Next Step Guide

Autism Society
Northwestern Pennsylvania

Our values.

Dignity,
where the value and self-determination of every individual is upheld

Equity,
where everyone with Autism achieves the highest possible quality of life

Inclusion,
where every person is integrated into society without barriers or exceptions in a collaborative environment

Diversity,
where everyone is respected for their unique and individual differences

Integrity,
where we conduct ourselves with honor, truth, and respect in our thoughts, words, and actions

Making Informed Decisions

The Autism Society strives to empower individuals on the autism spectrum and their families to make informed decisions in the planning and delivery of individualized, evidence-based services and supports. Each individual and family has the right to choose the services that best meet their individual needs.

The Board of Directors of the Autism Society affirms that each person on the autism spectrum (ASD) is a unique individual. To the maximum extent possible, informed decisions should be made by the individual with ASD and their family members in partnership with a multidisciplinary team.

The selection of current evidence-based intervention practices should be guided by objective assessment, goals, and outcomes. Services and supports should be delivered with fidelity by qualified and appropriately trained professionals. All services should promote self-determination, enhance inclusive community engagement, and result in improved quality of life. Abuse of any kind is not acceptable.

No single service or intervention is likely to meet the needs of every individual with ASD. Each person should have broad and equal access to high quality, individualized support, and services. Selection of a program, service or method of treatment should be based on a comprehensive assessment of the person’s abilities, needs and interests. Services should be outcome-based to ensure they meet the individualized goals of the person with ASD.

The Board of the Autism Society expects that individuals with ASD will have dignified, productive lives and reach their fullest potential through access to appropriate education, employment, community living opportunities, medical care, mental health services, and family support.

-Adopted by Autism Society NWPA Board of Directors; 2022.01.10

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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 44 children (CDC December 2021). 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 few 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 several 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

<u>Signs</u>

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.

Communication

Young children with autism tend to be delayed in babbling and speaking and learning to use gestures. Some infants who later develop autism coo and babble during the first few months of life before losing these communicative behaviors. Others experience significant language delays and don't begin to speak until much later. With therapy, however, most people with autism do learn to use spoken language and all can learn to communicate.

Many nonverbal or nearly nonverbal children and adults learn to use communication systems such as pictures, sign language, electronic word processors or even speech-generating devices.

When language begins to develop, the person with autism may use speech in unusual ways. Some have difficulty combining words into meaningful sentences. They may speak only single words or repeat the same phrase over and over. Some go through a stage where they repeat what they hear verbatim (echolalia).

Some mildly affected children exhibit only slight delays in language or even develop precocious language and unusually large vocabularies – yet have difficulty sustaining a conversation. Some children and adults with autism tend to carry on monologues on a favorite subject, giving others little chance to comment. In other words, the ordinary "give and take" of conversation proves difficult. Some children with ASD with superior language skills tend to speak like little professors, failing to pick up on the "kid-speak" that's common among their peers.

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 a 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 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-2) 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 31) which will offer some 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 32) 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 autism spectrum disorder, you should contact Erie County Care Management Autism Division (814) 528-0600. Erie County Care Management will do an evaluation and provide you with Autism Supports Coordinator. A child with an intellectual disability is also eligible for FSS (Family Support Service) funding.

https://www.eccm.org/services/autism-supports-coordination

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 body-language, 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 service 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 experienced some or all the emotions you may be going through at this time. The Autism Society NWPA (814-455-3540) wants to help! Often, 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 medications 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 Intensive Behavioral Health Services or IBHS are what previously were known as BHRS or wraparound services, in-home personal care services, diapers, nutritional supplements, prescriptions, and transportation 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
3. 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.)
4. 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 based on 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?

The Health Insurance Premium Payment (HIPP) Program is a program developed to help families, who have at least one person enrolled in Medical Assistance (MA), pay for private health insurance through an employer. HIPP is administered by Pennsylvania's Department of Human Services (DHS). It was designed as a cost containment program in order to save taxpayers money by purchasing cost effective employment related health insurance available to a Medical Assistance recipient.

How is eligibility determined?

A HIPP Operation Specialist (HOS) conducts a review of the medical insurance that is available through the employer. They will conduct a cost analysis based on the amount of the premium and the policy benefits that are offered. If the Medical Assistance costs for a client are greater than the cost of the employer insurance, the client is enrolled into the HIPP Program.

Can I choose not to participate in HIPP?

No. If the employer health insurance is determined to be cost effective, the client is required to participate in the HIPP Program as a condition of continued eligibility for Medical Assistance. The client maintains the ACCESS card, but the employer insurance is used as the primary medical resource.

Does a client maintain their Medical Assistance eligibility and their ACCESS Card?

Yes! A client must remain active in Medical Assistance to be eligible for HIPP. They use their ACCESS card in the same manner as every other Fee-for-Service Client. HIPP clients are advised to use Medical Assistance providers to ensure that Medical Assistance is available to pay any policy deductibles or services not covered by the employer insurance.

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 ensure 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. S0ome 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)

If you or anyone in your family is a medical assistance recipient, you may be able to get help with transportation you need to get to and from medical providers. The Medical Assistance Transportation Program (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. This funding will only reimburse for trips covered by Medical Assistance. For more information call (814) 455-3330.For more information: https://ride-the-e.com/paratransit-service

MATP application: https://ride-the-e.com/wp-content/uploads/2017/12/MATP-Application-1.pdf

IBHS (formerly called: BHRS)

Intensive Behavioral Health Services or IBHS are what previously were known as BHRS or wraparound services. These services are the most recommended services for children with Autism. These services include behavioral consultation, applied behavior analysis, and mobile therapy. The goal for IBHS is to create and implement a treatment plan and then transfer the skills and procedures from the child’s treatment plan 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 and actively participate with the consultant or therapist when the services are provided. The service providers are not allowed to provide childcare or take the child into the community without a parent.

<u>How do I get IBHS services?</u>
In the past, BHRS could only be provided after your child was evaluated by a master's level clinician, psychologist, psychiatrist, or neurologist. A parent or caregiver would meet with the evaluator and provide information about the 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

These evaluations, often referred to as Medical Necessity Evaluations (MNE) were usually completed by licensed psychologists working either independently or through a service provider agency. In some counties of PA (such as Crawford County), the NME had to come from an independent evaluator.

However, with the arrival of IBHS in January of 2021, came a much easier way to get these services. Now, a written order from an individual with a qualifying license is all that is needed to obtain IBHS. A psychological evaluation as described above, can still be used as long as it has all the requirements for a written order. Many providers are opting to use the written order because it is easier than the MNE and is good for one year from the date that it was written (compared to the 60-day life of the old MNE).

The licensed person who completes the written order could be a physician or physician's assistant, such as your family doctor (if they are familiar and comfortable with the process and are Promise-enrolled), a psychologist or psychiatrist, a Certified Nurse Practitioner (CNRP), or another licensed individual such as a licensed clinical social worker, a licensed professional counselor, or a licensed marriage and family therapist.

Just as with the NME, you need to give the written order to an IBHS provider for the IBHS provider to begin providing services with your child.

The old ISPT (Individual Service Planning Team) meetings are no longer required, so the initial process has been streamlined down to two steps:

- obtaining a written order
- contacting a provider and giving them your written order

IBHS has divided up the old BHRS into three main categories – Individual Services, ABA Services, and Group Services

- *Individual Services* includes Mobile Therapy (MT), Behavior Consultation (BC), and Behavior Health Technician (BHT). All three of these services will be described in detail below.
- *ABA Services* includes Behavior Analyst (BA), Behavior Consultation – ABA, Assistant Behavior Consultant – ABA (ABC – ABA), and Behavior Health Technician (BHT). All four of these services will be described in detail below.
- *Group Services* allow for IBHS to be provided in group settings – such as Summer Therapeutic Activities Programs (STAP).

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

With IBHS, the titles of the professionals who will provide services to you and your child have changed. The following are the primary services funded through IBHS:

Individual Services:

Mobile (MT) Therapist Services - MT services are used to provide talk therapy to your child and to work on identified goals. It is provided in your child's home or other appropriate community setting. MT services include conducting formal assessments to determine your child's needs and developing an Individual Treatment Plan (ITP) that includes the interventions that will be used to meet your child's needs. Both the assessment and the ITP are based on discussions with important people in your child's life. MT services can also be used to help your child process emotional difficulties, trauma, or other behavioral health problems.

MT services are provided by a master's or doctoral level clinician who may be a counselor, social worker, Licensed Professional Counselor (LPC), Licensed Social Worker (LSW), or Licensed Clinical Social Worker (LCSW).

Behavior Consultation (BC) - Formerly known as Behavior Specialist Consultant or BSC, these services include a formal assessment of a child's behavioral needs and the development of an Individual Treatment Plan (ITP) that includes interventions that will be used to meet those identified needs. Both the assessment and the ITP are based on discussions with important people in your child's life. BC services also include coordination, consultation with other service providers such as your child's school. These consultations involve training and educating the other service providers about the behavioral interventions in your child's ITP that should be used and when they should be used. BC services can be used to address behaviors in the school, home, or any other place where your child needs behavior support and to learn strategies to better succeed.

BC services are provided by a master's or doctoral level clinician who is a PA Licensed Behavior Specialist.

Behavior Health Technician (BHT) Services - Formerly known as Therapeutic Staff Support, or TSS, these services are used to implement your child's ITP. The BHT is clinically supervised by the BC assigned to your child's case. As with the old TSS position, the BHT's primary task is to teach you how to implement the behavior change procedures outlined in your child's ITP so that you become confident and skilled in those procedures. For that reason, you, or an appropriate caregiver (over the age of 18) must be present and participate in the BHT sessions. The goal of the BHT is to work themselves out of a job – as you become less and less dependent on their guidance and support.

BHT services can be provided in your child's home, school, or other community setting as deemed appropriate by the BC. When conducted in school, the skill transfer process is focused on the teacher or paraprofessional aide instead of the parent.

BHT services are provided by technicians with either a high school diploma supplemented by 40 hours of ABA-focused training or a bachelor's level technician with that same level of ABA-focused training.

ABA Services:

Behavior Analyst (BA) Services and Behavior Consultation – ABA (BC-ABA) - Formerly known as Behavior Specialist Consultant or BSC, these services include a formal assessment of a child's behavioral needs and the development of an Individualized Treatment Plan (ITP) that includes interventions that will be used to meet those identified needs. Both the assessment and the ITP are based on discussions with important people in your child's life. BA and BC-ABA services also include coordination, consultation with other service providers such as your child's school. These consultations involve training and educating the other service providers about the behavioral interventions in your child's ITP that should be used and when they should be used. BA and BC-ABA services can be used to address behaviors in the school, home, or any other place where your child needs behavior support and to learn strategies to better succeed.

BA services are provided by a master's or doctoral level behavior analyst who is also a Board-Certified Behavior Analyst (BCBA)
BC-ABA services are provided by a master's or doctoral level clinician who is a PA Licensed Behavior Specialist.

Assistant Behavior Consultant – ABA (ABC-ABA) - This is a new position that never existed in BHRS in the past. An Assistant is a bachelor's level clinician that works under the guidance and direction of a master's level Behavior Analyst or Behavior Consultation – ABA. They can complete many of the duties of the BA or BC-ABA such as assisting with assessments, collecting, and graphing data, and the monitoring of BHT or family implementation of ITP goals. All their work must be approved and signed off by a BA or a BC. They can also directly implement the behavior change procedures outlined in your child's ITP and work on transferring those skills to you or to your child's teacher or classroom staff.

Behavior Health Technician - ABA (BHT-ABA) Services - Formerly known as Therapeutic Staff Support, or TSS, these services are used to implement your child's ITP. The BHT is clinically supervised by the BA or BC assigned to your child's case. As with the old TSS position, the BHT's primary task is to teach you how to implement the behavior change procedures outlined in your child's ITP so that you become confident and skilled in those procedures.

For that reason, you or an appropriate caregiver (over the age of 18) must be present and participate in the BHT sessions. The goal of the BHT is to work themselves out of a job – as you become less and less dependent on their guidance.

BHT services can be provided in your child’s home, school, or other community setting as deemed appropriate by the BA or BC. When conducted in school, the skill transfer process is focused on the teacher or paraprofessional aide instead of the parent.

BHT services are provided by technicians with either a high school diploma supplemented by 40 hours of ABA-focused training or a bachelor’s level technician with that same level of ABA-focused training.

What happens next?

After your child has been seen by a licensed psychologist, psychiatrist, neurologist, CNRP, or a PCP with experience with IBHS, a written order for services may be provided to you. Recommendations may also be made for additional testing, medication, or adjunctive therapies such as occupational therapy, physical therapy, and/or speech therapy.

The written order will recommend specific services and prescribe a number of hours per month for each service. For example, the order may read “BC-ABA services at a rate of 12 hours per month”.

The written order is good for one year before having to be updated, so that original “prescription” of hours can last for up to one year.

You, as the parent, have the right and the responsibility to then select an IBHS provider that best fits your and your child’s needs. Assistance with selecting an IBHS provider could come from the licensed professional who provided the written order, a case manager, a supports coordinator, or any other knowledgeable friend or advocate.

You would then provide a copy of the written order to the IBHS provider that you have chosen.

Once you have chosen an IBHS provider agency

The written order will also prescribe a number of hours to be used during the first weeks of service for your lead clinician (your BA, BC, or MT) to complete a formal assessment.

Depending on which category of service you have prescribed – Individual or ABA Services, your clinician will be given a specific time frame in which to complete that assessment.

- For ***Individual Services*** – the assessment must be completed within 15 days of your starting services with the provider agency
- For ***ABA Services*** – the assessment must be completed within 30 days of your starting services with the provider agency

The BA, BC, or MT would then begin the assessment of your child's behavioral or emotional needs and develop an Individual Treatment Plan (ITP). The lead clinician can recommend staying with the number of hours prescribed in the written order or, in some instances, recommend a reduced number of hours – if, after observing and assessing your child for some time, they come to the conclusion that your child does not need the full prescription of hours.

The lead clinician cannot, however, independently increase the prescribed hours above what was included in the written order. Some Managed Care Organizations (MCOs) and Commercial Insurance Providers do have processes in place for the team to reconvene and ask for more hours than was originally prescribed.

Once the assessment is complete, your lead clinician will write your child's Individual Treatment Plan (ITP). You have the right to have input in your child's ITP and your clinician should be including you in the development of a plan that:

a. meets your family's and your child's needs

b. is reasonable and can be implemented in your home or your child’s school without great hardship to you or your family

Your provider agency will then submit a copy of the written order along with the Assessment, the ITP, and a Plan of Care to your MCO or commercial insurance company. Your MCO or insurance company will review all of those documents and will determine if the services recommended are medically necessary. If they do so, then they will authorize the services and your child’s active treatment can begin.

Each MCO and commercial insurance company has its own timelines and rules about the turnaround time on your child’s packet of documents submitted to them.

Particularly with commercial insurance companies (ACT 62 carriers), there may be changes in how long they will authorize services (for example, some will not honor the full year of a written order) or where services can take place (some will not approve services in schools).

It is always best to check ahead, particularly if you have a commercial insurance, to confirm the details and limitations of their authorization process.

As noted earlier, the old ISPT meetings are no longer necessary and do not need to take place before services start. Team meetings among those providers working with your child are encouraged to keep all team members updated on your child’s progress and to discuss possible changes in treatment. Those team meetings do not however, have anything to do with your child’s authorization for service hours.

Continuing IBHS

With IBHS, the written order is good for one year. Your provider agency should notify you prior to the expiration of your written order to make arrangements (if you desire to continue services) to see either the same licensed professional who provided the previous written order or to arrange for a different licensed professional to do so.

During the year that services were provided, you should be having an ongoing conversation with your child's lead clinician (BA, BC, or MT) about the need to continue services beyond that first year. Plans should be made, and data gathered by the lead clinician to make that case when you have your appointment with the licensed professional to gain a new written order.

Grievance Process

If you are denied authorization of services (either a full denial or even a partial denial of hours prescribed) or you do not agree with Community Care Behavioral Health (the most commonly used MCO in the NWPA region), you can file a grievance. Community Care will send you a letter stating that your services were either denied or not approved as requested.

You can file a grievance 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.

For services denied by commercial insurance companies, the grievance process may be similar to what was described above for Community Care Behavioral Health, or it may be very different. Again, it is always a good idea to do your homework ahead of time and find out what your insurance company's policies and procedures are when it comes to grievances before beginning this entire process with them.

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.

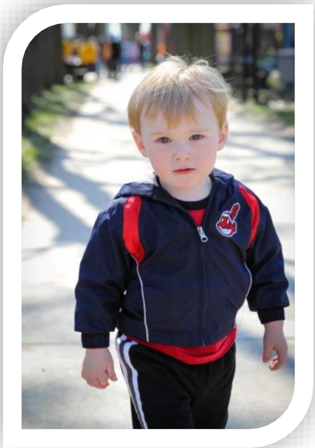
Infants and Toddlers

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 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 individual's 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 14 for a list of items needed.
- See glossary for representative payee definition.
- Bank Account requirements (page 16).

Applying for Social Security Income Benefits

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. In the SSI program, a child becomes an adult at age 18. SSI uses a different medical and non-medical rule when deciding if an adult can get SSI disability payments. For example, they don't count the income and resources of family members, except for a spouse, when deciding whether an adult meets the financial limits for SSI. They count only the adult's and spouse's income and resources. They also use the disability rules for adults when deciding whether an adult has a disability.

- If your child is already receiving SSI payments, they must review the child's medical condition when they turn age 18. They usually do this review during the one-year period that begins on your child's 18th birthday. They will use the adult disability rules to decide whether your 18-year-old is eligible for SSI.

- Even if your child wasn't eligible for SSI before their 18th birthday because you and your spouse had too much income or too many resources, they may become eligible for SSI at age 18

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.

HELPFUL LINKS:

- Applying for SSI Checklist: https://www.ssa.gov/hlp/radr/10/ovw001-checklist.pdf

- Benefits for Children with Disabilities (What happens when your child turns age 18: https://www.ssa.gov/pubs/EN-05-10026.pdf

<u>When can I appeal?</u>
If you wish to appeal, you must make your request in writing to the SSA within 60 days from the date you receive your denial letter. It is assumed that you receive the denial letter five days after the date on the letter, unless you can show that you received it later. How many appeal levels are there?

There are four levels of appeal. They are

- Reconsideration.
- Hearing by an administrative law judge.
- Review by the Appeals Council; and
- Federal Court review.

- Disability Benefits | Appeal a Decision: https://www.ssa.gov/benefits/disability/appeal.html

- Your Right to Question the Decision Made on Your Claim: https://www.ssa.gov/pubs/EN-05-10058.pdf

How to appeal

You must request your appeal in writing. You can call Social Security and ask for an appeal form (Form SSA-561, HA-501, or HA-520), or send a note with your Social Security number stating that you wish to appeal the decision in your case. The fastest and easiest way to file an appeal of your decision is by visiting www.ssa.gov/disability/appeal. You can file online and provide documents electronically to support your appeal. You can file an appeal online even if you live outside of the United States. You can upload documents online to support your appeal, which will help decrease the time it takes to receive a decision from us. If you live outside of the United States, now you can also appeal your Social Security disability decision online.

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)

The Supplemental Nutrition Assistance Program (SNAP), formerly known as food stamps, may be available if you receive SSI. Your household must meet certain requirements to be eligible for SNAP and receive benefits. Please apply using the option that best suits you. If you do not know if you are eligible, you may still apply.

- Online: Apply for or renew your SNAP benefits online by using COMPASS - http://www.compass.state.pa.us/
- In-person: File an application at your county assistance office. You can download an application, fill it out, and return it to your county assistance office. Application for cash assistance, SNAP, and Medical Assistance benefits.

- (English version) - https://www.dhs.pa.gov/Services/Assistance/Documents/Benefits%20Applications/PA-600-2-20-Final.pdf
- Spanish version - https://www.dhs.pa.gov/Services/Assistance/Documents/Benefits%20Applications/PA%201935-S.pdf

If you need help completing the application form or need more information about benefits, trained county assistance office staff can help you in person.

SNAP Helpful information:

- SNAP Facts: https://www.ssa.gov/pubs/EN-05-10101.pdf
- SNAP Information: https://www.dhs.pa.gov/Services/Assistance/Pages/SNAP.aspx

Selective Service Registration

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 chart of who must register is also available.
https://www.sss.gov/wp-content/uploads/2020/11/WhoMustRegisterChart.pdf

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.

Four Waivers in our area:

- Consolidated Waiver
- Person/Family Directed Support Waiver (PFDS)
- Adult Autism Waiver (AAW)
- Community Living Waiver 9CLW)

What is the Consolidated Waiver for individuals with Intellectual Disabilities? (Amendment effective, October 1, 2019)

The Pennsylvania Consolidated Waiver is designed to help individuals with an intellectual disability, autism, or developmental disability to 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.

<u>Eligibility criteria:</u>

- There is no age limit for individuals with an intellectual disability or autism. Individuals with a developmental disability with a high probability of resulting in an intellectual disability or autism are eligible from age 0 through 8.
- Level of Care
- Medical Evaluation
- Diagnosis of an intellectual disability, autism, or developmental disability
- Recommended for an intermediate care facility (ICF) level of care based on a medical evaluation
- Determined eligible for Medical Assistance (MA)
- Meet the financial requirements as determined by your local County Assistance Office

Services:

- Advanced Supported Employment
- Assistive Technology
- Behavioral Support
- Benefits Counseling
- Communication Specialist
- Community Participation Support
- Companion
- Consultative Nutritional Services
- Education Support
- Family/Caregiver Training and Support
- Home Accessibility Adaptations
- Homemaker/Chore
- Housing Transition and Tenancy Sustaining Services
- In-Home and Community Support
- (Licensed and Unlicensed) Life Sharing
- Music, Art, and Equine Assisted Therapy
- (Licensed and Unlicensed) Residential Habilitation
- Respite
- Shift Nursing
- Small Group Employment
- Specialized Supplies
- Supported Employment
- Supported Living
- Supports Broker
- Supports Coordination
- Therapy
- Physical
- Speech/Language
- Occupational
- Orientation, Mobility and Vision
- Transportation
- Vehicle Accessibility Adaptations

What is the Person/Family Directed Support Waiver? (Amendment effective, October 1, 2019)

The Pennsylvania Person/Family Directed Support Waiver is designed to help individuals with an intellectual disability, autism, or developmental disability to 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:

There is no age limit for individuals with an intellectual disability or autism. Individuals with a developmental disability with a high probability of resulting in an intellectual disability or autism are eligible from age 0 through 8.

- Level of Care
- Medical Evaluation
- Diagnosis of an intellectual disability, autism, or developmental disability
- Recommended for an intermediate care facility (ICF) level of care based on a medical evaluation
- Determined eligible for Medical Assistance (MA)
- Meet the financial requirements as determined by your local County Assistance Office.
- Individual cost limit of $33,000 per person per fiscal year
- Excludes Supports Coordination and Supports Broker Services
- The limit can be exceeded by $15,000 for Advanced Supported Employment or Supported Employment services

Services:

- Advanced Supported Employment
- Assistive Technology
- Behavioral Support
- Benefits Counseling
- Communication Specialist
- Community Participation Support
- Companion
- Consultative Nutritional Services
- Education Support
- Family/Caregiver Training and Support
- Home Accessibility Adaptations
- Homemaker/Chore
- Housing Transition and Tenancy Sustaining Services
- In-Home and Community Support
- Music, Art, and Equine Assisted Therapy
- Participant-Directed Goods and Services
- Respite
- Shift Nursing
- Small Group Employment
- Specialized Supplies
- Supported Employment
- Supports Broker

What is the Adult Autism Waiver? (Amendment effective, October 1, 2019)

The Adult Autism Waiver (AAW) is a 1915(c) Home and Community-Based Services (HCBS) Medicaid waiver designed to provide long-term services and supports for community living, tailored to the specific needs of adults aged 21 or older with ASD. The program is designed to help adults with autism spectrum disorder participate in their communities in the way they want to, based upon their identified needs.

Who is eligible for the Adult Autism Waiver?

- Must be age 21 or older.
- Level of Care
    - Have substantial functional limitations in three or more major life activities as a result of ASDs and/or other developmental disabilities that are likely to continue indefinitely: self-care, receptive and expressive language, learning, mobility, self-direction and/or capacity for independent living, and
- Medical Evaluation
- Diagnosis of autism
- Recommended for an intermediate care facility (ICF) level of care based on a medical evaluation
- Determined eligible for Medical Assistance (MA)
- Meet the financial requirements as determined by your local County Assistance Office

Diagnostic Criteria:

Have a diagnosis of autism spectrum disorder (ASD) manifested before the age of 22 as determined by a licensed psychologist, certified school psychologist, psychiatrist, developmental pediatrician, licensed physician, licensed physician assistant, or certified registered nurse practitioner using the most recent version of the Diagnostic and Statistical Manual of Mental Disorders (DSM) applicable at the time of the diagnosis.

Services:

In addition to Supports Coordination, the following services are offered under the Adult Autism Waiver:

- Assistive Technology
- Career Planning
- Job Finding
- Vocational Assessment

- Community Transition Services
- Day Habilitation
- Family Support
- Home Modifications
- Nutritional Consultation
- Residential Habilitation
- Respite
- Small Group Employment
- Specialized Skill Development
- Behavioral Specialist Services
- Systematic Skill Building
- Community Support
- Supported Employment
- Extended Employment Supports
- Intensive Job Coaching
- Temporary Supplemental Services
- Therapies (Occupational, Speech and Language, Counseling)
- Transportation
- Vehicle Modifications

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.

What is the Community Living Waiver (effective January 1, 2020)

The Community Living Waiver supports individuals with an intellectual disability, autism, or developmental disability to live more independently in their homes and communities through the provision of a variety of services that promote community living, employment, communication, self-direction, choice, and control.

Eligibility Criteria:

There is no age limit for individuals with an intellectual disability or autism. Individuals with a developmental disability with a high probability of resulting in an intellectual disability or autism are eligible from age 0 through 8.

- Level of Care

- Medical Evaluation
- Diagnosis of an intellectual disability, autism, or developmental disability
- Recommended for an intermediate care facility (ICF) level of care based on a medical evaluation
- Determined eligible for Medical Assistance (MA)
- Meet the financial requirements as determined by your local County Assistance Office
- Individual cost limit of $70,000 per person per fiscal year (Supports Coordination is excluded from this limit)

Services:

- Advanced Supported Employment
- Assistive Technology
- Behavioral Support
- Benefits Counseling
- Communication Specialist
- Community Participation Support
- Companion
- Consultative Nutritional Services
- Education Support
- Family/Caregiver Training and Support
- Home Accessibility Adaptations
- Homemaker/Chore
- Housing Transition and Tenancy Sustaining Services
- In-Home and Community Support
- Life Sharing (Needs Groups 1 and 2, or less than 30 hours per week)
- Music, Art, and Equine Assisted Therapy
- Participant-Directed Goods and Services
- Respite
- Shift Nursing
- Small-Group Employment
- Specialized Supplies
- Supported Employment
- Supported Living (Needs Groups 1 and 2)
- Supports Broker
- Supports Coordination
- Therapy
- Physical
- Occupational
- Speech
- Language
- Orientation, Mobility, and Vision
- Transportation
- Vehicle Accessibility Adaptations

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?

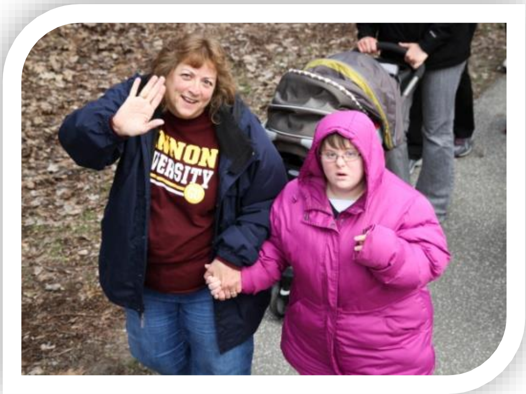
You may apply for more than one waiver or the Adult Community Autism Program at a time, including the Adult Autism Waiver. However, individuals may not enroll in more than one.

FOR MORE INFORMATION:
https://www.dhs.pa.gov/Services/Disabilities-Aging/Pages/Autism-Services.aspx

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 whose 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."
- Volunteer Work
- Day Programs
- Specialized employment programs
  - The Precisionist https://theprecisionists.com
  - Neurodiverse Solutions https://www.cai.io/neurodiverse-solutions/overview
  - AHEDD (A Specialized Human Resource Organization) https://www.ahedd.org
  - Uniquely Abled Academy https://uniquelyabledproject.org
    Erie PA (opening date TBD):   https://regionalcollegepa.org
    Meadville PA (opening 8/22): https://www.pmionline.edu

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 must 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.

What is the ABLE Act?

The ABLE Act enables people with disabilities to have savings accounts while receiving benefits. People with disabilities, have on average, 28% more costs associated with disability-related expenses than those who do not have a disability. ABLE plans allow people to save for those extra costs associated with having a disability, while maintaining public benefits, such as SSI and Medicaid.

ABLE accounts can provide funding for qualified disability expenses that supplement, but do not replace, benefits otherwise available through private sources, employment, public programs, or other sources. The Internal Revenue Service (IRS) does not restrict the usage of the ABLE funds, leaving it open to items or services that relate to the unique needs of each individual, including those related to COVID-19.

Who is eligible for an ABLE account?

The ABLE Act limits eligibility to individuals with disabilities with an age of onset of disability before turning 26 years of age. If you meet this age requirement and are also receiving benefits under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI but still meet the age of onset disability requirement, you could still be eligible to open an ABLE account if you meet Social Security’s definition and criteria regarding functional limitations and receive a letter of disability certification from a licensed physician, a doctor of medicine or osteopathy, a doctor of dental surgery or dental medicine, and, for some purposes, a doctor of podiatric medicine, a doctor of optometry, or a chiropractor. They may not be signed by a licensed psychologist, clinical therapist, or certified vocational rehabilitation counselor. You do not have to be younger than 26 to be eligible for an ABLE account. You can be over the age of 26 but must have had an age of onset before your 26th birthday.

Who Can Open A PA ABLE Account?

An adult Eligible Individual with the legal capacity to enter into contracts must open the account for themselves. If the Eligible Individual is a minor or a person without legal capacity to enter into contracts, a parent, guardian or someone who has Power of Attorney may open the account and they become the “Authorized Individual.” The Authorized Individual acts as a fiduciary, must control the account for the benefit of the Eligible Individual, and may not have a beneficial interest in the account. At all times, the Eligible Individual is both the Beneficiary of the account and the Account Owner.

The Account Owner or Authorized Individual may wish to grant access to the Account to other people, called “Authorized Agents.” An Authorized Agent may be granted one of four levels of access from the ability to make inquiries to full control over the Account. In order to name an Authorized Agent, the Account Owner or Authorized Individual must complete an Agent Authorization/Power of Attorney Form, depending on the level of access granted.

For more information: https://www.paable.gov

Power of Attorney vs. Guardianship

Power of attorney 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 agent’s authority by specifying the types of decisions you would like them to make on your behalf (a Limited Power of Attorney).

Guardianship 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 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 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 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:
https://www.specialneedsnewyork.com/wp-content/uploads/2013/05/Letter-of-Intent-Special-Needs-2013-02-SCAN.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.

ONE TEAM ONE GOAL

Intensive Behavioral Health Services Acronym Lists

General Acronym List

ABA – Applied behavior analysis

ASD – Autism spectrum disorder

EBT – Evidence-based therapy

IBHS – Intensive behavioral health services

ITP – Individual treatment plan

Services Acronym List

Asst. BC-ABA – Assistant behavior consultation-applied behavior analysis

BA – Behavior analytic

BC – Behavior consultation

BC-ABA – Behavior consultation-applied behavior analysis

BHT – Behavioral health technician

BHT-ABA – Behavioral health technician-applied behavior analysis

MT – Mobile therapy

Board Certification Acronym List

BCaBA – Board-certified assistant behavior analyst

BCAT – Board-certified autism technician

BCBA – Board-certified behavior analyst

RBT – Registered behavior technician

Glossary

– A –

Autism Diagnostic Observation Schedule (ADOS) - 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.

Applied Behavior Analysis (ABA) - Behavior analysis focuses on the principles 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 –

Biomedical Treatment for Autism - Biomedical treatment is a systematic 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 –

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

Echolalia (also known as echologia or echophrasia) - 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 oneself, 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.

Family Driven/Family Support Services - 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.

Family Support Service Funding (FSS) - the Office for People with Developmental Disabilities' Family Support Services Program funds services through not-for-profit 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.

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

Functional Behavioral Assessment (FBA) – 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.

– H –

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.

– I –

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

Individualized Educational Plan (IEP) - 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.

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

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

Intellectual Disability (ID) – (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.

Intermediate Unit (IU) – 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.

– L –

Least Restrictive Environment (LRE) – 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.

Local Educational Agency (LEA) – 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 –

Medical Assistance Program (MA) – 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.

– O –

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: https://www.dli.pa.gov/Individuals/Disability-Services/ovr/Pages/default.aspx

– P –

Perseveration - 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.

Perseverative Speech - 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.

Pivotal Response Treatment - 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 –

Sensory Integration Therapy - 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.

Special Needs Trust (SNT) - 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).

– V –

Verbal Behavior Therapy - 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.

– W –

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	SSDI
$20.00	General income exclusion
($20.00)	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_rehabilitation/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

Autism Society
Northwestern Pennsylvania

Our mission.

We create connections, empowering everyone in the Autism community with the resources needed to live fully.

Our vision.

Creating a world where everyone in the Autism community is connected to the support they need, when they need it.

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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.