

Getting started with services for your child with autism







Dear Pennsylvania Families,

I wanted to take a moment to introduce myself and the ABA in PA Initiative. ABA stands for Applied Behavior Analysis. As of the launch of this edition, I serve as the President of the ABA in PA Initiative, Professor of Pediatrics at Penn State Health Children's Hospital and the new Medical Director of Meliora Health. I am a native of Brooklyn, New York, and trained in Boston, Massachusetts. When I relocated to Pennsylvania in 2010, I was immediately struck by the scarcity of quality, evidence-based treatment for individuals with autism. I made it my mission to make a difference.

In 2012, in a small conference room, the ABA in PA Initiative was born. With a dedicated Board of Directors, and over 100 volunteer 'change agents' working throughout the state, we strive to disseminate quality information and be advocates for families. Our group understands that raising a child with autism comes with its challenges, but it also comes with many joys and triumphs. Our hope is that the advocacy the initiative does will make it easier for families to find quality services for their children. Through our website and social media, The ABA in PA Initiative will continue to share our progress as an advocacy organization as well as helpful information related to autism and quality treatment. We hope the directory of providers on our website is useful to you, and that our support groups, such as the ABA in PA Parent Group and Provider Group on Facebook, provide support and connection across Pennsylvania. The members of the ABA in PA Initiative are excited to present to you our most recent updates in this third edition of Embark.

Cheryl D. Tierney, MD, MPH Developmental Pediatrician ABA in PA Initiative

What is the Applied Behavior Analysis (ABA) in PA Initiative?

Founded in 2012, the ABA in PA Initiative is a not-for-profit organization, made up of parents and professionals in fields of autism service who are committed to improving access to high quality ABA treatment for children and their families. Members of ABA in PA volunteer their time and efforts to support the organization's mission through active advocacy.

Why is ABA in PA providing this information?

The mission of ABA in PA is to educate families and individuals on ABA, the most up-to-date, effective, evidence-based treatment for autism; and how and where to access ABA and supportive services in Pennsylvania.



How this guide is arranged

Getting started with services for your child can be overwhelming. You may have a lot of inforation being given to you all at once. In this guide we break down some topics related to services. In the first part of this book, *Get Started*, you will find just enough information to help you begin accessing a certain service. In the second part of this book, *Get More*, we will provide more details about the services and links to find out even more information. We hope this helps you to be able to take in the information at your own pace and reference different parts of *Embark* as needed on your family's journey.

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Get Started: Parent and Family Resources

Hello,

You are beginning a journey that I began when our child was diagnosed with autism several years ago. I still clearly remember the anxiety, confusion, anger, and outright denial I felt. I spent every moment worrying about our son's future and fearing the unknown of all that was in store. It is a journey that is at times soul-crushing, and it will test your strength and patience beyond what you think you can endure. I assure you, though, there are definitely moments of pure celebration when accomplishments and goals are reached. Your child will be as proud as you are in their achievements.

You will find yourself questioning your choices and decisions as well as the advice and intentions of all those around you who are involved in your child's life. It is important to make sure you are heading on the right path for your child, but know that there is no perfect solution to help "fix" your child. Trust your specialists, trust the proven treatment methods, and above all, trust your child. When things are right, your child will respond and make progress.

The best piece of advice I can give is to seek out other parents. They are often the best resource for good doctors and therapists, judging alternative treatments, understanding education systems, and navigating the nightmare of insurance and medical assistance. But above all, we understand each other. We've experienced many of the same things that parents of typically-developing children could never in a hundred years begin to imagine. I encourage you to join our parent forum on the ABA in PA Facebook page to find solace and solidarity in other parents.

www.facebook.com/groups/ABAInPAParentGroup/

Best of luck, Gerren Wagner

Get Started: What is Autism?



- Autism is a neurodevelopmental disorder that can result in challenges in behaviors, social skills, and learning, in varied severity.
- Individuals with autism express unique strengths and needs related to social communication and interaction.
- Autism symptoms are different in everyone.
- Autism is a spectrum disorder-meaning that each person's symptoms, skills, and levels of disability can vary greatly.
- Individuals with autism often have an uneven neurodevelopmental profile, meaning that they might have weak skills in some areas, but very strong skills in other areas.
- Autism is a lifelong journey. With the right strategies and interventions, individuals with autism can improve symptoms and increase independence and often self-advocate for their needs.
- Individuals with autism learn new skills with targeted teaching methods focused on their learning needs.



Get Started: Funding

Services for your child can become very costly, even with private insurance. Fortunately, a diagnosis of autism allows parents to seek additional funding through Medical Assistance (MA) in Pennsylvania and this is not based on financial need. If you have health insurance through an employer, MA is considered secondary insurance.

When filing an application with the Department of Human Services, you must first apply for Supplemental Security Income (SSI) for your child:

1. Call 1-800-772-1213 (Social Security Administration). SSI is income-based, so your child may not qualify, but this step is required.

2. Within a few days, you will receive an appointment letter. With the appointment letter you can start the application process outlined below.

3. You must be available at the phone number you provided at the time of your appointment to complete this process. Start by telling the agent your income. SSI is a poverty program; therefore, if you earn too much, you will not have to complete the whole process.

You can apply for Medical Assistance online at www.compass.state.pa.us; however, applying on paper ensures that all documents are received as a complete packet by following these steps:

An application for Medical Assistance (Health Care Benefits only – Form 600) must be completed and signed. Write "MA for disabled child only" across the top of the application. Copies of the following documents must be included with the application (they will make copies for you at the County Assistance Office (CAO) if you do not have access to a copier):

- 1. Appointment letter or letter of determination from Social Security
- 2. Birth certificates (not all family members, but at least your child's)
- 3. Social security cards (not all family members, but at least your child's)
- 4. Proof of all income for one month (wages, interest, child support, etc.)
- 5. Proof of car insurance and registration for all vehicles
- 6. Any other health insurance for your child
- 7. Copies of drivers' licenses

8. Signed release of information for communication with County Assistance Office (included with your application)

- with a diagnosis listed)

- be signed, dated, and witnessed.

Drop off or mail the application and all documentation to your County Assistance Office.

After filing the application, you will receive a letter from Department of Human Services with the date the application will be reviewed by the caseworker. You will most likely not need to be present at that time; however, you need to scan the list to make sure you have given all the required information. Complete and return all paperwork sent to you.

This is an annual process. After your child is approved for Medical Assistance, you will receive renewal paperwork that you must complete and submit each year by the date indicated in the packet in order to maintain coverage.

9. Proof of disability (evaluations from school and/or physicians and hospitals, preferably

10. Photo ID (can be school ID) or letter stating you attest to your child's identity "I attest _is my child and dependent and is a United States Citizen". The letter needs to

Get Started: What is Applied Behavior Analysis

Applied Behavior Analysis (ABA) is a well studied therapeutic treatment shown to be effective for treating individuals with autism, with more support than any other behavioral or educational intervention. ABA is considered medically necessary as the standard of care for many individuals with autism.

- ABA identifies and teaches new behaviors that the child may need to be successful in learning and getting along with others.
- ABA collects and tracks data on behaviors, to ensure progress is being made.
- ABA uses practices that are individualized for each child.
- Though most people know ABA from the successful treatment of autism, ABA is used across many disabilities (e.g. ADHD, phobias, addiction, traumatic brain injury rehabilitation) and industries (e.g. employee performance and satisfaction).

When Should I Get ABA?

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Research shows that when children are provided with ABA skill-building programs at a young age, they have better outcomes and often can reduce the chance of more severe or dangerous behaviors later in life. However, ABA is appropriate for any age or developmental period. It is never too early or too late to start a quality ABA program.

Where Does ABA Happen?

- In most cases, ABA providers will come to your home to work with your child. This allows for ABA therapists to build intervention plans individually to each family environment, and identify areas of need quickly. In-home services allow for parents and caretakers to learn the teaching methods directly, and increases opportunities for communication and collaboration throughout treatment.
- ABA therapists can also provide services in school, daycare, and other community locations where problems occur or skill development is needed.
- Center, school, or clinic-based ABA programs are available as well.

Get Started: What is Applied Behavior Analysis

Who Provides ABA?

ABA is provided by trained clinicians, who are certified by the Behavior Analyst Certification Board (BACB).

- develop behavior plans, and monitor progress.
- from a BCBA or BCBA-D.
- the resources page under Provider Directory.

Caution should be used with providers that claim to "use ABA," but are not certified by the BACB. For example, in Pennsylvania, Licensed Behavior Specialists (LBS) with a Behavior Specialist License (LBS) and Behavior Health Technicians (BHT-ABA) can work with children with autism; however, these providers work under less stringent standards of education and experience. Parents are encouraged to look for the qualifications of BCBA, BCaBA, and RBT when searching for high-quality providers and programs.



• The role of a Board Certified Behavior Analyst (BCBA, or doctorate level, BCBA-D) is to provide the clinical direction for your child,

• Board Certified Assistant Behavior Analysts (BCaBA) may also play a lead role in monitoring progress for your child, with supervision

• A Registered Behavior Technician (RBT) is the trained individual that will implement the interventions, and usually spends the largest amount of time working directly with your child and family. • A list of agencies in Pennsylvania (non-exhaustive) that provide ABA services can be found on the ABA in PA Initiative website on

Get Started: ABA Services

Intensive Behavioral Health Services (IBHS)

ABA services in PA are provided in the community through Pennsylvania's Intensive Behavioral Health Services (IBHS) program. ABA can be provided by agencies funded through private insurance or agencies funded through Medical Assistance (MA).

Depending on the agency you choose and the type of funding you use, the process may vary. However, below are some general ways to get started and some common features to expect in the process.

- IBHS is a community-based state program designed to meet emotional and behavioral health needs of children in PA (ages 0-21).
- IBHS programs treat various diagnoses, such as depression, anxiety, emotional or conduct disorders, ADHD, as well as autism.
- A written order, or prescription, is required to access ABA through the IBHS program.







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Get Started: ABA Services

Get Started: ABA Services

Obtain a Written Order for ABA

An order for ABA can be written by a licensed physician, licensed psychologist, certified registered nurse practitioner or other licensed professional whose scope of practice includes the diagnosis and treatment of behavioral health disorders. The provider writing the order needs to be enrolled in PA's Medical Assistance if you will be billing MA as a primary or secondary insurance.

The written order must be based on a face-to-face visit with the professional. The written order must be written within 12 months prior to the initiation of ABA services.

The order must include:

*A behavioral health disorder diagnosis listed in the most current DSM or ICD

*An order or recommendation for ABA including:

- Clinical information to support the medical necessity of each ABA service ordered
- Maximum number of hours of each ABA service per month
- Settings where ABA may be provided
- Measurable improvements in targeted behaviors or skill deficits that indicate when services may be reduced, changed or terminated



Get Started: ABA Services At your appointment

- The medical or psychological professional (provider) providing the
- If you have other evaluations that you think are accurate, bring copies of those to share.
- Your child must be present for the appointment. The provider will want to observe and interact with your child in order to assess strengths and needs. Most providers understand that a child's to daily routines in familiar settings. If your child behaves very differently in the appointment, explain the differences that you observe in other settings.
- Tell the provider your goals for your child, as well as the type and that you want ABA services.
- You can request, and be prescribed, up to 40 hours of ABA services per week! This is the recommended amount of early intensive teachers, and other caretakers in your child's life. The amount requested can be decreased, but cannot be increased without how to decide this).
- The written order requirements were new in 2020. You can take this what must be included in the written order.
- If the provider determines that your child does not need ABA services and you disagree, you can seek a second opinion.

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written order must be enrolled in PA's Medical Assistance, if you will be billing MA as a primary or secondary insurance. You should verify that your provider is enrolled before your appointment if needed. • Most providers rely heavily on information from the parent(s). Come prepared to give real examples of your child's problem behaviors, developmental concerns or delays, as well as your child's strengths.

behavior can be very different in a novel, clinic setting, compared

amount of services you would like to see for your child. Be specific

intervention for autism, combined among ABA providers, parents, another written order/appointment. We recommend advocating for the maximum number of hours you think your child will need per week (see Get More: Starting ABA Services for more information on

book with you to your appointment, to ensure your provider knows

Get Started: ABA Services

Accessing Services

All ABA agencies must be licensed and compliant under IBHS, however not all agencies must accept MA insurance as payment.

Through a Private Agency/ Private Insurance Provider

- Call your primary insurance to inquire if your insurance plan covers Applied Behavior Analysis. Ask for a list of providers in your area, or utilize the <u>ABA in PA directory</u> to find a provider in your area.
- Call the ABA provider that you are interested in working with to obtain service availability information in your area. The provider will gather information from you regarding your child's diagnosis, written order, and your insurance.

Through MA Funded Providers

- Call Member Services for your child's Behavioral Health Managed Care Organization (MCO) and ask for a list of providers in your area. The names and contact information for the different MCOs in PA can be found in the Resources section.
- Call the provider that you are interested in working with to obtain availability information in your area. The provider will gather information from you regarding your child's diagnosis and written order.

Funding Through Fee-for-Service, HIPP, or CHIP

• Call Member Services for details on coverage and agencies in your area. Be sure to note your insurance when calling ABA providers to assist with authorization of service initiation.

Once you have your written order for ABA and have contacted an agency in your area that has availability, the provider will contact your primary insurance or MCO to obtain authorization for an assessment.



Get Started: ABA Services

Get Started: with quality services

- Ask about the credentials of your providers and their clinical education, supervised experience, and continuing education.
- On the ABA in PA website, there is a document to help you identify

Provider Assessment

- Once you have your written order for ABA and have contacted an agency in your area that has availability, the provider will obtain authorization for an assessment from your insurance.
- Each insurance company may have different requirements for assessment of your child's needs. The assessment will include in his/her various settings (more information about assessments caregivers to complete.
- The ABA provider should assist you with necessary paperwork and explain expectations for the assessment.
- Once assessments are completed, the ABA provider will send the of services.
- If services or specific hours are denied by insurance and you regarding appeals in the Get More: ABA Services section of this book.

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• Providers must make quality assurance reports available to families when requested. We suggest that you request a report, read it and ask questions if you have concerns or do not understand something. supervisors. BCBAs and BCBA-Ds have the most requirements for

if you are receiving quality ABA services (Resources page and scroll down to document downloads). There is also more information in Get More: Starting ABA Services in the next section of this book.

observation, testing and data collection of your child's current skills available in the Get More: ABA Services section of this book). Some insurances may require additional standardized tests for parents and

initial assessment and request for services to the primary insurance. It can take 4 weeks or longer from the start of assessment to the start

disagree, you can appeal the decision. There is more information

Get Started: Other Therapies and Services Available

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Appropriately addressing the symptoms of autism often requires the coordinated efforts of a number of professionals. The following charts provide information on related services that may be helpful to your child, depending on their unique needs.



For SLP, OT and PT:

If your child is under the age of 5, contact your local Early Intervention Agency. Services are delivered in your home or community setting.

If your child is 5 or older, contact the Office of Special Education at your local school district. Services are delivered in the school environment.

Outpatient services may also be available in a hospital or clinic setting.

Your child can access ABA therapy, the services described in this section and educational services described in the next section at the same time. The services can be overlapped and work together to increase your child's progress.

Advocate for all the services your child needs!

Get Started: Other Therapies and Services Available



Case management is provided through your local county. Contact your county office to find case management options in your area.

To access outpatient, social skills or advocacy services:

- Consult case management for available options
- Search for services that specialize in autism in your area
- Ask for advice in the ABA in PA Parent forum on Facebook

Services focused on age-appropriate interactions, play and conversations skills, understanding others and managing emotions

Provides help with finding providers and services, coordinating services, planning, evaluation and advocacy

Includes psychological and psychiatric evaluations, ongoing medication management or counseling/ therapy services

Assists parents with understanding laws and rights related to services and support at meetings with providers

To access case management:

Check the ABA in PA DIRECTORY for groups or programs near you.

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Educational Services in PA

Education in Pennsylvania takes many forms ranging from early intervention to school-age public education to alternative approaches such homeschooling, charter schooling, or cyber schooling. Educational laws state that every child who meets eligibility criteria can receive free and appropriate educational services from birth to 21 years of age. The educational services offered in Pennsylvania are governed by state and federal laws, and may differ based on the age of your child.

FEDERAL LAW services for children birth to age five: **Early Head Start and Head Start Program**

Head Start is a federal program that promotes school readiness for children from low-income families and children with disabilities. At least 10% of a Head Start program's enrollment must serve children with disabilities, and their families do not need to demonstrate financial need. Special services are available to ensure that children with disabilities can fully participate in all aspects of the program.

Ages 0-3:

- Early Head Start programs serve infants and toddlers under the age of three.
- Services can begin when your child is an infant if your child qualifies.

Ages 3-5:

- Head Start provides a learning environment that supports children's educational and social-emotional needs.
- Head Start emphasizes the role of parents as their child's first and most important teacher, and focuses on supporting family well-being as well as child development.

Getting Started with Head Start Services

For more information on locating an Early Head Start or Head Start program in Pennsylvania near you, access the Head Start Program Locator at

https://eclkc.ohs.acf.hhs.gov/center-locator.

Get Started: Educational Supports

STATE LAW services for children birth to age five: **Early Intervention Programming (EI)**

Pennsylvania's EI program provides supports and services to families with children from birth to age five with developmental delays and disabilities.

EI services have two distinct components, based on age:

Age 0-3:

- Birth to age 3 EI programs are provided through the child's local county.
- Services may include educational supports, speech, occupational and/or physical therapy, depending on the needs of your child.
- The model promotes education, coaching and collaboration among all providers and caregivers involved with the child.
- Services may be delivered wherever your child spends his/her time.

Age 3-5:

- Services for preschoolers from three to five years of age are provided by Intermediate Units (IUs).
- disabilities across several local counties. Some of the classrooms are ABA based, and may have various therapy services in the classroom. Ask about available services in your local IU.
- to receive special education services in that setting.

Getting Started with EI Services

Eligibility for services begins with an evaluation process. Your child does not need a diagnosis of autism be evaluated. EI evaluations, supports, and services are provided at no cost to families.

Parents who want to begin the process or have questions about their child's development should contact the CONNECT Helpline at 1-800-692-7288 or through the website at: https://www.dhs.pa.gov/Services/Children/Pages/Early-Intervention-Services.aspx.

If the results of the evaluation determine a need for your child, an individualized education plan (IEP) is developed to specifically address the area(s) of need. The IEP may include services such as parent education, occupational, physical or speech/language therapies, developmental therapies, and other family-centered services that assist in child development.

• Most children attend IU classrooms, which can include children with various

• Children who are already enrolled in a daycare or preschool are allowed by law

Get Started: Educational Supports 20

School-Aged Services (ages 5-21)

Local school districts are responsible for the education of children starting at ages 5-6 and can last through age 21 if the individual remains eligible. The local school district is the point of contact for all issues related to the education of your child when he/she enters the school-aged system.

Getting Started with School-Aged Services

Transition from EI into school age programming:

- For students who began with EI and continue to qualify for special education services, a process has been established to transition from EI into school-age programming.
- Contact a representative from the EI agency (often a case manager from the IU) for details about this process.
- This transition ensures that your school district has all of the necessary information, so appropriate programming is available when your child starts school.

Children without prior EI Services:

- Request the process of evaluation and identification of needs from the local school district in writing, noting diagnosis and developmental concerns.
- In order to have services start on day one of kindergarten, families must request an evaluation at least 90 days prior to the end of the previous school year.
- If the results of the evaluation determine a need for your child, a plan is developed to specifically address the area(s) of need.
- Often, a representative from the special education department will be assigned to you as a point of contact for all matters related to evaluations and educational programming.

For detailed information about school-aged special education services in Pennsylvania, see below in the Get More: Educational Services section of this booklet and reference the Pennsylvania Parent Guide to Special Education for School-Age Children.

https://www.pattan.net/assets/PaTTAN/2a/2a2a5b53-4694-41c8-aea6-0769490a89ed.pdf

Get Started: Educational Supports Which School-Aged Support Plan is Right for My Child?

The 504 Plan:

- A 504 Plan provides services and accommodations to ensure your child has the same access to school programs as non-disabled has attention difficulties.
- More children qualify under the 504 Plan because the 504 Plan activity."

The Individualized Education Plan (IEP):

- An IEP goes further than the 504 Plan by providing "specialized instruction" necessary to meet your child's unique needs.
- Specialized instruction includes making changes to the learning in school.
- To be eligible for an IEP, your child's disability must fall within a specific eligibility category and impact his/her education.
- Children with autism all have varying social deficits. Social deficits often impact education, requiring an IEP.

If you are unsure if your child is on the right plan for his/her needs, speak with your school district special education representatives, seek support of an advocate, or seek the advice of an attorney who specializes in special education law to help you decide.



students. For example, a 504 Plan can be written for your child to have front row seating in a classroom or extra testing time if he/she

only requires that your child has a disability that impacts "major life

material, methods or type of instruction, and providing additional services, such as speech therapy or behavioral supports, to meet the needs of your child. An IEP contains goals, objectives, modifications, accommodations, and specific data about your child's performance

Get More

In the Get More section of Embark, you will find more details about the services and topics addressed in the *Get Started* section. The *Get* More section also includes various links to informational websites on the topic. It is not meant to be an exhaustive list, but we hope it will help you as are ready to learn more and gain the right supports for your family. We understand that it is a lot of information to take in and encourage you explore this section at your own pace. If you are using a printed copy of this guide, the QR code will take you to The ABA in PA website where an online version with active links to the informational pages can be found.

Topics:

Parent and Family Resources What is Autism Funding What is Applied Behavior Analysis (ABA) **ABA Services** Other Therapies and Services Available **Educational Supports**





Get More: Parent and Family Resources

Resources for Parents and Caretakers

We encourage families to seek out other families. Experienced parents of children with autism can be strong resources to recommend books, online blogs, and local resources for support. While no two families may have the same exact experience, you will find that many are dedicated to supporting each other with their individual journeys. Use the links below to communicate with other families, and find online and local in-person support networks.

Autism Society of America Search your location for local parent support groups

The organization's mission is to link families of children and adults with disabilities or special needs together to a Peer Supporter for purposes of support and information. Peer Supporters are also parents of a child or adult with a disability or special need and are willing to share their experience.

Resources for Teens and Young Adults with Autism

Autism Service, Education, Resources & Training (ASERT): ASDNext Connecting teens and adults with autism to information, resources and others in their community.

Autism Speaks information of Self-Advocacy

ASAN: Welcome to the Autism Community Information and links to related to self-awareness, self-advocacy and selfdetermination.

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ABA in PA Parent Facebook Group

Parent to Parent

Get More: Parent and Family Resources

Resources for Siblings of Children with Autism

Siblings Perspectives: Some Guidelines for Parents, by Marcia Wheeler

Organization for Autism Research (OAR), Sibling Support page OAR provides 3 booklets, for 3 different audiences (parents, teenage siblings and young siblings) to validate sibling experiences and provide guidance on some challenges they may encounter.

Autism Speaks Family Support Toolkits

Toolkits designed for Parents, siblings, grandparents and friends, to provide encouragement in understanding and accepting autism diagnoses.

The Sibling Support Project

Offers online groups, books and workshops to support siblings of individuals with special health, developmental and mental health concerns. The organization also helps local communities start SibShops – peer support groups for school aged children.

Siblings of Autism

Organization dedicated to supporting the siblings of individuals on the autism spectrum through educational scholarships, respite funds and outreach programs.



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Get More: What is Autism

Autism and Initial Diagnosis Resources

American Autism Association

Autism Speaks 100 day toolkit for young children

Autism Speaks 100 day toolkit for school age children

<u>Center for Autism Research Resources page</u> at Children's Hospital of Philadelphia



Get More: Funding

MEDICAL ASSISTANCE (MA)

Services for your child can become very costly, even with private insurance. Fortunately, a diagnosis of autism allows parents to seek additional funding through Medical Assistance (MA) in Pennsylvania.

Medical Assistance Eligibility

- A child with an autism spectrum diagnosis is eligible for Medical Assistance (MA) benefits under the Disabled Child category (PH95).
- The Disabled Child category is not based on financial need. Household income does not affect eligibility, unless the income is for the child (survivor's benefits, trust, etc.).
- MA covers most medical services and therapies, including Applied Behavior Analysis (ABA).
- If you have health insurance through an employer, MA is considered secondary insurance.
- If your child is enrolled in a Children's Health Insurance Program (CHIP) insurance, he/she cannot be covered by both CHIP and MA. Check with your child's CHIP plan and their coverage of ABA before deciding to switch to MA.

Health Insurance Premium Payment (HIPP) Program

If your child is covered by a commercial insurance plan through an employer and becomes eligible for MA, you may become enrolled in the HIPP Program.

- The state determines who is enrolled based on cost-effectiveness.
- If you are chosen to be enrolled in HIPP, the state will pay your monthly health insurance premiums for your commercial insurance. MA stays in effect; however, if your child was enrolled in a Managed Care plan through MA (Amerihealth, Aetna, Gateway, etc.), he/she will be disenrolled and placed into the Medical Assistance fee-for-service program. The fee-forservice plan may not be accepted by all of your child's medical or therapy providers.
- This may be an issue with providers other than ABA providers.
- You can appeal your enrollment in HIPP if you can demonstrate that enrollment is detrimental to your child's care.

Get More: Funding

Private Insurance Information/ Act 62

In 2008, the Autism Insurance Act (PA Act 62) went into effect. Act 62 requires commercial insurance companies to pay for the first \$36,000 of autism services annually.

- Insurance plans that are self-funded, out of state, or through a company with less than 51 employees are exempt.
- All deductibles and co-pays are still the responsibility of the family, unless your child is also eligible for Medical Assistance.
- part of their benefits package.

It is important to understand how treatment is covered through either your primary and/or secondary (MA) insurance. If your child is covered under a private health insurance, you should call the member line on the back of the card to obtain information on coverage of ABA services and details of coverage for other services you may need.

If your insurance company does not cover services, you can also appeal to your Human Resources department to request that your employer cover services.



• Some plans that are exempt under Act 62 will still cover ABA therapy as a

Get More: Funding

Family Grants and Gifts

In addition to private insurance and Medical Assistance (MA), there are some grant and gift opportunities families with children with autism. Below is one local Pennsylvania gift organization, and a link to Autism Speaks' family grant website. If your family is in need of specific resources, be sure to look for and ask about grants and gifts, locally, statewide, and nationally. Funding availability may vary.

Andrew's Gift

Andrew's Gift was developed to provide support to individuals with an autism spectrum disorder and their families. Family members and individuals living in Dauphin, Cumberland, or Perry Counties may apply for grant money to be used for things that directly improve the life of an individual with autism.

Autism Speaks

Autism Speaks maintains a list of national family grant opportunities:

Get More: Funding

Further Information About Funding Services

Pennsylvania Department of Human Services Website regarding <u>PA Autism Insurance Act (Act62)</u>

Pennsylvania Department of Human Services website regarding Health Insurance Premium Payment (HIPP) Program

Pennsylvania Health Law Project (PHLP) <u>Guide Book for Obtaining</u> <u>Medical Assistance (MA)</u> for a child with a disability

PHLP Medical Assistance Fact Sheet

Apply for Medical Assistance online





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Get More:

What is Applied Behavior Analysis

How ABA Works

- Goals are targeted to meet the needs of the individual
- Skills are broken down into a series of manageable steps that are easier to learn
- Individuals are provided multiple opportunities to practice and perfect each step of the skill
- Success is rewarded with reinforcement, providing a high motivation for improvement
- Progress is tracked and changes are made through studying the child's behavior
- Skills are focused on functional use and integration into daily life



What can ABA teach?

ABA has been used successfully to teach individuals of all ages a variety of different skills:

- language/communication
- academic engagement
- play skills
- tolerance and coping skills
- toileting

- social skills
- following directions
- self-management skills
- dressing & hygiene routines
- and more!

In addition, ABA is effective in decreasing problem behaviors, such as:

- physical aggression towards others
- interfering self-stimulatory behavior
- feeding/eating difficulties

- tantrums
- bedwetting
- self-injury

Get More:

What is Applied Behavior Analysis

Additional Applied Behavior Analysis Resources

The website for the Behavior Analyst Certification Board contains information about becoming certified as a BCBA-D, BCBA, BCaBA, and RBT. Parents can also use the site to find a BCBA in their area, or verify that a provider is credentialed with the BACB.

Autism Service, Education, Resources & Training (ASERT) **Applied Behavior Analysis resources**

Autism Speaks: Applied Behavior Analysis

The ABA in PA Initiative Resources: Applied Behavior Analysis



It is important that parents/caregivers are able to understand the qualifications of the providers overseeing their child's treatment.

On the next page you will find some roles of ABA providers, their associated acronyms and the minimum qualifications, education levels, and credentials for each role.

Families are encouraged to ask about the qualifications of their specific providers, as they may vary and may be above the minimum qualifications.

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Behavior Analyst Certification Board

Get More: What is Applied Behavior Analysis

Get More: What is App

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Acronym and Title	Education Level	Required Exam	Supervised Experience	Ongoing Supervision	Re- certification	Continuing Education
BCBA-D Board Certified Behavior Analyst, Doctoral level	Doctoral degree in an ABA accredited program	YES - through BACB	1500 hours by BCBA or BCBA-D	N/A	Must recertify with the board (BACB) every 2 years.	32 hours every two years, 4 hours related to professional ethics. (All CEs must be BCAB approved.)
BCBA Board Certified Behavior Analyst	Master's degree in applied behavior analysis, psychology or education; required courses must be verified by the BACB	YES - through BACB	1500-2000 hours by BCBA or BCBA-D	N/A	Must recertify with the board (BACB) every 2 years.	32 hours every two years, 4 hours related to professional ethics. (All CEs must be BCAB approved.)
BCaBA Board Certified Assistant Behavior Analyst	Bachelor's degree with verified coursework in ABA	YES - through BACB	1000 hours by BCBA or BCBA-D	Ongoing supervision by a BCBA or BCBA-D.	Must recertify with the board (BACB) every 2 years.	32 hours every two years, 4 hours related to professional ethics. (All CEs must be BCAB approved.)
RBT Registered Behavior Technician	High school (or equivalent) or higher; Completion of 40 hour RBT training program	YES - athrough BACB	Complete Competency Assessment: Must be observed by a BCBA-D, BCBA or BCaBA	Ongoing supervision by a BACB-D, BCBA or BCaBA	Must complete a competency assessment and submit to the board every 1 year.	N/A
LBS Licensed Behavior Specialist	Master's degree from in a human services or mental health field AND 45 hours of coursework or training related to ABA	N/A	-1 year supervised Functional Behavior Assessment experience with children AND 1000 supervised hours working with individuals with autism or behavioral challenges -Supervisor does not need to be licensed or certified	N/A	Must recertify with the state of Pennsylvania every 2 years	N/A
BC-ABA Behavior Consultant - Applied Behavior Analysis	Hold an LBS or other approved state license AND -40 hours of approved training in ABA plus supervised experience OR -12 credits in ABA from a college and one year full time experience (with no specified supervision)	N/A	-1 year of full-time experience in the provision of ABA under the supervision of a BCBA	1 hour each month from a Clinical Director. 1 additional hour if BC-ABA supervises BHT-ABA services.	N/A	16 hours annually
aBC-ABA Assistant Behavior Consultant- Applied Behavior Analysis	-Meet the educational requirements for LBS (without experience requirement) OR -12 credits in ABA from a college or university and six months experience	N/A	N/A	2 hours a month supervised by BC-ABA	N/A	20 hours
BHT-ABA Behavioral Health Technician - Applied Behavior Analysis	-Two years experience and 40 hours training related to ABA OR -High school diploma and completed 40 hour training for the RBT (without competency assessment or credentialing)	N/A	N/A	Supervised by BC- ABA or aBC-ABA; minimum 1 hour individual and 1 hour group supervision	N/A	20 hours

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Get More: ABA Services

As noted in the Get Started: Starting ABA Services section, ABA services have a specific process for getting authorization through your insurances. This section describes in more detail what to expect from assessments, treatments and on-going therapeutic services.

Assessment

- When you begin working with an ABA agency, the BCBA or BC-ABA will complete an assessment with you and your child.
- One part of the assessment process may include your agency providers observing and collecting data on your child's behavior. You will notice that the team may do little to no intervening at times. This is because they want to observe and understand how your child is functioning in his/her natural environment and interactions. Knowing what your child is doing currently can help them decide the best interventions for improvement and skill development.
- Another part of the assessment may include a Functional Behavior Assessment, or FBA. If your child exhibits challenging behavior, an FBA will help the team understand what new skills your child may need to learn in order to stop the unwanted behavior and replace it with more appropriate behaviors or communication so his/her needs are met. Your ABA team may ask you to collect some data at times when they are not in the home, specifically about what was going on before the difficult behavior occurred, and also what occurred to end the behavior.
- Your team may also engage your child and test various developmental skills. Again, you may notice that they do not provide a lot of correction for errors during the assessment period, as they are just looking objectively at what your child can do right now - assessing his/her "starting point."
- Assessments may also include interviews with parents, or other caretakers that know your child well, or standardized questionnaires for you to fill out.
- When the assessment period is complete, the BCBA (or BC-ABA) will make a recommendation to your insurance for how many hours of service your child should receive in order to make progress. Your team should also suggest goals that they feel will help your child the most, based on data collected during the assessment period.

Get More: ABA Services

Treatment Plans

- The treatment plan is a document that specifies the goals for your child members responsible for carrying out the interventions.
- The different services your child receives may all have their own child, so that all team members are consistent and work together to maximize progress.
- the difference!
- The activities and interventions that your ABA providers work on with your child at home, school, or in the community should be related to achieving the goals defined in the treatment plan.
- Treatment plans will be updated by your ABA provider. Treatment plans must be updated every six months, but can be updated at any time. more as goals are achieved or priorities revised.
- If your child has not made progress with a goal on the treatment plan,



and tracks progress towards those goals. The treatment plan will also list the interventions planned for your child's treatment and the team

treatment plans and specific goals. It is helpful to ask providers to share copies of their treatment plans with other individuals working with your

• Goals on your child's treatment plan should be specific, measureable and observable. That means that they should be written clearly, so that when your child achieves the goal, you will be able to know it happened and see

Therefore, it is not necessary to list every area of need on the treatment plan. It is sometimes better to prioritize a few targets at a time and add

the lead clinician (usually a BCBA or BC-ABA) should propose changes to increase success. This may include changes to the teaching strategies, increasing practice time or focusing on pre-requisite skills for the goal.

Get More: ABA Services

Treatment

- Once treatment begins, you should notice your team members working more directly with your child. They should still be collecting data on your child's behaviors in order to track their progress with goals.
- The interventions your BCBA (or BC-ABA) and RBT (or BHT-ABA) do with your child should be relevant to your child's goals. If you have questions about interventions and how they are addressing goals, ask! You, as a parent or caregiver, are an important part of treatment, and should understand the purpose of what you (or other providers) are doing.
- If you are concerned or struggling with an intervention your team suggests, talk to your BCBA or BC-ABA. Your child will make the most progress when interventions are consistent and when everyone is on the same page.

Initial Authorization and Re-authorization

- As described in the Get Started: Starting ABA Services section, your ABA provider will complete an initial assessment and submit that to your insurance/s. The insurance or MA will then provide an initial authorization, which states how many hours of services (by each ABA professional on your team) will be covered through insurance.
- The insurance/MA will determine "medical necessity" for the services. This means that they will want to see that the service is necessary to prevent or reduce effects of your child's disability and/or help your child achieve or maintain their highest level of functioning.
- Re-authorization is the process used by the insurance/MA to determine the "medical necessity" for ongoing service and to approve the amount of services that will be paid for in the next authorization period.
- Re-authorization must take place within the necessary timelines. If there is a lapse in time between the end of one authorization period and the beginning of the next authorization period, services may be interrupted.
- Written orders will need to be re-evaluated and prescribed yearly in a faceto-face evaluation.
- Re-authorization processes and documentation for private insurances may vary. Your ABA provider or the insurance specialist for the agency can guide you through the process.

Appeals

- If the primary insurance denies specified hours, there is an appeal work with your ABA provider to complete the process.
- MCO website or by calling the MCO member services.



Some ABA terms or acronyms you might hear

Below are some names and acronyms associated with ABA interventions, assessments, and curricula. This is not an exhaustive list, it is just to highlight some of the terms you may encounter or may want to explore further with your child's ABA team.

- Discrete Trial Teaching (DTT)
- Natural Environment Training (NET)
- Pivotal Response Training (PRT)
- Precision Teaching
- Functional Communication Training (FCT)
- Competent Learner Model (CLM)
- MAPP)
- PEAK Relational Training System
- PEAK Life Assessment
- Essentials for Living (EFL)
- The Assessment of Functional Living Skills (AFLS)
- Acceptance and Commitment Therapy (ACT)

Get More: ABA Services

process. Contact the appeals department of your insurance company and

• If the MCO denies specific hours, the appeal process is called a grievance. You can find out more information about the grievance process on the

• Functional Behavior Assessment (FBA) and Functional Analysis (FA) • Verbal Behavior Milestone Assessment and Placement Program (VB-

Get More: ABA Services

Disability Rights Network - Pennsylvania

Disability Rights Pennsylvania protects and advocates for rights of people with disabilities. They can be a resource for families who are denied funding for or access to quality services.

We recommend that if you are having trouble finding or accessing quality ABA that you reach out to Disability Rights Network - PA via email at jhergenreder@disabilityrightspa.org and copy ABA@pa.gov

Resources for Accessing ABA Services

Below is a list of Managed Care Organizations (MCOs), which authorize and fund services through Medical Assistance. On each MCO website, you will be able to find contact information for providers, their process for funding behavioral treatment, complaints and grievances.

Community Care Behavioral Health Organization

Department of Behavioral Health and Intellectual Disabilities Services-**Community Behavioral Health**

Value Behavioral Health of PA

Autistic Self Advocacy Network (ASAN) Information on advocacy for autism treatment coverage and how to navigate private insurance.

Pennsylvania Health Law Project IBHS description and guide

The ABA in PA provider directory Includes a (non-exhaustive) list of IBHS providers in Pennsylvania

Council of Autism Service Providers Applied Behavior Analysis Treatment of Autism Spectrum Disorder: Practice Guidelines for Healthcare Funders and Managers



Get More: ABA Services

Magellan

PerformCare

Get More:

Other Therapies and Services Available

More on Additional Therapies and Services

Autism Service, Education, Resources & Training (ASERT) ASERT: What to look for when choosing a therapist

ASERT: Speech services and Autism Spectrum Disorders

ASERT: Occupational Therapy and Autism Spectrum Disorders

ASERT: Physical Therapy Services

ASERT: Early Childhood Learning Centers/Day Care Services for children with autism

American Occupational Therapy Association, Inc.

American Speech-Language-Hearing Association

Autism Speaks social skills groups

The ARC of Pennsylvania An advocacy organization for individuals with intellectual and developmental disabilities.

ABA in PA provider directory List of social skills groups in PA

Get More: Other Therapies and Services Available

More on Additional Therapies and Services

Health Care Quality Units

The Health Care Quality Units (HCQUs) work to support and improve the health information and knowledge for the intellectual disabilities community service system by building capacity and competency within the physical and behavioral health care systems as well as the stakeholders of the ID system. HCQUs support complex care needs of individuals with intellectual or developmental disabilities.

> National Autism Center's National Standards Report For effective treatments for individuals with autism

Association for Science in Autism Treatment

Among other resources, the website contains links to scientifically reviewed theories, therapies and methods, to recommend those that have been shown to be effective and those that have not. It includes a list of recommended and not recommended information sources.





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Autism Watch



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Educational Laws Important to You

Federal Laws

- Individuals with Disabilities Education Act (IDEA)
- Section 504 of the Rehabilitation Act
- Americans with Disabilities Act (ADA)
- Every Student Succeeds Act (ESSA)

Pennsylvania State Laws

• The Pennsylvania Code- The Pennsylvania Code is a publication of the Commonwealth of Pennsylvania listing all rules, regulations, and other administrative documentation. Chapter 14 outlines IDEA and Chapter 15 outlines Section 504



Early Intervention

Some children, with specific genetic and medical factors present at birth, are automatically entitled to a birth to age three evaluation. There are several criterion that one must meet in order to receive an evaluation. One of those qualifying criterion is having a sibling with autism. So even if the sibling is not exhibiting symptoms, parents can request that the sibling be followed, so that any delays are identified and treated early.

However, any parent at any time from birth to age 5 can request an evaluation through EI or the Intermediate Unit (IU).

> Autism Service, Education, Resources & Training (ASERT) links for Early Intervention:

Pennsylvania Training and Technical Assistance Network (PaTTAN) A Family's Introduction to Early Intervention in Pennsylvania

ASERT

Quick link to finding your county assistance office contact information

Get More: Educational Supports

There are 13 categories of special education that qualify for an IEP:

blindness autism emotional disturbance intellectual disability orthopedic impairment specific learning disability visual impairment



Advocating For Your Child

- If your child is not receiving educational services, but you have concerns, days from receipt of your letter to respond.
- If the school responds by sending you a Permission to Evaluate Form, an Evaluation Report.
- The school can also choose to send you a Notice of Recommended not evaluate your child. If you disagree, you can appeal this decision.
- If you have concerns or disagreement with the school district decisions, you can obtain a private or third party advocate to assist you.

Did You Know...?

- You can invite anyone you would like to your child's Individualized even just to help take notes for you, you can ask the team to include them.
- Also, you can request an IEP team meeting anytime you, as a parent, have new concerns or new information about your child to share.

deafness hearing impairment multiple disabilities other health impairment traumatic brain injury speech or language impairment

you can request an evaluation from the school or school district at any time. If you request an evaluation in writing, the school has ten calendar

you should sign and return it. The school will have 60 days (from the date they receive it signed from you) to complete an evaluation and give you

Placement/Prior Written Notice (NOREP/PWN) indicating that they will

Education Plan (IEP) meeting. If you have other service providers that know your child, or would like another parent to support you there, or

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Educational Information Resources

Pennsylvania Association of Intermediate Units and PA Map of IU areas

Local Task Force

The Local Task Force is a group of parents and professionals working together to ensure that the intent and spirit of the Right to Education Consent Agreement is carried out throughout Pennsylvania. Contact your Intermediate Unit to find information on your local task force. State Task Force on the Right to Education Phone: 1-800-446-5607 ext. 6828

Special Education Timelines

According to Pennsylvania law, special education services must be delivered according to specific timelines. This guide explains those timelines in detail.

Bureau of Special Education's ConsultLine, A Parent Helpline

The ConsultLine is designed to assist parents and advocates of children with disabilities with any questions concerning their child's special education program or the laws related to the provision of services in their child's IEP (Individualized Educational Program). Phone: 800-879-2301

Parent Education and Advocacy Leadership Center (PEAL)

The mission of the PEAL Center is to ensure that children, youth, and adults with disabilities and special health care needs lead rich, active lives and participate as full members of their schools and communities by providing training, information, parent leadership, and technical assistance based on best practices to individuals and families and all people who support them. Phone: 866-950-1040

Get More: Educational Supports

The Pennsylvania Training and Technical Assistance Network (PaTTaN) -Autism Initiatives

The mission of the Pennsylvania Training and Technical Assistance Network is to support the efforts and initiatives of the Bureau of Special Education, and to build the capacity of local educational agencies to serve students who receive special education services. The website includes blog posts, articles and videos that may be helpful to families. Phone: 800-360-7282

Mission Empower provides advocacy, education, and the promotion of inclusion, to assist families and their children with disabilities. Phone: 814-825-0788

The Office for Dispute Resolution (ODR) provides the resources for parents and educational agencies to resolve educational disputes for children served by the early intervention system, students who are gifted (or thought to be gifted), and students with disabilities (or thought to have disabilities). Phone: 800-222-3353

Hispanos Unidos Para Niños Excepionales (Philadelphia Hune, INC) HUNE is a not-for-profit organization that provides free bilingual English and Spanish training, technical assistance and individual assistance to parents of infants, toddlers, children, and youth with disabilities and to professionals who work with children. Phone: 215-425-6203

Mission Empower

Office for Dispute Resolution





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