fill out the paper application, you must either mail it or drop it off at your local County Assistance Office. If mailing, send it certified or get a mailing certificate to prove when you mailed it. If you are dropping it off at the County Assistance Office, ask for a receipt. After applying, you will be asked to provide certain documentation, either in person or by mail, to your local County Assistance Office.

Remember: If an SSI beneficiary has savings of \$2,000 or more they could lose entitlement to SSI benefits.

Get an SSI eligibility determination

SSI (Supplemental Security Income) is a program administered by Social Security that provides a monthly check and Medical Assistance to persons who meet Social Security's disability criteria and have low

incomes and assets. Even if the family is not seeking SSI, the County Assistance Office may require that you get a determination from Social Security as to the child's eligibility for SSI. Unlike Medical Assistance under the loophole, parental (and stepparent) income and assets DO count in determining eligibility for SSI. However, Medical Assistance will not be denied if parental income or asset exceeds the SSI limits. Therefore, it is sufficient to get a denial for SSI from Social Security so long as the denial is on the basis of income or assets- not because Social Security has determined the child does not meet their disability requirements. The SSI eligibility screening can be done with a simple phone call in most cases. To get a determination as to whether the child meets the income and resource requirements, you should do the following:

- 1. Call Social Security at 1-800-772-1213. When you hear the recorded message, choose the option that allows you to get a live Social Security representative. The parent/guardian should request an appointment be set up for an SSI eligibility screening over the phone. Some representatives will give you a date and time when a Social Security representative will call to take the necessary information to make a determination on financial eligibility for SSI. Unfortunately, there does not appear to be a clear policy or practice regarding phone interviews so you may need to go into your local Social Security office to make an SSI application.
- 2. Remember that parent's and stepparent's income and assets count for SSI when under the age of 18 so be sure to have pay stubs, bank statements and other income and resource records available on the date Social Security calls back. You will be required to provide original pay stubs, bank account, birth certificates, identification, etc. If you choose to do your interview via telephone, you will need to mail those documents to social security and they will mail them back to you. If you don't want to relinquish these documents in the mail it is better to make an appointment at the social security office.

3. If the Social Security representative determines that the parent/stepparent/child's income or resources are over the SSI limits, ask the representative to send a written letter to that effect. Keep that letter to submit to the County Assistance Office as proof that the child was denied SSI. If the child had been on SSI recently (in the last year or so) and was terminated due to parental income or resources of the parent(s) or child, the County Assistance Office will usually accept the fact that the child had been on SSI as proof the child meets the Social Security disability standards so long as the child was not terminated on grounds that he/she was no longer disabled.

Tip: If the child was terminated on the grounds that he/she no longer meets the disability standards, it is essential that the parent/guardian appeal the SSI termination (they have 65 days from the date on the SSI termination notice to do so). Otherwise, the determination of Social Security that the child does not meet the disability standards will be binding on Medical Assistance and the child will not qualify under category PH-95.

PLEASE NOTE: BANK ACCOUNT - You must receive your Social Security payments electronically. One of the ways you can choose to receive your benefits is through direct deposit. Be sure to have your checkbook or account statement with you when you apply. We will need that information, as well as your financial institution's routing number, to make sure your monthly benefit is deposited into the right account. If you do not have an account with a financial institution or prefer to receive your benefits on a prepaid debit card, you can sign up for the Direct Express® card program. With Direct Express®, payments are made directly to the card account. Another payment option you may want to consider is an Electronic Transfer Account. This low-cost federally insured account lets you enjoy the safety, security and convenience of automatic payments.

What happens next for Medical Assistance?

Once the application and necessary documentation has been submitted, the caseworker at the County Assistance Office has authority to immediately find that the child meets the disability standards, pending a final decision by the Medical Review Team (MRT).

Will my child be enrolled in a Health Management Organization (HMO)? Children receiving MA will be in a HMO or a Health Insurance Premium Payment (HIPP) program. The services the child needs (other than behavioral health services) are then obtained through the HMO, rather than through Medical Access itself, although the HMO must cover all the services regular MA covers.

The parent can choose from one of 3 Medical Access HMOs. If the parent does not choose, Medical Assistance will pick one. The parent is also asked to choose a primary care physician practice for their child. If the parent does not choose, the HMO will assign the child to one.

What is HIPP?

HIPP stands for Health Insurance Premium Payment. A child will qualify for HIPP if he or she is an active Medical Assistance (MA) recipient who has access to medical insurance through employment (or the family's employment). HIPP representatives conduct a cost analysis based on who is eligible for the employer insurance, the amount of premium, and the policy benefits. If the anticipated MA costs of the clients are greater than the cost of the employer insurance, the child is enrolled in a HIPP program. A child with HIPP will NOT be covered by the Medical Assistance HMO but will still have access to the plain ACCESS (fee for service).

Are Medical Assistance benefits retroactive?

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

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

Act 62 Pennsylvania's Autism Insurance Act

What is Act 62?

Prior to Act 62 private insurers did not cover autism services. Act 62 was set to insure that private insurance companies provide some coverage for autism. It requires some insurance companies to pay for diagnostic assessments and treatment for individuals diagnosed with autism, and who are under the age of 21. In 2014, to comply with the Affordable Care Act – health care reform – a change was made for certain employer-sponsored benefit plans that provide coverage for care under Act 62. Specially, some groups will need to remove the annual dollar maximum (up to \$40,000 to be adjusted annually for inflation beginning in 2012) that has applied to these services since state mandate Pennsylvania Act 62 of 2008 became effective. This change is effective when the employer's coverage renewed in 2014. You may want to check with your benefits administrator to find out if you are affected by this change. You can also call Member Service at the number on your insurance identification card

Am I covered?

Your child may be covered by Act 62 if:

- Your child has an autism spectrum disorder and is covered by a health group insurance, but only IF the policy covers 51 or more employees and is not self-funded
- Your child has autism and is enrolled in Pennsylvania's CHIP program.

What is covered?

- Any diagnostic assessment used to test for autism
- Treatments for autism. Which include:
 - Prescription medications and blood level tests
 - Services of a psychiatrist
 - Services of a psychologist
 - Applied Behavior Analysis
 - Other "rehabilitative care"

- Therapies (Speech/ language pathologies,
 Occupational therapists,
 Physical therapists)
- Pharmaceutical care

Please note: Your child is covered until the allotted limit is reached. Act 62 is subject to copayment, deductible and coinsurance provisions and any other general exclusions or limitations to the same extent as other medical services provided by the policy. Act 62 is only required to cover services that are medically necessary.

What if I am denied services?

If your private insurance company denies services because they feel they are not medically necessary, you should use the grievance process available under Act 62 as a challenge to the decision.

What if I exceed the annual cap?

If your employer-sponsored benefit plan covers autism services with an annual cap and you are enrolled in Medical Assistance then the Medical Assistance program will pay services that exceed the annual Act 62 cap. It is important to check if your autism services are enrolled in the Medical Assistance and with your private insurance company to assure continuity of services in the case that you do exceed the annual cap.

Medical Assistance Transportation Program (MATP)



As a medical assistance recipient, you may be able to get help with the transportation you need to get to and from medical providers. MATP provides rides to medical care at no cost to you. You can also get mileage reimbursement if you use your own car or find someone

willing to give you a ride. The program is offered through the Erie Metropolitan Transit Authority (EMTA). You can obtain transportation services while you are completing the registration process. However, the county MAPT must receive assigned registration form from you within 30 days of when your services begin. For more information:

http://www.ride-the-e.com/_pdfs/MATP.pdf

MATP application: http://www.ride-the-e.com/files/docs/file28.doc

BHRS Services

BHRS is also known as wraparound services. These services are the most commonly recommended services for children with Autism. These services include a range of behavior management treatment for the individual, and also include rehabilitation services provided in community settings. Such settings refer to the child's home or school, as well as other settings such as camps, recreational venues, or commercial establishments. The goal for BHRS services is to create and implement a treatment plan and then transfer those skills to the parent or teacher who will be responsible for implementing that plan and future behavior plans. Parents and/or teachers will need to be present when the services are provided. The service providers are not allowed to provide child care or take the child into the community without a parent.

How do I get BHRS services?

In order to obtain BHRS, your child can be evaluated by one of the mental health providers in your county. You should bring as much information as possible to this appointment. A master's level clinician will ask you questions about your child's developmental history as well as current and past behaviors, including:

- Definitions of the behaviors
- Frequency and intensity of the behaviors
- Past medical history review of strengths
- Current school or pre-school placement, if relevant
- Drug and alcohol history, if relevant
- Family psychiatric history
- Past treatment
- Medical history

Who determines if my child will receive the recommended services?

Coverage for behavioral health services for all children comes through a separate entity called a "Behavioral Health Managed Care Organization" which has a contract with the county MH/MR agency. There are different Managed Care Organizations for different counties.

The contracted "Behavioral Health Managed Care Organization" (as of 2014 *Community Care Behavioral Health Organization (CCBHO)*) will review the information presented for behavioral health services. If the care manager feels the presented information meets the criteria for "medical necessity" for the services requested, the service provider will

be contacted with an authorization number.

If the care manager is uncertain if your child's information meets the medical necessity criteria or required materials are missing, the evaluation will



have to be further reviewed. The care manager may request more information from evaluators or providers. The parents are not required to do anything further from this point. If more information is requested it does not mean that services will not be approved. It simply means the care manager needs more information to better understand the child's individual case. The provider will have 5 business days to provide the requested information, and then the behavioral health managed care organization has 2 business days to make their decision.

BHRS are the most widely used treatment for children with Autism that are deemed medically necessary. Some professionals can be used to determine if a BHRS program is necessary for your child.

ALL SERVICES ARE SUBJECT TO CHANGE PER DEPARTMENT OF PUBLIC WELFARE REGULATIONS.

These professionals include:

<u>Behavior Specialist Consultants (BSC)-</u> Master's or doctoral level staff that assess and analyze behavioral data, develop child specific treatments plans, and consult with the treatment plans, and consult with the treatment team concerning the implementation of the treatment and behavioral plan

Mobile Therapists (MT)- Master's or Doctoral level staff who provide intensive individual or family therapy services to children with Autism and their families in settings other than a provider agency or office, including the child's home, school, church, community center, a neighbor or extended family member's home, and other community settings. They provide child-centered, family-focused individual and family psychotherapy, as defined in the treatment plan and agreed upon by the therapist and family using formats that may vary according to the individualized needs of the child.

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



What happens next?

After the evaluation of BHRS is over your child may be prescribed BHRS services. Recommendations may be made for additional testing, medication, or adjunctive therapies such as occupational therapy, physical therapy, and/or speech therapy.

After a recommendation

Subsequent to an evaluation your child will receive a prescription for necessary services. These services will be requested in "hours per week." These services will be provided for a period of time. The typical length of time for a prescription period is 6 months.

Interagency Service Planning Team (ISPT)

After the evaluation, the facility used for services will hold a treatment team meeting with you known as an 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.

An ISPT meeting usually consists of the service providers, family members, school personnel, a care manager from Community Care Behavioral Health Organization, and/or other recommendations. The team may discuss the evaluator's recommendations. If the team members are not in agreement, they can request that the evaluator change his or her original recommendations.

After the evaluation, recommendations and ISPT meeting, all related documentations will be sent to Community Care for review for authorization.

What happens once services are approved?

If services are approved, identified providers will be contacted to begin to provide services. The provider looks over the child's case to make sure they have available staff and the right expertise for the individuals services needed. After reviewing the case, the provider contacts the family with notifications of a start date. The family is able to choose a

provider but may have to wait longer depending on the availability of the provider. Once the child starts the program, the BSC* may begin with a Functional Behavioral Assessment (FBA*). FBA is a process that attempts to understand the function of each behavior and development strategies for reducing the identified behaviors in all settings. These services will be provided over the length of the authorization period.

How do I keep getting these services?

Once you're toward the end of the authorization period, the agency will contact you to be re-evaluated. They will look at the impact of services, changes in behavior, and the continued needs of your child. Another evaluation will be completed as well as ISPT meeting with relevant team members. Discuss with your service provider what information you will need to provide at the meeting.

What if I'm denied the recommended services by Community Care? If you are denied or don't agree with Community Care you can file a grievance. Community Care will send you a letter stating that you were not completely approved.

You can file if Community Care does any of the following:

- 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?

In your letter about being denied services, they will explain how to file a grievance. You will have 45 days from the date you received the letter to file the First Level grievance. To file your grievance you can call your Community Care Customer Service Representative. Or, write down your grievance and send it to the Community Care office in your area. Also, you can ask your provider to file the grievance for you. If your provider is filing a grievance for you, you cannot file a separate grievance on your own.

Through the lifespan

Like any other person, an individual with autism goes through significant life changes. Their quality of life depends not only on foundations established in childhood but specific supports throughout their life.



Infants and Toddlers

A child's first three years are important to their development. Children make numerous trips to the doctors in this time span. During the 18 and 24 month checkup the American Academy of Pediatrics recommends autism screenings for all children. If a child has a sibling with autism, further screenings should be done. Early symptoms can detect autism at 18 months. Parents can look for developmental milestones starting at about 3 months. The average age of getting a diagnosis is between 3-6 years.

Detecting autism early can make a huge impact on your child's life because early intervention can begin. Without early intervention the symptoms of autism can worsen and cost of living for the individual with disabilities can become colossal.

Early Intervention (EI)

Early Intervention is the most valuable investment you can make for your child with autism. Each child who is diagnosed with autism share

common symptoms but have a difference in severity. Because of this difference each child should be assessed accordingly and early intervention should accommodate the child's specific problem areas. Although severities in symptoms are different, early intervention focuses on the major deficits of autism. All early intervention programs should have the resources for communication, social, sensory and academic difficulties. The program should match the child and the family's needs.



The Autism Society recommends the following things to consider when designing a program:

- A curriculum that addresses deficit areas focuses on long-term outcomes and considers the developmental level of each child.
 Deficit areas include:
 - Inability to attend to relevant aspects of the environment, shift attention, and imitate the language and actions of others
 - Difficulty in social interactions, including inappropriate play with toys and others, and symbolic and imaginative play
 - Difficulty with language comprehension and use, and functional communication
- Programs that capitalize on children's natural tendency to respond to visual structure, routines, schedules, and predictability
- A focus on generalization and maintenance of skills, using technology such as incidental teaching approaches
- Effective and systematic instructional approaches that utilize technology associated with Applied Behavior Analysis

- Coordinated transitions between service delivery agencies, including 0-2 programs, early intervention/ preschool programs, and kindergarten environments
- Use of technology associated with functional behavioral assessment and positive behavioral supports with a child who presents behavioral challenges
- Family involvement, including coordination between home and involved professionals; an in-home training component; and family training and support

ERIE COUNTY: Early Intervention contact Erie County Care Management 1601 Sassafras Street, Erie, PA 16502 PHONE: (814) 528-0600

School-aged

Educational Mandates

Once your child is ready to go to school, there are many programs that help the child become appropriately assimilated to the school environment. The Individuals with Disabilities Education Improvement Act (IDEA) is a federal mandate that states students with disabilities can get a free, appropriate education. IDEA is the primary educational law for students with disabilities. The child's education should be free, appropriate for his/her age and developmental level. IDEA was developed to further define educational rights for children and to strengthen the role parents have in their child's education. IDEA required that all students with disabilities be placed in the Least Restrictive Environment (including preschool placement) and that parents and student participate in that decision.

Individualized Education Plan (IEP*) or 504 Plan*?

Not all students who have disabilities require specialized instruction. For students with disabilities who do require specialized instruction, the Individuals with Disabilities Education Act (IDEA) controls the procedural requirements, and an IEP is developed. The IDEA process is more involved than that of Section 504 of the Rehabilitation Act and requires documentation of measurable growth. For students with disabilities who

do not require specialized instruction but need the accommodations that ensure they will receive equal access to public education and services, a document is created to outline their specific accessibility requirements. Students with 504 Plans do not require specialized instruction, but, like the IEP, a 504 Plan should be updated annually to ensure that the student is receiving the most effective accommodations for his/her specific circumstances.

Individualized Educational Plan (IEP)

An IEP is a contract between a school district and a student and his parents. Students with Autism are ensured to have an Individualized Educational Plan (IEP) that parents and teachers design for the specific needs of the child. This plan allows the child to reach appropriate needs

as well as tracks the progress of the child. There is no one plan that will work for all students, therefore parents must work with the school to ensure they are providing all educational needs. To determine what is appropriate for your child several steps should be followed:



- Identify students area of strengths and weakness in as much detail as possible
- The IEP team will generate and identify appropriate goals and objectives for the student to develop throughout the year. This decision is based on goals that have been developed to meet the individual needs of the child. Also, the team must be able to provide the supplementary aids and services in order for the student to succeed in the given educational setting.

The IEP Team for each child with a disability includes:

- the parents of a child with a disability;
- not less than 1 regular education teacher of such child (if the child is, or may be, participating in the regular education environment;
- not less than 1 special education teacher, or where appropriate, not less than 1 special education provider of such child;

- a representative of the local educational agency
- an individual who can interpret the instructional implications of evaluation results
- at the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the child, including related services personnel as appropriate; and
- whenever appropriate, the child with a disability

Students have the right to receive an appropriate education. Some other supportive services may be required to assist a child with a disability to receive benefits of the program. All related services should be written in to the IEP with duration and frequency of services as well as relevant objectives.

These related services may include but are not limited to the following:

- Audiology
- Counseling services
- Early identification and assessment of disabilities in children
- Medical services (for diagnostic or evaluation purposes only)
- Occupational therapy
- Physical therapy

- Parent counseling and training
- Psychological services
- Recreation
- Rehabilitation counseling
- School health services.
- Social work services
- Speech pathology
- Transportation

Any service that benefits the child's education that is developmental, corrective or supportive should be considered a "related" service and should be provided.

State standardized testing in schools

Schools are required by law to test students for yearly progress. Students with very severe disabilities who meet specific criteria may be exempted by the State. These students are typically videotaped to show their inability to take the tests. Most students with IEP's are required to take these tests, but accommodations can be written into the IEP to help students.

Private Schools

Private school students who have been parentally placed do not have the same rights to special education services as public school students; however, intermediate units are required to meet with the administrators of their area private schools to discuss the services they will provide via equitable participation. At minimum, the local school district must provide the following to students enrolled in private schools:

- Upon request they must evaluate the student for special education, without cost, and determine whether the student is eligible for special education services.
- If eligible, the resident school district must offer a free appropriate public education (FAPE) in the public school. The parent can refuse the offer of FAPE and parentally place the child in a non-public school.



The Federal law "No Child Left Behind" (NCLB) enacted years ago to require students to pass their standardized tests in order to graduate with a diploma. Pennsylvania is one of many states that have been granted a waiver from NCLB. But even under that law provisions were made for students with IEPs. Students who failed the tests were permitted to be tested using an alternate method on the subject material. There are provisions however, that permit a student with an IEP to graduate without passing the Annual Standardized testing as long

as they meet their IEP goals and the school team agrees. Students with IEP's may remain in school until the end of the school year when they turn 21. Students are afforded the right to walk through graduation ceremonies with their graduating class at the end of their senior year. The school then issues the diploma at the end of the school year when the student leaves (21 or before). The diploma will be dated at the time issued.

What is Extended School Year (ESY*)?

Extended School Year (ESY) services are special education and related services that are provided to students with disability beyond the 180-day school year. ESY services are not day care or respite services. ESY services are not a summer recreation program or other programs or services that are not required to ensure the provision of FAPE to a student – even if they provide some educational benefit. ESY **must** be considered each year for **every** student with a disability.

There are 7 factors that the IEP team must consider to determine if a student is eligible for ESY services. However, no one factor by itself can be used to determine eligibility for ESY services.

- 1. Regression
- 2. Recoupment
- 3. Regression/Recoupment
- 4. Mastery

- 5. Self-sufficiency and independence
- 6. Successive interruptions
- 7. Severity of disability

Transition

Transition planning should begin when the student turns 14 years old or when the student starts high school. The transition team should include the student, their parents, teachers, therapists, and any agency representatives that will be involved in the student's transition process. At this age,



the IEP only needs to include course work and the educational program $% \left(1\right) =\left(1\right) +\left(1$

that the individual is to be involved in. It should also include some prospective information about the possible post-secondary goals that the student is interested in.

Individuals with Disabilities Education Improvement Act (IDEIA) require that transition plan be in place by age 16. Much like an IEP, the Individualized Transition Plan (ITP*) is an outline of transition services that should be developed. The ITP may include education or vocational training, employment, living arrangement and community participation, among other services.

To begin this step in transition planning, interests, abilities and needs of the individual should be looked at. For example:

- Further education.
 - College, vocational training, adult education.
- Employment.
- Living arrangements.
- Social opportunities.

The Pennsylvania Office of Vocational Rehabilitation (OVR)* provides vocational rehabilitation services to help persons with disabilities prepare for, obtain, or maintain employment. OVR provides services to eligible individuals with disabilities, both directly and through a network of approved vendors. Services are provided on an individualized basis. The OVR counselors, during a face-to-face interview, assist customers in selecting their choice of vocational goals, services and service providers. An Individualized Plan for Employment (IPE) is developed, outlining a vocational objective, services, providers and responsibilities. OVR provides diagnostic services, vocational evaluation, counseling, training, restoration services, job placement assistance, support services and assistance with learning assistive technology. Referrals to OVR can be made by agencies, schools, clergy, hospitals, families or any interested individuals. The assessment process may begin with OVR after the individuals 17th birthday.

For more information:

http://www.dli.state.pa.us/portal/server.pt/community/vocational_rehabilitation/10356

What Happens at 18?

At the age of 18, all rights to make decisions about the disabled individual's welfare are transferred to the individual from their parents or guardians. This means that the student can make all decisions about their well being on their own. However, for special education purposes, the age of majority is 21 years old.



When a person with a disability becomes an adult the entitlement programs that provided education and other services throughout their childhood end, as an adult the services available will depend on the possibility of obtaining a waiver. Under federal law, students with disabilities are entitled to special education and related services until the end of the school year following his or her 21st birthday or, whenever the student accepts a diploma — whichever comes first. Once a student accepts a diploma — regardless of the student's age — the right to special education and related services terminates.

Things to Do

- 1. Call Department of Welfare (DPW) by the end of the month your child turns 18.
- 2. Tell DPW you are applying for SSI benefits. DPW will hold your son/daughter's Medicaid coverage. This is important so your insurance isn't cancelled
- 3. Register for the selective services
- 4. Register to vote
- 5. Get State issued photo identification (if not done)
- 6. Open joint bank account (if not done)

Be prepared when applying for social security benefits.

- Refer to page 13 for a list of items needed.
- See glossary for representative payee definition.
- Bank Account requirements (page 15).

When your child turns 18, several things happen in relation to his/her benefits. First, the young adult must reapply (if you are currently receiving benefits) or apply for SSI benefits as an adult. The parents or guardian should go to the local Social Security office and file a claim for SSI (see list page 13). The family's income and resources will no longer be considered when determining your child's financial SSI eligibility. Only your child's resources and income will count. Social Security will make a determination as to your son/daughter's disability and then benefits will begin. The monthly maximum Federal amount for 2014 is \$721 for an eligible individual. These amounts are subject to change yearly. For an eligible person living in another person's household, and receiving inkind support of rent and food, the monthly amount is \$481. This is the "Value of One-Third Reduction Rule". The rule states if you are living in somebody else's household, and somebody in that household gives you both food and shelter (no matter its value) then the maximum amount of SSI you are eligible for goes down by 1/3. While the SSI will provide your son/daughter with a modest monthly income, the Medicaid benefit is more important in the long run. Social Security often rejects applications for SSI, claiming that the applicant is not disabled. If your application for Social Security benefits is denied, you may not be out of luck. A substantial percentage of denials are reversed on appeal.

- To appeal a denial of an initial claim, complete Form SSA-561-U2 (Request for Reconsideration). If you are appealing the denial of disability benefits, you'll also need to complete Form SSA-3441-BK (Disability Report -- Appeal).
- The forms ask you for basic information, such as your name and Social Security number. You will also need to state the reasons why you think you were unfairly denied benefits. When you submit your forms, you can attach other material for the administrators to consider, such as recent medical records or a letter from a doctor or employer about your ability to work. All of the forms are available at your local Social Security office or from the agency's website at www.ssa.gov.

If your son or daughter (aka, the SSI benefit recipient) is unable to manage his/her personal finances and does not have a court-appointed legal guardian, the SSI benefit recipient can request that a friend/family member or other agency/person act as his/her Representative Payee*. If the SSI benefit recipient has been found to be incapacitated by a judge, the guardian of the estate/finances will be appointed Representative Payee.

Supplemental Nutrition Assistance Program (SNAP). If you receive SSI, you may be able to get help through SNAP, formerly known as food stamps. SNAP can help you buy more food without spending more money. However, Social Security does not decide if you qualify for SNAP. Most SNAP rules apply to all households, but there are a few special rules for households that contain a disabled member. Households may have \$3,250 in countable resources if at least one person is disabled (\$2,000 in countable resources if no member is disabled). Certain resources are NOT counted, such as a home and lot, the resources of people who receive SSI, the resources of people who received Temporary Assistance to Needy Families, and most retirement (pension) plans. Most households have to meet both a monthly gross income test and a monthly net income test to be eligible for SNAP benefits. However, households in which all members are receiving SSI or TANF are considered to be eligible based on income. Other households with one or more elderly or disabled members only have to meet the net income test. Net income is gross income minus certain deductions. For more information visit: http://www.fns.usda.gov/snap/eligibility

Almost all male U.S. citizens, and male immigrants living in the U.S., who are 18 through 25, are required to register with Selective Service. It's important to know that even though he is registered, a man will not automatically be inducted into the military. In a crisis requiring a draft, men would be called in sequence determined by random lottery number and year of birth. Then, they would be examined for mental, physical and moral fitness by the military before being deferred or exempted from military service or inducted into the Armed Forces.

Disabled men who live at home must register with Selective Service if they can reasonably leave their homes and move about independently. A friend or relative may help a disabled man fill out the registration form if he can't do it himself. Men with disabilities that would disqualify them from military service still must register with Selective Service. Selective Service does not presently have authority to classify men, so even men with obvious handicaps must register now, and if needed, classifications would be determined later.

A <u>chart</u> of who must register is also available. https://www.sss.gov/RegVer/wfRegistration.aspx

Health Insurance

If your child has been covered under your private insurance policy, it is

important to know what happens when your child reaches the age of majority. Some policies allow the adult child to continue coverage if he or she is a full time student. Most policies will now allow continued cover for dependents up to age 26. Some will allow indefinite continued coverage for



adult children if they are disabled, and if the parent continues to provide 50% or more of that adult child's support and maintenance. Because some aspects of SSI payments are based on whether or not the young adult is claimed as a dependent by his or her parents, you need to carefully consider that later option. Adults with disabilities who qualify for SSI disability benefits also qualify for Medicaid coverage.

Adulthood

While federally mandated services through the school system are entitled until age 21, it can be a challenge to transition to the next step of adulthood. Adult services follow two (2) tracks. 1. Diagnosed with an intellectual disability; 2. No intellectual disability diagnosis.

Waiver Supports

Waivers provide funding for supports and services that help individuals with disabilities live in their homes and communities. Waiver Services go beyond those provided by medical assistance.

Unlike Medicaid, waivers are not an entitlement program. In Pennsylvania, the Department of Public Welfare administers multiple Medical Assistance/Medicaid waivers. Each waiver has its own unique set of eligibility requirements and services. An intellectual disability must be diagnosed by the age of 18.

Three Waivers most common in our area:

- Consolidated waiver for individuals with intellectual disabilities
- Person/Family Directed Support Waiver
- Adult Autism Waiver

What is the Consolidated Waiver for individuals with Intellectual Disabilities?

The Pennsylvania Consolidated Waiver for individuals with intellectual disability is designed to help persons with intellectual disabilities live more independently in their homes and communities and to provide a variety of services that promote community living, including self-directed service models and traditional, agency-based service models.

Eligibility criteria:

- Be age three and older
- Have a diagnosis of intellectual disability
- Require active treatment
- Be recommended for an intermediate care facility level or are based on a medical evaluation
- Determined eligible for Medical Assistance (MA)

- \$2,000 resource limit (does not apply to dependent children under age 21)
- Income limit 300% of the Federal Benefit Rate

Services:

- Assistive technology
- Behavior support
- Companion
- Education support
- Home accessibility adaptations
- Home and community habilitation (unlicensed)
- Homemaker/chore
- Licensed day habilitation
- Nursing
- Prevocational
- Respite

- (Licensed or unlicensed) residential habilitation
- Specialized supplies
- Supported employment
- Supports broker
- Supports coordination
- Therapy (physical, occupational, visual/mobility, behavioral and speech and language)
- Transitional work
- Transportation
- Vehicle accessibility adaptations

What is the Person/Family Directed Support Waiver?

The Pennsylvania Person/Family Directed Support Waiver is designed to help persons with developmental disabilities live more independently in their homes and communities and to provide a variety of services that promote community living, including self-directed service models and traditional, agency-based service models.

Eligibility criteria:

- Be age three and older
- Have a diagnosis of intellectual disability
- Require active treatment
- Be recommended for an Intermediate Care Facility/Intellectual disability level of care based on a medical evaluation
- Determined eligible for Medical Assistance
- \$2,000 resource limit (does not apply to dependent children under age 21)
- Income limit 300% of the Federal Benefit Rate
- Individual cost limit of \$30,000 per person per fiscal year (excluding supports coordination)

 Does not require Office of Developmental Programs licensed community residential services

Services:

- Assistive technology
- Behavior support
- Companion
- Education support
- Home accessibility adaptations
- Home and community habilitation (unlicensed)
- Homemaker/chore
- Licensed day habilitation
- Nursing
- Prevocational
- Respite
- Specialized supplies

- Supported employment
- Supports broker
- Supports coordination
- Therapy (physical, occupational, visual/mobility, behavioral and speech and language)
- Transitional work
- Transportation
- Unlicensed residential habilitation
- Vehicle accessibility adaptations

What is the Adult Autism Waiver?

The Adult Autism Waiver is a Medical Assistance program that provides home and community-based services specifically designed to help adults with an autism spectrum disorder participate in their communities in the way they want to.

Who is eligible for the Adult Autism Waiver?

In order to be eligible for the Adult Autism Waiver, a person must be age 21 or older, a U.S. citizen or qualified alien, a resident of Pennsylvania (or planning to be a resident at the time of enrollment) and meet certain diagnostic, financial and functional eligibility criteria listed below. Priority is given to people not already receiving ongoing state funded or state and federally funded, long-term care services.

If eligibility starts at age 21, how far in advance should I apply for the Adult Autism Waiver, so that services can be in place when I turn 21? Individuals can request an application at any time. However, applications will be denied if they are received prior to 90 days before the applicant's 21st birthday.

Diagnostic Criteria:

Must have a diagnosis of an autism spectrum disorder (ASD), which includes: Autistic Disorder, Pervasive Development Disorder, Not Otherwise specified (PDD-NOS), Asperger Syndrome, Childhood Disengretitive Disorder, Retts Disorder

Services:

In addition to Supports Coordination, there are 18 services:

- Assistive Technology
- Community Inclusion
- Counseling
- Environmental Modifications
- Family Training
- Job Finding
- Residential Habilitation
- Supported Employment
- Therapies (Occupational, Speech and Language, Counseling)

- Transitional Work Services
- Behavioral Specialist Services
- Community Transition
 Services
- Day Habilitation
- Family Counseling
- Job Assessment
- Nutritional Consultation
- Respite
- Temporary Crisis Services

Financial Eligibility:

Must meet the income and resource limits for Medical Assistance and Payment of Long Term Care Services. The income limit is currently 300% of the Supplemental Security Income Federal Benefit Rate. More information on the Federal Benefit Rate can be found at www.ssa.gov.

Functional Eligibility:

Must have substantial functional limitations that are likely to continue indefinitely in three or more of the major life activities listed below. These functional limitations, which must be evident before the person reaches the age of 22, include limitations in: self-care, understanding and use of receptive and expressive language, learning, mobility, self-direction, capacity for independent living

What are some of the important features of the Adult Autism Waiver?

- Priority given to individuals not receiving ongoing state/federally funded services
- Participant retains Health Choices or ACCESS Plus; physical health services are not included as waiver services

- Choice of enrolled provider for each service
- Residential Habilitation Services (24/7) available if assessment determines need
- Higher income eligibility threshold than the eligibility threshold usually applied to persons living in the community

How many adults can be served under the Adult Autism Waiver?

The waiver program can currently serve 418 (as of 2014) adults with autism. Priority is given to those individuals not already receiving state or federally-funded services.

Is there a waiting list for the Adult Autism Waiver?

This program is enrolling participants. The Bureau of Autism Services maintains a list of individuals who have requested applications but have not received them, in order of the date and time of their initial call to the toll free number. Applications will be sent and eligibility for these individuals will be determined as waiver capacity allows. Priority for the Adult Autism Waiver is given to people not already receiving state or federally-funded services and they will receive applications first. Requests for applications are processed in the order they are received.

Can I apply for more than one Pennsylvania waiver or the ACAP adult program at once, or will applying for one make me ineligible for the other ones?

You may apply for more than one waiver or the Adult Community Autism Program at a time, including the Adult Autism Waiver. However, individuals may not enroll in more than one.

What are some of the differences between the Adult Autism Waiver and other programs for adults in Pennsylvania?

- Designed to meet the needs of adults with an autism spectrum disorder
- Administered at the state level directly by the Bureau of Autism Services
- Does not use IQ as an eligibility factor
- Providers required to complete autism-specific training and meet standards

- Clinical and behavioral support, as well as technical assistance, is available to enrolled providers
- Service planning and measures of success based on individual goals
- Services based on proven approaches to help participants realize these goals

FOR MORE INFORMATION:

http://www.dpw.state.pa.us/foradults/autismservices/index.htm

Education Options

Autism varies in severity therefore it is possible that some individuals on the spectrum are able to continue their education. This allows the

individual to focus on areas of interests as well as further social interaction opportunities. Parents may work with their young adult in selecting classes that take advantage of the individual's strengths and weaknesses. There are programs that can assist the



young adult in the postsecondary world in support and preparation to navigate the daily demands of college life.

- College
- Trade Schools
- Special Certificate Programs
- Auditing classes and classes to improve life
- Job Training (OVR* and Unemployment Office)
- Hiram G. Andrews (vocational rehabilitation facility)*

Employment

Individuals who have a mild degree of autism may be able to hold a job. Young adults ready to work should find a place who's boss will understand the social limitations and have a well-defined goal as part of the job. Some adults may have a job where they don't need any support offered from the work environment. Others however may require support from the community with a job that was especially designed for them. Contacting certain agencies such as state employment offices, state departments of vocational rehabilitation, social services offices, mental health departments, and disability-specific organizations may be able to help look for the right employment.

- Full time and part time employment
 - Special rules make it possible for people with disabilities receiving Social Security or Supplemental Security Income (SSI) to work and still receive monthly payments and Medicare or Medicaid. Social Security calls these rules "work incentives."*
- Sheltered workshops (for individuals with ID diagnosis)
- Volunteer Work
- Day Programs

Housing/Living Arrangements

An adult with ASD can decide to live independently if he/she can handle daily tasks with little or no supervision. Some examples of daily tasks include handling housework, cooking, shopping and bill paying. Many families decide to start with some supportive living arrangement and move towards an increase of independence. Individuals may need a supervised apartment, where there is no daily supervision but weekly visits. Individuals with ASD are expected to get to work, prepare meals, as well as personal care and housekeeping.

Supportive services are explicit to complex problem-solving such as managing money, not day-to-day living. Support systems within the community will also help with the transition of independent living. This support system may include bus drivers, waitresses, or coworkers.

Intellectual Disability

- Supported living
- Payee reps
- Group Homes
- Foster Families
- Remaining at home

No Intellectual Disability

- Independent living
- Remaining at home

Social Opportunities

Becoming an adult means establishing a meaningful place in the community. Individuals with ASD may need encouragement to establish friendships. Friends can help the individual deal with bullies and find special interests. Personal friendships are built on interests between two people. They can share their thoughts as well as experiences. Some individuals with ASD can be very open and honest which can make for a meaningful close friendship but coworkers and others in the community might not be willing to share their personal information, and may be uncomfortable when someone is sharing too much with them.

It may be a challenge but people with ASD can develop close personal relationships with whom they can confide in, share experiences with, and enjoy spending time together. Many people with Autism have a strong interest in certain areas. Depending on what the interest is there are many ways to find people who share those same interests.

Long-Term Planning (Estate Planning)

As a parent of a child with special needs, you need to educate yourself about the many options available. It is never too early to start planning for your child's future.

How can you ensure that your child receives appropriate therapies and medical treatments? How can you present the nature of your child's disabilities and needs to those who may care for them without "scaring" them away? How can you



find appropriate caregivers who will carry out your wishes AND respect your child's goals, dreams and life expectations?

What are Trusts?

You already know you have to plan your estate carefully to provide the best quality of life for your child. Did you know that there are several types of trusts for special needs children? The most common types are Support Trusts and Special Needs Trusts.

- Support Trusts: Support Trusts require the trustee to make distributions for the child's support in areas like food, shelter, clothing, medical care, and educational services. Beneficiaries of Support Trusts are not eligible to receive financial assistance through Supplemental Security Income (SSI) or Medicaid. If your child will require SSI or Medicaid, you should avoid a Support Trust.
- Special Needs Trusts: For many parents, a Special Needs Trust is the most effective way to help their child with a disability. A Special Needs Trust manages resources while also maintaining the child's eligibility for public assistance benefits. There are two types of Special Needs Trusts: Third-Party and Self-Settled.
 - Third-Party Special Needs Trust: Created using the parents'
 assets as part of an estate plan; distributed by a will or living
 trust.
 - Self-Settled Special Needs Trust: Generally created by a parent, grandparent or legal guardian using the child's assets to fund the trust (for example, when the child receives a settlement from a personal injury lawsuit and will require lifelong care). If assets remain in the trust after the beneficiary's death, a payback to the state is required.

Power of Attorney vs. Guardianship

<u>Power of attorney</u> is a legal document where one person (the principal) authorizes another (the agent) to act on their behalf. There are powers of attorney for assets which allow your agent to make decisions regarding your property and there are powers of attorney for health care which allow your agent to make decisions regarding your health care needs. Your power of attorney can be broad in scope, giving your agent the ability to make any and all financial and personal decisions for you (a General Power of Attorney) or you can limit your agents authority by specifying the types of decisions you would like them to make on your behalf (a Limited Power of Attorney).

<u>Guardianship</u> is a legal relationship where a court gives a person (the guardian) the power to make personal or financial decisions for another (the ward). A family member, public or professional guardian initiates the proceedings by filing a petition in the proper court. A guardianship over the person gives the guardian the power to make personal decisions for the Ward. A guardianship over the estate gives the guardian the power to make financial decisions for the ward. Often the court appoints the same person as guardian of the person and guardian of the estate.

Appropriate documentation is necessary to establish the need for a guardianship. A court determines whether the individual is unable "to properly manage and take care of himself or his property, or both." (NRS 159.019). The guardian is required to report to the court on an annual basis.

Differences: power of attorney is a private way to decide who will have the legal authority to carry out your wishes if you can no longer speak or act for yourself. It is less costly than a guardianship, which is a public proceeding and the person appointed as your guardian may not be the person you would have chosen. A power of attorney is limited in its authority to the scope of the document. Financial institutions sometimes

refuse to honor powers of attorney for assets, due in part to their fraudulent use by agents. In contrast, a guardian has broad legal authority which is recognized by medical providers and financial institutions. A guardian is subject to court supervision for protection. Contact an attorney to appropriately address your situation.

Letter of Intent

A Letter of Intent is written by you (the parent or guardian) and describes your son or daughter's history, his or her current status, and what you hope for him or her in the future.

What would happen if you suddenly became unable to provide your child with the necessary supports he needs? Without you, your child would become dependent on other caregivers who simply do not possess all of your personal knowledge and insight. However, there are steps you can take now to minimize the natural disruption and disorientation that will occur upon your death or if you become unable to care for your child during your lifetime.

First and foremost, you should appoint a legal guardian for any child who is not expected to be able manage personal financial or medical decisions without assistance. Second, you could prepare a letter of intent to help loved ones and your child manage a difficult transition when you no longer are the primary caregiver. A letter of intent is an important planning tool for parents of children with special needs (including adult children), and also may be useful when planning for minor children who are not expected to face special challenges.

Although a letter of intent is one of the most important estate planning documents a parent can prepare, it is not a formal legal document that must be created by an attorney. The goal of a letter of intent is to memorialize your knowledge of your child's needs so that you may guide future caregivers, guardians and trustees in providing the best possible care to your child. Simply put, a thoughtful letter of intent ensures that

those who come after you need not waste precious time figuring out the best way to manage and care for your child.

Sample Letter of Intent:

http://www.prudential.com/media/managed/Letter_of_Intent.pdf



As you gain knowledge and try to make sense of this disorder, please know that many of the people have probably experience some or all of the emotions you may be going through at this time.

Autism Society NWPA wants to help!

Often times, just talking to someone who has "been there" can really help.

Glossary

- A -

<u>Autism Diagnostic Observation Schedule (ADOS)</u> - is a semi-structured assessment of communication, social interaction, and play (or imaginative use of materials) for individuals suspected of having autism or other pervasive developmental disorders. The ADOS consists of four modules, each of which is appropriate for children and adults of differing developmental and language levels, ranging from nonverbal to verbally-fluent.

<u>Applied Behavior Analysis (ABA) - Behavior analysis focuses on the principles</u> that explain how learning takes place. Positive reinforcement is one such

principle. When a behavior is followed by some sort of reward, the behavior is more likely to be repeated. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning. ABA can be used in structured situations such as a classroom lesson as well as in "everyday" situations such as family dinnertime or the neighborhood playground. Some ABA therapy sessions involve one-on-one interaction between the behavior analyst and the participant. Group instruction can likewise prove useful.

-B-

BHRS/Behavioral Health Rehabilitation Services- (formerly known as wraparound services) Community-based mental health treatment available to children with mental health needs in Pennsylvania. These services are prescribed by physicians to be provided in home and school settings. Services are based on medical necessity criteria (MNC) and funded through Medical Assistance. Three components can be provided in almost any combination-behavior specialist consultation (BSC), mobile therapy (MT), and therapeutic staff support (TSS).

<u>Behavior Specialist Consultants (BSC)</u>- an individual who designs, implements, or evaluates a behavior modification intervention component of a treatment plan to produce socially significant improvements in human behavior through skill acquisition and the reduction of problematic behavior.

<u>Biomedical Treatment for Autism - Biomedical treatment is a systematic</u> approach to treating the underlying issues of autism inside the body.

Biomedical treatment is managed by a physician and is individualized to the patient's particular ailments. There are many different biomedical therapies available to treat a child's needs. FROM: Generationrescue.org

— E—

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

<u>Echolalia (also known as echologia or echophrasia)</u> - is the automatic repetition of vocalizations made by another person. Echolalia may be an immediate reaction to a stimulus or may be delayed. Echolalia is one of the most salient aspects of communication disorders in autism, but is neither unique to, nor synonymous with ASD.

Extended School Year (ESY) — refers to the delivery of special education and related services during summer vacation or other extended periods when school is not in session. Not all students who receive special education require extended school year services. The IEP team must consider the need for EYS at each meeting and must describe those services specifically with goals and objectives. EYS services must be individually crafted.

- F -

504 Plan - A student that does not qualify for special education services under IDEA (an educational law) still may qualify for services under Section 504 (a civil rights law) if the disability is shown to substantially limit his or her educational performance. A child with a disability is one who has a physical or mental impairment that substantially limits major life activities, such as caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working. Accommodations often refer to building accessibility, classroom adjustments and curriculum modifications and may be updated or revised as the need changes.

<u>Family Driven/Family Support Services</u> - family-driven is a method of providing family support services whereby the family or the person with intellectual disability (ID), rather than the service system, are given the responsibility for deciding which services will best address the family's specific needs. In a family-driven model, family members also have a primary responsibility for planning, implementing, evaluating and setting priorities on services to address their specific needs. Your Erie County Case Manager will fill out forms to determine the amount of money your family member with an ID diagnosis is eligible to receive, if there are funds available.

<u>Family Support Service Funding (FSS)</u> the Office for People with Developmental Disabilities' Family Support Services Program funds services through not-forprofit agencies in the community and through the regional Developmental

Disabilities Services Offices (DDSO). Services may include: respite (day, evening, overnight); recreation (day, evening, summer/day camp); family reimbursement/cash subsidy; case management/ service coordination; counseling; behavior management; crisis intervention; financial and life planning assistance; information/referral/outreach; training; transportation; special adaptive equipment and environmental modification.

Floortime Therapy - derives from the Developmental Individual-difference Relationship-based model (DIR) created by child psychiatrist Stanley Greenspan, M.D. Its premise is that adults can help children expand their circles of communication by meeting them at their developmental level and building on their strengths. According to Greenspan, the technique challenges children with autism to push themselves to their full potential. It develops "who they are," rather than "what their diagnosis says." Floortime encourages parents to engage children literally at their level – by getting on the floor to play. Families can combine it with other behavioral therapies or use it as an alternative approach.

Overall, Floortime aims to help children reach six developmental milestones crucial for emotional and intellectual growth. They are:

- Self-regulation and interest in the world
- Intimacy, or engagement in human relations
- Two-way communication
- Complex communication
- Emotional ideas
- Emotional thinking

Floortime does not target speech, motor or cognitive skills in isolation. Rather, it addresses these areas through its focus on emotional development.

<u>Functional Behaviors</u>- are basic behaviors (e.g. mealtime skills) a child has mastered or needs to master to get along as independently as possible in society.

<u>Functional Behavioral Assessment (FBA)</u> — is an assessment used to identify the reason for, or purpose of, a child's problem behavior(s); to develop and implement a plan to change the things that maintain the behavior; and to teach the child appropriate replacement behaviors.

Hiram G. Andrews (under OVR) - in Johnstown provides vocational training and comprehensive rehabilitation services to people from across the state. A comprehensive program of services featuring the integration of education on campus at the Commonwealth Technical Institute (CTI), counseling, evaluation, and physical restoration in a barrier-free environment. A continuum of support services ranging from vocational evaluation and career exploration to independent living skills combines to offer our students the skills they will need to live, work and contribute in the community. Interested applicants are urged to visit HGAC and explore its opportunities. Tours for individuals and groups can be arranged by appointment. Call 814-254-0645 or use our toll-free number, 800-762-4211, extension 0645, to arrange a tour of the HGAC and to see the career opportunities provided through an education at the Commonwealth Technical Institute.

-1-

<u>Idiosyncratic Language</u> -Idiosyncratic language refers to language with private meanings or meaning that only makes sense to those familiar with the situation where the phrase originated.

<u>Individualized Educational Plan (IEP)</u> - 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.

<u>Individualized Family Service Plan (IFSP)</u>- is a written document that defines the Early Intervention services provided to a child and the child's family base upon family-identified priorities.

<u>Individualized Transition Plan (ITP)-</u> A plan which facilitates the transfer of a student from one setting to another, such as to a classroom, school or work environment.

<u>Intellectual Disability (ID) –</u> (formerly known as Mental Retardation) – refers to a pattern of persistently slow learning of basic motor and language skills during childhood, along with deficits in adaptive behavior and a significantly

below-normal global intellectual capacity during adulthood. Individuals with ID may be described as having developmental delays, global developmental delays, or learning difficulties.

<u>Intermediate Unit (IU) —</u> is a regional educational agency that provides services to local educational agencies including curriculum, special education, technology and information services, human resources, instruction, and professional development.

<u>ISPT/ Interagency Service Planning Team</u> is a necessary step in the process of getting BHRS approved by your child's Behavioral Health Managed Care Organization (MCO).

-L-

<u>Least Restrictive Environment (LRE)</u> – is an IDEA requirement indicating that children with disabilities, including children in public or private institutions or other care facilities, must be educated with children who are not disabled, to the maximum extent possible. Removal of children with disabilities from the general education environment occurs only when the nature and/or severity of their disabilities are such that education in general classes with the use of supplementary aids and services cannot be achieved satisfactory.

<u>Local Educational Agency (LEA)</u> – is a school district, charter school, or other educational entity responsible for providing free, appropriate, public education in accordance with Pennsylvania Department of Education statutes, regulations, and policies with or without support from other agencies.

-M-

<u>Medical Assistance Program (MA)</u> – assures access to quality healthcare for Pennsylvanians eligible for services. Sometimes referred to as Medicaid, it provides payment for health care services on behalf of children with limited income and children with disabilities.

<u>Mobile Therapists (MT)-</u> master's level clinician who provides individual therapy for the child or adolescent. Therapy can be done at home, in school, or in the community

Office of Vocational Rehabilitation (OVR) - provides vocational rehabilitation services to help persons with disabilities prepare for, obtain, or maintain employment. OVR provides services to eligible individuals with disabilities, both directly and through a network of approved vendors. Services are provided on an individualized basis. The OVR counselor, during face-to-face interviews, assists customers in selecting their choice of vocational goals, services and service providers. An Individualized Plan for Employment (IPE) is developed, outlining a vocational objective, services, providers and responsibilities. Certain services are subject to a Financial Needs Test (FNT) and may require financial participation by the customer. Counseling and guidance, diagnostic services, assessments, information and referral, job development and placement, and personal services such as readers or sign language interpreters are provided at no cost to the individual. Also, by law OVR customers receiving Social Security benefits for their disability (SSI, SSDI) are exempt from OVR's Financial Needs Test. For more information: http://www.dli.state.pa.us/portal/server.pt/community/vocational rehabilit ation/10356

- P -

<u>Perseveration</u> - the term perseveration refers to repeating or "getting stuck" carrying out a behavior (e.g., putting in and taking out a puzzle piece) when it is no longer appropriate.

<u>Perseverative Speech</u> - Children with ASD who learn to talk usually have repetitive use of language. Perseverative speech refers to repeating the same phrase or word over and over or bringing up the same topic repeatedly with a sense of "getting stuck" when it is no longer appropriate.

<u>Pivotal Response Treatment</u> - or PRT, was developed by Dr. Robert L. Koegel, Dr. Lynn Kern Koegel, at the University of California, Santa Barbara. Pivotal Response Treatment was previously called the Natural Language Paradigm (NLP), which has been in development since the 1970s. It is a behavioral

intervention model based on the principles of ABA. PRT is used to teach language, decrease disruptive/self-stimulatory behaviors, and increase social, communication, and academic skills by focusing on critical, or "pivotal," behaviors that affect a wide range of behaviors. The primary pivotal behaviors are motivation and initiation of communications with others. The goal of PRT is to produce positive changes in the pivotal behaviors, leading to improvement in communication skills, play skills, social behaviors and the child's ability to monitor his or her own behavior. Motivational strategies are used throughout intervention as often as possible. These include varying tasks, revisiting mastered tasks to ensure the child retains acquired skills, rewarding attempts, and using direct and natural reinforcement. The child plays a crucial role in determining the activities and objects that will be used in the PRT exchange. For example, a child's purposeful attempts at functional communication are rewarded with reinforcement related to their effort to communicate (e.g. if a child attempts a request for a toy, the child receives the toy).

-R-

Representative Payee (Social Security Income) - A representative payee is an individual or organization appointed by SSA to receive Social Security and/or SSI benefits for someone who cannot manage or direct someone else to manage his or her money. The main responsibilities of a payee are to use the benefits to pay for the current and foreseeable needs of the beneficiary and properly save any benefits not needed to meet current needs. A payee must also keep records of expenses. When SSA requests a report, a payee must provide an accounting to SSA of how benefits were used or saved. Having power of attorney, being an authorized representative or having a joint bank account with the beneficiary is not the same thing as being a payee. These arrangements do not give legal authority to negotiate and manage a beneficiary's Social Security and/or SSI payments. In order to be a payee a person or organization must apply for and be appointed by SSA.

- S -

<u>Sensory Integration Therapy</u> - this type of therapy is usually performed by an occupational therapist or physical therapist who takes "patients" through a

series of sensory and motor skill exercises. The goal of sensory integrative therapy is to facilitate the development of the nervous system's ability to process sensory input in a more normal way. Sensory integration is a term for a process in the normal brain which pulls together all of the various sensory messages in order to form coherent information on which we can act.

<u>Special Needs Trust (SNT)</u> - legal document and a very important part of your child's long-term financial plan.

The trust may be used to hold money:

- that you save
- that others give your child as gifts
- that you receive from an insurance settlement

Funds in the SNT will not interfere with your child's eligibility for federal benefits like Medicaid and Supplemental Security Income (SSI).

-T-

<u>Therapeutic Staff Support (TSS)-</u> Works one-on-one with child or adolescent on a regular basis. The primary role of the TSS is to make sure all elements of the treatment plan are being fulfilled. The TSS works with the child at home, in school, and in the community. Typically, a TSS is a college graduate (at least bachelor's level) with at least one year of experience in the mental health or a human service field.

-V-

<u>Verbal Behavior Therapy</u> - teaches communication using the principles of Applied Behavior Analysis and the theories of behaviorist B.F. Skinner. By design, Verbal Behavior Therapy motivates a child, adolescent or adult to learn language by connecting words with their purposes. The student learns the words that can help obtain desired objects or other results. Therapy avoids focusing on words as mere labels (cat, car, etc.) Rather, the student learns how to use language to make requests and communicate ideas. The intervention focuses on understanding why we use words.

Work Incentive (Social Security Income) - Special rules make it possible for people with disabilities receiving Social Security or Supplemental Security Income (SSI) to work and still receive monthly payments and Medicare or Medicaid. Social Security calls these rules "work incentives." The first \$65 of the earnings you receive in a month, plus one-half of the remaining earnings. This means less than one-half of your earnings our counted when figuring your SSI payment amount in addition to the \$20 general income exclusion. First apply the \$20 general income exclusion to any unearned income that you may receive.

EXAMPLE:

| \$0.00 \$20.00 (\$20.00) | SSDI General income exclusion Remaining general income exclusion |
|--------------------------------|---|
| \$450.00 | Earned income |
| (\$20.00) | Remaining general income exclusion |
| \$430.00 | |
| (\$65.00) | Earned income exclusion |
| \$365.00 | |
| (\$182.50) | ½ remaining earnings |
| \$182.50 | Countable earned income |
| | |
| \$721.00 | 2014 Federal Benefit Rate |
| (\$182.50) | Total countable income |
| \$538.50 | SSI payment |

Available income:

\$450.00 Earned Income

\$538.50 SSI

\$988.50 Total Monthly Income

SOURCES

1. Bureau of Autism Services

http://www.dpw.state.pa.us/dpworganization/officeofdevelopmentalprograms/bureauofautismservices/index.htm

2. Office of Vocational Rehabilitation Services

http://www.dli.state.pa.us/portal/server.pt/community/vocational_rehabilitatio n/10356

3. Centers for Disease Control and Prevention

http://www.cdc.gov/

4. Pennsylvania Health Law Project

http://www.phlp.org/

5. Pennsylvania Department of Education

http://www.portal.state.pa.us/portal/server.pt/community/special_education/7746

6. Special Needs Alliance

http://www.specialneedsalliance.org/the-voice/letter-of-intent-3/

7. Wrightslaw

http://www.wrightslaw.com/info/future.plan.index.htm

8. Boyer, Kim – Power of Attorney vs. Guardianship

http://www.elderlawnv.com/articles/power-of-attorney-v-guardianship-2/

9. Prudential – Letter of Intent

http://www.prudential.com/media/managed/Letter_of_Intent.pdf

10. Autism Research Institute

http://www.autism.com/symptoms sensory king

11. Autism Genetic Resource Exchange

https://research.agre.org/program/aboutados.cfm(vs. 08.29.2014)

| IMPORTANT NUMBERS | | |
|-------------------|--------|--|
| NAME/PROVIDER | NUMBER | |
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ASA-NWPA will make every effort to keep the Next Step Guide updated. Next Step Guide (online) will be updated as information/services change.



To improve the quality of life across the lifespan for persons on the Autism Spectrum and their families through: advocacy, education, service, support, and research.

Autism Society NWPA is a parent/member organization that provides support for individuals and families living with an Autism Spectrum Disorder in Erie, Crawford, Venango, and Mercer Counties.



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Autism Society—Northwestern Pennsylvania is a non-profit organization exempt from Federal tax under section 501c(3) of the Internal Revenue Code.