



# Does my child have autism?

A thorough guide on developmental milestones & how ABA can help



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# Does my child have autism?

## A thorough guide on developmental milestones & how ABA can help

If you suspect your child may have autism but are unsure of what to look for, this guide created by Forta, is for you. Learn about the warning signs and developmental milestones, as well as the steps involved in screening, evaluation, and diagnosing a child with autism before obtaining evidence-based therapy like Applied Behavior Analysis (ABA).

Forta, a tech-based service company, is revolutionizing ABA treatment for children with autism spectrum disorder (ASD). We hope that this information will help you in identifying early signs of autism and give you clarity.



# What is autism?

## What is it and what does it mean?

The Centers for Disease Control and Prevention (CDC) estimates that as many as one in every 54 children has an autism spectrum disorder (ASD).

The Autism and Developmental Disabilities Monitoring Network (ADDM) reported that the prevalence of the neurological disorder increased by 178% between 2000 and 2020. Social interaction, speech, and behavior can all be affected by autism.

Autism affects the way people interact, communicate, and learn. Autism is present in individuals with a vast range of abilities, including different levels of verbal communication and a broad spectrum of functional capabilities. People with ASD require varying levels of help; some may be able to manage on their own, while others need continual supervision and care. Mild to severe symptoms of ASD can

be present, and no one collection of symptoms is prevalent in every individual with ASD.

Autism is a treatable disorder; however, there is no cure. To treat their symptoms, people with autism spectrum disorders can benefit from various treatments, including behavioral, speech, occupational therapy, physical therapy and medication. Early intervention treatments are considered crucial for circumventing and addressing pervasive symptoms that can affect the quality of life and hinder living independently.

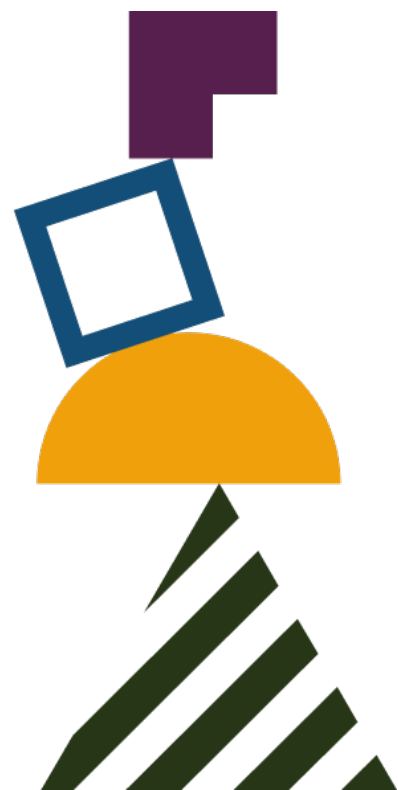
There are three main types of autism spectrum disorder: ASD Level 1 - Requiring Support, ASD Level 2 - Requiring Substantial Support, ASD Level 3 - Requiring Very Substantial Support. We discuss these in more detail later on.

# Early intervention

## What are early intervention programs and how to gain access to them

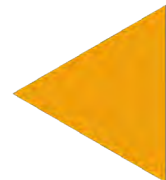
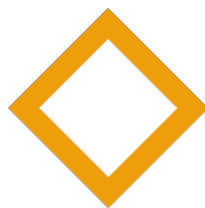
First implemented in 1975, the Individuals with Disabilities Education Act (IDEA) demands that each state provide all eligible students with a public education that is individualized to their unique needs. Early intervention (EI) programs are funded through the IDEA, which distributes federal funds to states. These programs are available to any child under the age of three with a developmental delay or a medical or mental condition likely to result in a delay. A child's early intervention services are free if they are confirmed to be eligible.

Infants and toddlers who are eligible for early intervention might benefit from instruction in a variety of fundamental abilities that normally emerge throughout the first three years of life. Cognitive, communicative, physical, socio-emotional, and self-help skills are among these important goals.



**Those services will be customized to the child's specific requirements, and may include, but are not limited to:**

- Auditory services
- Family counseling and training
- Medical services
- Nursing care
- Occupational Therapy
- Provision of technological devices that assist with skill building
- Psychiatric help
- Speech/Language Therapy
- Psychological Therapy



## Chapter 2

Other services tailored to the specific needs of the child's family are also available. The goal of family-directed services is to assist parents and other family members to better understand their child's unique requirements and how to best meet those needs.

If your child qualifies for early intervention, they must be provided an Individual Family Service Plan (IFSP) prepared by a team of specialists. This team can include your child's doctor, therapist, Early Intervention teacher, advocate, daycare provider and others. The IFSP is the document that outlines a child's requirements and the services they will receive. An in-depth assessment of the child should serve as the foundation for the IFSP. It should include information on the child's present abilities and future objectives. Additional details on what services will be offered to your child and your family are required for this document.

EI services aim to mitigate the impact of disability on a child's development. The most prevalent early childhood therapy is ABA. Today, the term «ABA» describes a wide range of treatments that utilize rewards to promote and reinforce needed skills. Children's services may involve a variety of therapies such as speech and language therapy, occupational therapy, physical therapy, and psychological assessment. State and regional EI services differ significantly from each other. Please contact your local Early Intervention Agency for information on early intervention services. The [Autism Speaks Resource Guide](#) provides contact information.





# Autism and missed milestones: what you should know

## Things to look out for in your child's development that may be indicative of autism

A developmental milestone is an indicator of average child growth. The CDC categorizes developmental milestones into four main categories: physical/motor movement, cognitive, language/communication, and social/emotional. Each age has a corresponding list of milestones.

Multiple developmental milestones are often missed by children with autism, resulting in a solid and evident delay in development. On the other hand, missed milestones can be obscured or even overlooked because children with autism learn and act differently than their peers.

If a young child fails to fulfill an anticipated developmental milestone, it does not necessarily imply that they have autism.

Symptoms may not appear for up to two years in some instances.

Children with autism can appear to develop normally until 18 - 24 months before their cognitive development stalls or the regression of their skill sets.



## Chapter 3

The American Academy of Pediatrics (AAP) has made recommendations on their website regarding autism screening:



The AAP recommends that **all children be screened for ASD at ages 18 and 24 months**, along with regular developmental surveillance. Toddlers and children should be referred for diagnostic evaluation when increased risk for developmental disorders (including ASD) is identified through screening and/or surveillance.

The Centers for Disease Control and Prevention (CDC) cites the AAP's recommendations and adds:



The American Academy of Pediatrics (AAP) recommends developmental and behavioral screening for all children during regular well-child visits at these ages:

9 months

18 months

30 months

In addition, AAP recommends that all children be screened specifically for ASD during regular well-child visits at these ages:

18 months

24 months

# Diagnostic criteria for autism spectrum disorder: DSM-5

Diagnosis of current mental health issues are outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association.

The DSM-5, the manual's most recent revision, went into effect in May 2013.

There are ongoing revisions to the DSM to reflect changes in our understanding of mental health

problems and the best methods for identifying them. This is done by the American Psychiatric Association (APA).

Many diagnoses that were formerly classified independently, have now been combined into a single ASD diagnosis: autism, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome.

## According to the DSM-5, diagnostic criteria consist of:

**Criterion A. Persistent deficits in social communication and social interaction across multiple contexts**, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

- A1. Deficits in social-emotional reciprocity [...].
- A2. Deficits in nonverbal communicative behaviors used for social interaction [...].
- A3. Deficits in developing, maintaining, and understanding relationships [...].

**Criterion B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following**, currently or by history (examples are illustrative, not exhaustive; see text):

- B1. Stereotyped or repetitive motor movements, use of objects, or speech [...].
- B2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior [...].
- B3. Highly restricted, fixated interests that are abnormal in intensity or focus [...].
- B4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment [...].

**Criterion C. Symptoms must be present in the early developmental period** (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

**Criterion D. Symptoms cause clinically significant impairment in social, occupational, or other important areas** of current functioning.

**Criterion E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.** Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level. (American Psychiatric Association, 2013).





Autism spectrum disorder is also categorized into three primary spectrum categories based on the level of support required by the individual.

**ASD  
Level 1**

Requiring Support

**ASD  
Level 2**

Requiring  
Substantial Support

**ASD  
Level 3**

Requiring Very  
Substantial Support

These categories help doctors identify the best therapy and behavioral programs for your child.

# Being autism aware of delayed developmental signs

Autism symptoms can appear as early as the first year of a child's life. It is essential to be aware of the symptoms of autism to facilitate a diagnosis as quickly as possible.

### **In the early stages of autism, you may see:**

- Your child's social and communication conduct is not typical, such as avoiding eye contact or not replying to their name before nine months.
- No response to sounds or track objects with their eyes.
- They do not share interests with others (e.g., pointing to objects) or is not interested in engaging with peers.
- They have intense, often obsessive interests and prefers to play with particular items in particular ways (e.g., focused on spinning toy car wheels or lining up toy animals).
- They repeat words or phrases and/or has a speech delay.
- They can get quickly agitated and does not like a change in routine.
- No "make-believe" play or regression in some abilities.



## Chapter 3

Detecting early signs of ASD is more difficult in very young children because they are defined by the absence of typical behaviors rather than the presence of atypical ones. First-time parents sometimes overlook early signs of speech delay and attention deficits and may wait longer before mentioning their concerns to their doctor.

Therefore, the first year of life is critical for establishing an initial diagnosis and therapy. There is a high likelihood that a primary care physician will first identify a patient with ASD, so be sure to speak to your pediatrician if you have any concerns. Early intervention is essential to treating the long-term effects of autism.



# Pediatric screening for autism

## What is the process of screening for autism and how is it different from getting a diagnosis?

Every child should have regular checkups from a doctor or pediatrician. According to the [Autism Society](#), children as young as 24 months old can be diagnosed with autism. The [American Academy of Pediatrics](#) advises screening for developmental delays at 9, 18, 24, and 30 months, with autism screenings at 18 and 24 months. Children with ASD should be diagnosed early to better understand their strengths and limitations.

A child suspected of having an ASD or developmental delay may be referred by their medical doctor for further evaluation. If a child has a family member who suffers from the disease, has particular symptoms that are diagnostic of ASD, or has an older parent, they are more likely to be impacted and therefore screened for ASD.

# Screening vs. getting a diagnosis

It is essential to point out that diagnostic tools for autism identification should be distinguished from developmental screening methods. You can get a screening for autism done by your primary care physician or a nurse during a routine checkup. Screening tools do not provide an official diagnosis of autism. The screening simply advises your healthcare practitioner that your child may require a full assessment, which could lead to an official diagnosis of autism. Screening tests are commonly performed at the 18 and 24-month check-ups if there are concerns.

A doctor may refer children with developmental delays for additional evaluation during a screening.

Screening tools aim to find out if a child has any developmental delays or other neurological issues. Screening techniques do not give conclusive proof of the existence of a developmental delay and do not lead directly to a diagnosis. A positive screening result necessitates an in-depth evaluation or assessment.

There's not enough information in screening tools to truly comprehend deep-rooted issues affecting developmental areas. Children who exhibit indicators of ASD will almost certainly be referred to an expert for an in-depth developmental review. If you have concerns, please ask your doctor for a referral.



# Tools commonly used for screening autism

A wide variety of methods are available for the early detection of developmental delays. Screening methods for general development and autism spectrum disorder (ASD), as recognized by the Centers for Disease Control and Prevention (CDC), are included in this section:

### Ages and Stages Questionnaires (ASQ)

Parents fill out a questionnaire, which yields a pass/fail score for each of 19 age-specific assessments that test communicative, gross/fine motor, problem-solving, and personal adaptation abilities.

### Communication and Symbolic Behavior Scales (CSBS)

For children as young as 24 months, this is a nationally standardized screening instrument for communication and symbolic abilities. The Infant Toddler Checklist is a 1-page screening tool that parents complete.

### Modified Checklist for Autism in Toddlers (MCHAT)

A questionnaire meant to be filled out by a parent and is used to identify toddlers in the general community who are at risk for autism.

### Parents' Evaluation of Developmental Status (PEDS)

This is a generic screening tool for children of all ages. Useful as a monitoring tool, this parent interview form can be used to screen for developmental and behavioral issues that require further investigation.

### Screening Tool for Autism in Toddlers and Young Children (STAT)

This is an interactive screening tool for children who may have developmental issues that need to be addressed. It takes 20 minutes to conduct and includes 12 tasks to gauge a child's ability to play, communicate, and imitate others.

# Important resources and information on screening for autism

**Autism Research Institute** - this article breaks down different autism screening tools and assessments used by physicians, the importance of getting your child a formal diagnosis, how to do so, and tracking your child's progress through ongoing assessment.

**The Autism Society** - learn more about the differences between a medical diagnosis, an educational determination, and a school evaluation of Autism Spectrum Disorder. In this article, you can also learn about related conditions, the details of diagnosis at different life stages and ages, as well as how children can be evaluated

**Autism Speaks** - on their site, you can find a directory on professionals who specialize in evaluation and diagnosis by location as well as helpful tools and articles to reference while getting a diagnosis for your child from the perspectives of professionals and parents alike.

**The Autistic Self Advocacy Network** - this organization is run by and for people with autism and provides educational resources for diagnosis and self advocacy to support individuals in all life stages.

## Chapter 4

[The CDC](#) - View this list of screening recommendations, developmental screening tools, diagnostic tools, and information on myths about developmental screening to help you navigate getting a diagnosis for your child.

[Medicare & Medicaid Services](#) - Learn about the important provisions included for individuals with autism in the Affordable Care Act. Most health insurance plans are no longer allowed to deny, limit, exclude or charge more for coverage to anyone based on a pre-existing condition, including autism. Easily view plans and prices or get coverage directly from the site in order to start the diagnosis process for your child.

[US Department of Health & Human Services](#) - Read about protections and details pertaining to children with autism under the Affordable Care Act, as well as how to get autism screening for children at 18 and 24 months.

[The National Conference of State Legislatures](#) - Learn about autism services insurance coverage by state in this article and directory.

[Autism Speaks Health Insurance Coverage](#) - Learn about insurance coverage for autism and use the Health Benefits Guide to understand your plan.





# Receiving a referral and diagnosing autism

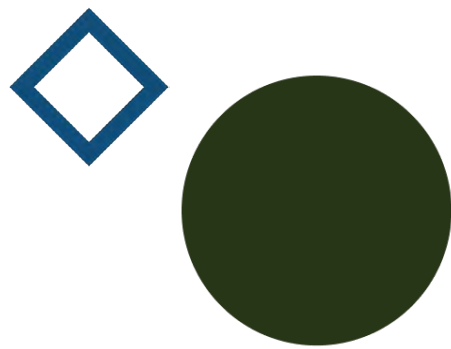
## How to receive a doctor's referral and what the evaluation process looks like

Neuroscientists believe that autism spectrum disorder (ASD) has a significant hereditary component. Unfortunately, no blood test, brain scan, or other test can identify autism. Instead, physicians and psychologists use history and observation of behavior to make an ASD diagnosis.

Diagnosis may be made using various methods, including but not limited to: patient observation, patient interviews, cognitive and language testing, and/or interviews with caregivers/parents. However, a diagnosis can only be made by a trained medical professional.

Choose an experienced specialist if you suspect your child has autism. Expertise in detecting and treating persons with autism is essential. If unsure, ask your child's medical doctor for a referral. Pediatric neurologists, child psychiatrists, and developmental pediatricians are trained to treat children with ASD. Specialty experts, such as speech-language pathologists, child psychologists, or occupational therapists, can conduct examinations in some situations.

# Receiving a diagnostic evaluation



A team of specialists who have previously identified ASD will conduct a diagnostic evaluation. Pediatric neurologists, child psychologists, psychiatrists, and occupational therapists may be part of this team of specialists. Medical and neurological tests will assess a child's cognitive and language abilities as part of the diagnostic assessment. Parents or guardians will also be interviewed in-depth about their child's behavior and development, and age-appropriate abilities required for daily activities like eating, dressing, and independent bathroom use will be evaluated as part of the process.

Assessments and diagnoses often rely on observations and semi-structured interactive sessions. Due to the complexities of ASD, complete testing may involve blood and auditory tests that can identify other possible issues. In the end, you may get an official diagnosis and suggestions for appropriate therapy for your child. Diagnosing ASDs early on can assist parents and their care team in determining the best course of action for addressing their child's needs.

# Tools commonly used for diagnosing autism

The four tests listed in the table below can be used to help establish a diagnosis. Be sure you have a discussion with your healthcare practitioner regarding the tests they recommend so you know what to expect.

<u>Autism Diagnosis Interview-Revised (ADI-R)</u>	A systematic interview used to diagnose autism and arrange treatment for individuals over 18 months.
<u>Autism Diagnostic Observation Schedule - Generic (ADOS-G)</u>	An observational evaluation and the “gold standard” of diagnostic tests for autism.
<u>Gilliam Autism Rating Scale - 2nd Edition (GARS-2)</u>	The GARS-2 includes a developmental history as well as questions regarding stereotypical behaviors, communication, and social interaction that are often found in children/adults (3-22) with ASD.
<u>Childhood Autism Rating Scale (CARS)</u>	Brief assessment for children 2 years of age and older. In order to identify children with autism from those with other types of developmental disorders, the CARS test looks at and assesses a variety of variables, including questionnaires and observations.



# Receiving an autism evaluation

## What is an autism evaluation, how to prepare for it, and what to expect during

Without a diagnosis, coping with ASD can be frustrating and confusing for all parties involved. Parents and professionals can help learn how to help the child best once diagnosed.

In order to receive a diagnosis, you must have your child participate in an autism evaluation. Keep reading to find out what you should expect.

# During an evaluation or assessment: what to expect

Both direct and indirect tools can be used in the evaluation process. Testing can take anywhere from 1.5 hours to 4 hours or more, and it can be done all in one day or spread out over a few visits. If several providers are evaluating your child, it will affect the amount of time needed to complete the entire assessment.

ASD diagnostic procedures should include age-appropriate testing for cognitive development, social communication, and engagement in all aspects. Some of these may include a diagnostic tool from our [Autism Screening Tools](#) section list. These tools allow specialists to compare a child's capabilities and conduct to those of other children of the same age.

However, screening and diagnostic techniques must be examined in the context of additional information from adults in the child's life. To get the whole picture of your child's health and well-being, a detailed interview with the child's parents should be part of the evaluation process. You may be questioned about your child's personal and family history and current and past medical conditions and treatments. ASD-related symptoms will be thoroughly examined throughout the interview as well. Additional parental questionnaires may be requested to gain further insight.



**Any qualified professional (as previously mentioned in our diagnosing autism section) may conduct an autism evaluation that includes the following:**

- A medical, educational, and social history of the individual
- An in-person observation and interactive session with a member of the team
- A behavioral evaluation tool
- An ASD-targeted evaluation tool

On the day of your evaluation, the BCBA will introduce themselves to you and your child before leading you to an area where the assessment will take place. Your child may choose from a wide range of toys and activities. To keep your child comfortable and cooperative, regular breaks are offered. Even though this may seem like an unstructured play session, the BCBA will be watching to see if your child can play independently, follow instructions, share, and engage in turn-taking.

In certain situations, and with very young children, parents may be permitted to stay in the room with their children during the evaluation. Parts of the evaluation may be done in the testing room by just the evaluators. In some cases, there may be a psychologist, a speech-language pathologist, and/or an occupational therapist doing the examination.





# Preparing for the evaluation

## Advice from Forta's Parent Ambassador, Miriam, who is a parent to two children with ASD

Preparing for an autism evaluation can be nerve-wracking. Oftentimes, the waitlist to receive an autism evaluation can be anywhere from weeks, to months, to years.

The unknown of what to expect and how you should prepare leading up to your child's evaluation can be difficult.



# Here are three ways that I prepared for my child's evaluation that I hope will help you:

### 1. Collect and organize all important information about your child

Create a folder with all pertinent records about your child. Include medical records and any previous evaluations (these could include speech, PT, and OT) they may have had. I found it beneficial to start from birth and create a list of things that I found could be relevant to the evaluation. I included information about development milestones, and any concerns and questions I had about their growth or development.

### 2. Gain a better understanding about autism

Autism is a spectrum, and there are many resources online that can help you gain a better understanding of autism. I found it helpful to learn more about what autism is and what different levels of autism there are. This helped me prepare as I was able to create a list of questions that I could ask the diagnostician at the

evaluation. You don't have to learn everything about autism, but this part will help you get started and prepare any questions you may have.

### 3. Check with the office that is doing the evaluation on what to expect

#### Some good questions to ask include:

- How long will the evaluation take?
- Will I be present for the entire evaluation?
- Can I bring any comfort toys or snacks for my child?
- What can I expect on the day of the evaluation?
- How long after evaluation is completed will I receive the official report?

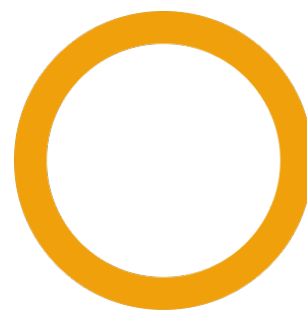
Preparing for an autism evaluation is not always an easy feat. Having lists, all your questions and documents ready before the evaluation will hopefully make you feel prepared and ready.

# Paying for autism screenings and diagnostic evaluations

**What your options are for financing the assessments needed to receive a diagnosis**

Autism screenings and diagnoses can be a costly and time-consuming process, but necessary to gain coverage and support for care and therapy by your insurance provider under the Affordable Care Act (ACA). Informally conducted screenings can range from free to \$500, but diagnostic testing might cost upwards of \$5,000 in a professional setting. Depending on your insurance coverage, the facility you choose, and the test technique, the cost of an autism diagnosis can be extremely expensive.

The price of diagnostic measurement tools is often higher than that of genetic screening questionnaires, and mandated coverage varies from state to state. Please see our [State by State Mandate Information in Chapter 12](#). The screening and evaluation procedures can be extremely time-consuming.



# Paying for an autism screening



Autism screenings are usually provided free of charge to you by your primary care physician or pediatrician. Screening is the first step to find out if you should pursue a diagnosis. The CDC recommends that screenings for autism are done for free during your child's monthly or annual well-child check visits.

At 18 and 24 months, the The Affordable Care Act (ACA) mandates that children can participate in a covered autism assessment. To find out more about receiving screening coverage through Medicaid, please visit our chapter on [How to Pay for ABA](#).

# Paying to receive an autism diagnosis



A certified autism diagnosis can be very costly. Complete assessments for autism require a skilled professional such as a developmental pediatrician or child psychiatrist to complete. This is different from the general screening process. The cost of these examinations is far more than the cost of a simple developmental screening, and range from \$800 - \$5000 depending on the clinic you visit.

Essential protections for people with autism and related conditions and their families are included in the Affordable Care Act (ACA). Preventive care for children must be included without copayments or dual coverage in all Marketplace health plans and most private insurance policies. To find out more about receiving evaluation coverage through Medicaid, please visit our chapter on [How to Pay for ABA](#).

# Insurance coverage for autism screenings and diagnosis

Autism therapy is required by law in all jurisdictions, yet the extent to which states pay for screenings and testing varies greatly. Specific insurance plans may also cover a portion of an autism screening. Medicaid may pay for autism screening tests for those under 21. In accordance with the Medicaid Early and Periodic Screening, Diagnostic, and Treatment clause, all required testing for children should be funded. Some states automatically cover all people with disabilities, including those with autism, regardless of their income.



## Chapter 7

Autism screening and diagnosis might be expensive if you don't have health insurance or Medicaid, but there are a few alternative methods to save money.

### Community-based services

Programs held by churches, early childhood education programs, child/teen centers, and clinics can offer extra resources.

### Local university support

Consider reaching out to nearby universities and institutions for assistance. They often conduct studies around autism, and some are willing to offer autism evaluations for free or lowered cost if you are willing to participate in the study.

### Direct assistance from providers

Some providers who perform autism evaluations will offer their clients a sliding scale, discount, or payment plan for services if requested and you are not covered by insurance.

### Direct assistance from providers

If your child is over the age of 3, contact your local school district to get started on getting your child evaluated if you have concerns.



# What to do next if your child received an autism diagnosis

Paving your family's way to success  
through treatment, education and  
a support network





# The challenges of receiving an autism diagnosis

## Advice from Forta's Parent Ambassador, Miriam, who is a parent to two children with ASD

As a parent, receiving a diagnosis of any kind can be discouraging. Having your child receive a diagnosis of autism can foster many feelings of the unknown. As a parent of two children with autism, and someone who was in favor and pushing for a diagnosis - it was still very hard to digest the words "your child has been diagnosed with autism".

Autism is a loaded word with different meanings to so many. Trying to understand what autism is and how it is now part of your world can bring about many challenges, but it can bring about so many blessings as well. As I've walked the same path you are about to walk, I'm here to share the biggest challenges that we faced navigating autism.



### **Challenge #1 - Understanding what autism means**

The first and biggest challenge we faced was trying to understand what autism actually was. Autism spectrum disorder (ASD) is defined as a neurological and developmental disorder that affects how people interact with others, communicate, learn, and behave. It's a spectrum disorder, and the spectrum is large and affects each person differently. Having two children with autism, who

are genetically identical - I saw this first hand. Yes, they are identical, but autism manifests differently in both of them. It has taken me years to understand how it affects both of them differently, and as they grow, the autism challenges they face change as well. What I have learned is finding the right providers for my children (doctors, therapists, and educators) helped me to better understand how I could support them.

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### **Challenge #2 - Figuring out which interventions and therapists are needed**

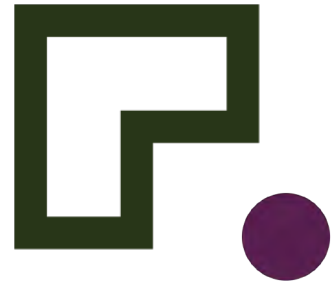
Another challenge that I found was trying to figure out the best way to help them through interventions and therapies. After much research, talking to other parents, meeting with different doctors and therapists, there was a lot of new information I needed to take in. Trying to understand which are the best therapies and which new things to try and help my children was a challenging task.

If another parent mentioned something that had helped their child (and it caused no adverse effects) we were willing to try it. We really have tried it all - supplements, different therapies, etc. I will say this was and is still the most challenging part of autism. We've spent lots of time and money, only to find out that many of these "things" that were supposed to help my children ended up being a gimmick. Unfortunately, many of the things we tried actually had no research to back them up.

After years of trying all the things, the first therapy we tried and continue to have them receive is ABA (Applied Behavior Analysis), speech and occupational therapy, all of which are research based practices.

These have been the most beneficial for our children. All of these therapies have helped my kids thrive and grow.

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### Challenge #3 - Building your support network

Lastly, another challenge that we've faced was trying to find and build a support network. It can be stressful for you and your family as you go through the motions of finding out your child has autism. For us, the more we shared with family and friends about our experience, the more support we were able to receive from them. Furthermore, connecting with the right providers and therapists proved to not always be easy, but once we found what worked for our boys we saw how much they flourished. Making all these connections helped us build a collaborative support network and team, for not only our boys but for our entire family.

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Although I've mentioned the challenges we faced and continue to face today, I would like you to know that through these challenges there are also so many blessings. My boys are special and unique, and they've taught us many great lessons. We've really learned to enjoy all the little things and be proud of how much growth they've made. Receiving an autism diagnosis is not easy, but know that as a parent you are your child's best advocate and know them best.

In the next section I share more of my experiences with building our family's support network and the most important things I wish we were told when getting started.

# Building your support network

Advice from Forta's Parent Ambassador, Miriam, who is a parent to two children with ASD



Being a parent of a child with autism brings about many challenges. As a parent of two children with autism, navigating the journey before they were diagnosed was difficult for our entire family. As we progressed through each stage, we found sharing about our kids and what we were going through was not only helpful for us but allowed friends and family to gain some insight into our lives. Furthermore, we found that when we were able to surround ourselves with people that had a better understanding of our daily lives - it made it easier for our entire family.

In the early stages of discovering that your child may have a developmental delay or that they could possibly be diagnosed with autism, it can be difficult as a parent to not only try and understand what an autism diagnosis means for your family but what it also means for your child. Autism is not a one size fits all, and it manifests in each person differently. Finding and building a support network is beneficial not only for your child but for your entire family.

### **Here are ways that our family built our support network that I hope can be helpful to you:**

#### **Sharing with your family & friends**

The more family and friends understand your needs, the easier it is to lean on them for support. Sharing with friends and family how your child is developing, things that your child enjoys, or things to help make your child's time spent with them

more enjoyable can all be helpful. If we are spending time with friends and family, I often include things they should avoid that may make it difficult for my child to enjoy their outing. I also encourage you to share your child's sensory needs and any special dietary restrictions that they may have.

## Chapter 9

### Finding autism support groups

There are many national autism support groups, and most cities have local support groups as well.

#### Different types of support groups that exist include:

##### Local support groups

These consist of support groups that provide resources for the entire family.

##### Caregiver support groups

These consist of Mom/Dad or parent support groups and also includes caregiver support groups. These groups often provide emotional support, and a place to ask for advice or guidance.

##### Sibling support groups

These consist of groups run by professionals and provide a safe space for siblings of children with autism to ask questions. Sometimes sibling support groups will organize activities so they can hang out with other siblings like themselves.

In most areas all of these groups can offer both face to face support and/or support through virtual groups. A quick Google or Facebook search with “autism + your city and/or geographical area” should help to get you started.

These groups are great at offering advice and comfort for the various stages you’re going through, provide you guidance and encouragement on things that will help you along the way, and share information on resources that may benefit your family.

# Professional resources

Researching and finding professional resources to help support your family is important - even in the early stages. These resources could include medical professionals, teachers, therapists, and social workers. When you find professional resources and are able to connect with them and build a special team for your child - it helps keep everyone connected and with the same goal in mind. This is also a great way to find out the different therapies that could help benefit children diagnosed with autism.

At the top of the list is Applied Behavior Analysis (ABA) which is considered the only evidenced-based treatment for autism by the US Surgeon General and by the American Psychological Association, followed by speech therapy, occupational therapy and physical therapy.

Building a support network takes time. As you navigate an autism diagnosis, you'll learn what works best for your family. With a support network in place, it will help provide your family much needed tools to help you along your journey.





# Understanding and learning about autism

Learning about the common core challenges that children with autism face



Individuals on the autism spectrum represent just that – a spectrum of personalities, behaviors, and symptoms. There are certain children with autism who have


substantial delays in cognition, behavioral issues, or bodily «stims» (for example, rocking or flapping). Other children's autism symptoms may seem less pervasive or even invisible.





### Some of the common core challenges that children with autism face include:

#### Communication concerns



Communicating and engaging in ordinary social interactions can be difficult for those with autism spectrum disorder (ASD). It might be difficult to grasp nonverbal signs and body language because individuals with ASD tend to socially isolate themselves from others. This makes it tough to interact with people, sometimes even minimally. Individuals often turn to echolalia (repeating well-known phrases and sounds) or «scripting» (repeating familiar language from a preferred book or program). To soothe themselves, some children with ASD employ scripting, while others utilize familiar language that is easy to recall when speaking with others. Some individuals remain non-verbal, while others may start to speak later in life.

#### Developmental delays

While some children on the autism spectrum exhibit significant delays, difficulties, or stims, many others do not. Delays in development may be challenging to detect if this is the case. Delays in language and motor skills, as well as cognitive or learning abilities, can impact learning and cognitive capacities. In this aspect, their social and linguistic issues are particularly apparent. Higher-level language and executive functioning are common areas of difficulty for children with ASD (includes organizing ideas, concentrating, attention, and self-regulation).



### Sensory issues

Problematic behavior and meltdowns in children with autism can be attributed to their sensitivity to “sensory overload” or dysregulation. Due to their inability to adequately filter external sensory input, people with autism spectrum disorders (ASDs) frequently feel sensory overload.

Children with ASD may exhibit both hyper- and hypo-responsivity to a wide variety of stimuli (under-responsive to stimuli). They often have a heightened sensitivity to bright lights, specific light wavelengths, or loud sounds. It is possible to develop a hypersensitivity to particular noises, aromas, textures, and tastes. As a result, neurodivergent learners’ capacity to comprehend and execute their communication, working memory, and mental flexibility might be hindered by anxiety coming from sensory overload.

“Stimming” is a type of repeated and self-stimulatory activity that can take numerous shapes depending on the person. It is common in children with autism. Such actions might involve flapping the hands, swaying back and forth, pacing, or repeating a word or sound. There are several reasons why children with ASD or sensory sensitivities may stim, but the most prevalent is the capacity to self-regulate and self-soothe.

### Rigidity and intense interests

Individuals with ASD can display various odd behaviors and strong interests. ASD is distinct from other neurological disorders because it is characterized by a lack of social interaction and involvement. Children’s activities, movements, and interests can be limiting or even obsessive. It is also commonly characterized by an inability to change. The interests, hobbies, behaviors, and routines of children with ASD tend to be rigid.

### Individual differences

A person's personality and other traits, such as age and gender, can significantly impact the severity of their symptoms. Most «typical» autism symptoms apply more to boys than to girls since males are four times more likely than females to be diagnosed with an autism spectrum disorder. Girls with autism might be: quieter, better at hiding their emotions (what we call masking), and better at copying the social cues of others.

### Strengths and weaknesses

Some children with autism show unique talents in certain areas, often called “splinter skills.” These skills might, for example, allow your child to count to 100 easily or read advanced words on a sign but be unable to have a reciprocal conversation with others, or even write the numbers they love to recite. Every child is different, and as the saying goes, “If you’ve met a child with autism, you’ve met one child with autism.”



# Assembling your team: autism specialists and their expertise

## Building your child's ultimate care team

When providing care for someone who has autism, it is often necessary to enlist the assistance of a group of professionals. Each member of your child's team is unique. They can support you in addressing all aspects of your child's life, including therapy, academics, enjoyment, and health. Here are some of the many specialists and care professionals you will likely enlist and/or interact with throughout your journey:



### **Specialist: Board Certified Behavior Analyst (BCBA)**

Individuals with a graduate-level behavior analysis certification are trained to provide and supervise behavior analysis. Often it is a BCBA who manages individuals providing ABA therapy. Neither ABA nor BCBA, by definition, is autism specific.

### **Specialist: Gastroenterologist (GI Doctor)**

Children on the autism spectrum are more likely to suffer from gastrointestinal issues. It is the job of gastroenterologists to identify and treat problems in the digestive system and liver. Some GI doctors specialize in autism-related GI issues.

### **Specialist: Physician**

The doctor's responsibility is to discover or rule out medical reasons for the child's developmental delay, prescribe medication for symptoms, and consult about feeding, sleeping, and elimination.

### **Specialist: Occupational Therapist (OT)**

A professional who evaluates and helps to develop fine motor (tiny muscle/hands/fingers), gross motor (large muscles/whole-body movement), daily self-care skills, and can also work on sensory issues, feeding difficulties, and adaptive behavior.

### **Specialist: Paraprofessional/Educational Aide**

A paraprofessional who works one-on-one with a student with ASD in a classroom to assist with academic assistance and behavioral intervention.

### **Specialist: Physical Therapist (PT)**

A professional who evaluates and helps to develop gross motor skills, such as strength, balance, coordination, posture, and mobility.



### **Specialist: Psychiatrist**

Psychiatrists who specialize in treating children and adolescents with autism diagnose and treat any psychological issues the child may have. Child psychiatrists also continue to give ongoing assistance and medication management following the initial diagnosis of the condition.

### **Specialist: Psychologist/School Psychologist**

Psychologists treat children with autism who have social anxiety, sadness, or persistent behavior. Aside from making treatment recommendations, they may also help with the evaluation, benchmarking, and ongoing evaluation processes.

### **Specialist: Registered Behavior Technician (RBT)**

A paraprofessional who practices under the close, ongoing supervision of a BCBA, BCaBA, or FL-CBA. The RBT is primarily responsible for the direct implementation of behavior-analytic services. The RBT does not design intervention or assessment plans.

### **Specialist: Social Worker**

Facilitating healthy relationships, coordination of EI and school/home services within the team, and assistance in getting needed resources can be provided by a social worker. You may find one at your local, regional center or local non-profit program for individuals with disabilities.

### **Specialist: Speech-Language Pathologist (SLP/Speech)**

A speech-language pathologist (SLP) is a professional who specializes in the evaluation, diagnosis, and treatment of abnormalities of the voice, swallowing, feeding, and speech.



# ABA therapy: utilizing evidence-based best practices

What ABA therapy is and why it is the gold standard for treating autism



# What is ABA therapy?

Children with autism can benefit from Applied Behavior Analysis (ABA) therapy, which is based on scientific evidence and targets a wide range of socially relevant behaviors. The primary goal of ABA (Applied Behavior Analysis) is to help children learn new skills, shape and improve their existing skills, and reduce their behavioral issues. The U.S. Public Health Service issued this report regarding ABA from the surgeon general in 1999:



**Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning and appropriate social behavior (Satcher, D., 1999).**

The American Psychological Association confirms ABA's validity by exemplifying its wide use by practitioners:

**Across the United States, applied behavior analysis is taught as a core skill in applied and health psychology programs. As such, the American Psychological Association (APA) affirms that the practice and supervision of applied behavior analysis are well-grounded in psychological science and evidence-based practice (American Psychological Association, 2017).**

The primary objective of ABA is the development of social, communicative, and practical skills. ABA treatments are recognized by both the American Psychological Association and the U.S. Surgeon General as having a solid basis in scientific research and currently remain the gold standard of autism treatment.





# ABA in simple terms

A person's actions and words are referred to as «behavior» in ABA. Behaviors that others may observe, as well as ideas, emotions, and memories, are included. The results of our thoughts and judgments guide our actions. In addition, a person's actions are impacted by their environment.

An essential principle of ABA theory states that rewarding positive behavior (known as positive reinforcement) increases the chance of it occurring again. In other words, positive reinforcement leads to an increase in behaviors, whereas negative reinforcement leads to a decrease in those behaviors and their elimination.



# How ABA evolved since 1970s



Behavioral psychologists like B.F. Skinner and Ivan Pavlov, trailblazers in their behavioral psychology discipline in the early twentieth century, transformed human behavior research. Dr. Ivar Lovaas of UCLA and his student Robert Keogel created the first ABA variation known as Discrete Trial Training in the 1960s and 1970s (DTT). As a result of the rigid structure, desired abilities and behaviors were broken down into smaller, more «discrete» elements.

These practices have evolved over time to incorporate other modernized strategies, which look to ABA as a reference point. To shape and reinforce new behaviors, the “new” ABA approach proposes utilizing deep-rooted learning principles, behavioral methods, and environmental modifications. According to the American Psychological Association:

**The most well-established treatments used applied behavior analytic techniques, which have typically become more natural, developmental in sequence, and more flexible (APA, 2022, “Autism Spectrum Disorder” section).**





At Forta, we practice only the latest methodology in current ABA research. Our ABA programs aim to help people with ASD gain social and communication skills and reduce or eliminate behaviors that interfere with daily living.

In terms of research-based treatments, Applied Behavior Analysis (ABA) is currently the most widely used worldwide. ABA practitioners now have access to a wide range of modern methods for working with children on the spectrum. Its availability has allowed people with autism to improve their social skills and communication abilities through the use of ABA-based approaches.

# Demystifying common myths about ABA

Parents and caregivers who have a child with ASD face an overwhelming amount of advice and information during their journey. It all can be tough to filter through and understand, especially if it's contradicting or not supported by an expert source. Parents may have difficulty making educated judgments about utilizing ABA treatment because it can be a source of controversy amid the confusion. Here, we go over a few of the main myths of ABA:





**Myth #1: ABA therapy is robotic, unnatural, and bribes children to behave a certain way.**

**Truth:** ABA is a systematic teaching style, yet children learn many ways to respond and work on flexibility and innovative thought processes. Modern ABA programs now include natural and generalized settings which remain an important part of the process. In addition to learning essential skills in the therapy session, the child will also learn how to apply them in everyday life, across stimuli, individuals, and environments in a methodical way. ABA simplifies more difficult activities by breaking them into smaller, more manageable chunks. Breaking down a complicated job is more effective for children with ASD, and the entire task should be taught step-by-step.

Parents are often concerned that ABA aims to develop a «robot» who parrots what they have learned. Rote memorization is employed in specific ways, but a good ABA program ensures that all programs have practical and socially legitimate components that are applied in the classroom while using memorization methods. Helping an individual grasp the larger context of their learning is an integral part of the ABA process. Children should also be taught how to negotiate and advocate for themselves, with the freedom to express their unique personalities through communicating their full needs, likes, dislikes, and emotions.

ABA employs positive reinforcement, not bribery, to encourage desired behavior. Bribery is negotiating with someone before something occurs; for example, a bribe might be «You can have candy if you hug grandma.» Often, bribes offer a reward before the desired behavior is done.

Rewarding experiences increase the likelihood of desired behaviors being repeated in the future.

Tokens, stickers, and snacks can be used for reinforcement. Learning and mastering a skill should fade to praise and more natural social reinforcement as the student progresses. Children with ASD may communicate their needs in ways that are challenging to assist them. ABA shows you how to support your child to express their needs and feelings in various settings properly. As a parent, you can discuss these goals with your child's BCBA.

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### **Myth #2: ABA therapy exists as a method to cure autism.**

**Truth:** Autism does not have a “cure.” People’s differences from their neurotypical counterparts are something to be embraced, not fought against. The goal of ABA treatment is to assist these persons in achieving independence and success in their daily lives in any way they and their families choose to do it.

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### **Myth #3: ABA therapy is only for children on the autism spectrum, and all programs are the same.**

**Truth:** Positive reinforcement is crucial to all human behavior, including for individuals with developmental disabilities, social and behavioral impairments, autism, addictions, and OCD. It can help people avoid restrictive behavior and participate in higher-level learning. Applied Behavior Analysis was established as a scientific remedy for autism in the 1960s and 1970s but has been around since 1938.

Famous behaviorist B.F. Skinner established this method using “operant conditioning,” or learning by consequence (such as with rewards.) Children and adults without autism can benefit from ABA treatment because it represents how all human brains adapt via both positive and negative reinforcement.

No ABA program should look entirely identical to another individual’s plan. You and your child’s unique learning style, preferences, and more should be evaluated while developing their ABA program. Emotions are real and should always be considered, not just when making a program but also when teaching a child how to communicate effectively. When a child has trouble with a task, learning, or performing a non-preferred activity, the therapeutic team should also be aware of and address their feelings. Emotions and appropriate responses are critical to fostering an individual’s sense of self-determination and self-confidence.

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# Top benefits of ABA therapy



Once your child receives their diagnosis, there are many services available to them in the private health system, in school, and in your community. Depending on your child's needs and the values of your particular family, some services will be more helpful than others. However, participating in ABA therapy from the start can be helpful for all families, due to its flexible nature. Your BCBA or program manager can help guide you through resources, provide you parent training and coaching, connect you to others in the autism community, and prescribe and manage ABA therapy for your child.

ABA is based in behavioral science and only utilizes researched, evidence based practices. Consistent and continuous data is collected, so parents should be able to see fact-driven progress along with feeling the changes at home. Because ABA has several different methods of teaching, a "good fit" can be found for your child where they are happily making steady progress toward their treatment goals.





### Other benefits of ABA therapy include:

**Individualized assessments and treatment** - there's not a one-size-fits-all curriculum; instead, each child receives their own assessments, treatment planning, and goals.

**Individualized parent coaching** - plans, resources, and strategies to be used at home are created for each individual family, so parents can make positive changes for a happy, healthy family.

**Functional skill acquisition** - self-help skills like toilet training, sleep routines, dressing, and other hygiene skills are taught through ABA, which can increase independence for your child.

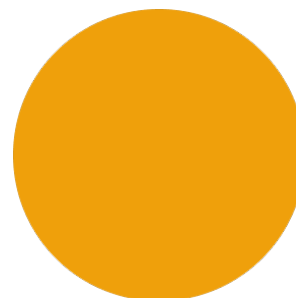
**Communication skill acquisition** - often ABA can help with functional communication for your child in whatever form works for them (verbal language, sign, PECS, or AAC device).

**High expectations** - because ABA therapists are experienced with children on the spectrum, they understand each child's abilities and potential, and hold them to a higher expectation than other adults who may wrongly assume low ability.

**Social skill acquisition** - children with autism can learn valuable building blocks to increase their social skill repertoire, helping them create and maintain friendships over time.

**Professional Collaboration** - ABA providers can collaborate with professionals in other areas of your child's life to increase all-around consistency and success in their lives.





**Access to environments** - because ABA can be provided just about anywhere, skills taught in one setting can then be generalized to whatever environment your child needs them, so that they can participate fully in all environments in their life.

**Parent skill acquisition** - parents can learn skills from their ABA team that will help them turn small moments at home into teaching moments, which will in turn increase the effectiveness of ABA and their child's overall success trajectory.

**Evidence-based** - ABA providers will not be trying just anything out; all systems within the treatment have already been researched and proven effective.

**Decreased problem behaviors** - individualized assessments and behavior plans are created for each client, which when used across environments can significantly decrease problem behaviors.

**Teaches perseverance** - because ABA breaks hard skills down to manageable pieces, children with autism learn to persevere and work hard to reach terminal goals.

**Insurance-covered** - ABA therapy for children with autism is covered by most health insurance carriers, so it can be a cost-effective service for most families.

**Access to community** - your ABA providers may be able to put you in touch with social resources, support groups, and other families who also have children with autism.



# ABA therapy: the bottom line

Research shows that ABA is the most effective research-based treatment for children with autism spectrum disorders. Most people's unfavorable attitudes towards ABA may be traced back to a fundamental

misunderstanding of the practice. Abilities in social interaction, adaptive behavior, communicative skills, and general quality of life can be improved through ABA treatment.



# Gaining access to treatment

**How to find the best ABA providers near you and things to look for when making your pick**

Once you know you want to pursue ABA therapy for your newly-diagnosed child, it can be difficult to know where to start. There are many options available, many different types, and many different philosophies and values throughout ABA companies and individual providers. In this section, you will find advice on how to find available providers, what to look for in high-quality providers, and how to choose a provider that will work well for your family.



# Researching local ABA providers

When you receive your child's diagnostic report, there will be recommendations attached to it. **Your diagnosing provider** may already have several ABA providers that they recommend, and this is a great place to start, especially if you had a good experience throughout the diagnostic process.

Many families also ask for recommendations from **other trusted professionals**, like your child's pediatrician, teacher/school administrator, your family's therapist or counselor, etc. These professionals come into contact with ABA providers regularly and will already have opinions on who is good to work with and who may not be.

You can also go to the **Behavior Analyst Certification Board's (BACB) website** at BACB.com. Click the "Find a Certificant" button to narrow search results to your geographic location, type of certification, disciplinary action status, and more. You can also use the "Verify a Certificant" button if you've already found a provider you like, and just want to check into their background.

Lastly, ask other **members of your family's community** for recommendations. Perhaps other parents of children with autism have already been through this process and can help speed your search, or they may at least have advice on where to look, who is considered great in the area, and who to avoid.

# Identifying the right ABA provider for your family

After you have a short list of ABA providers in your area that you might want to work with, it's important to find the correct fit. Not all providers will work well with all clients, as each family is unique. Once you've narrowed down your options to those you like, and who have availability and take your insurance, then it's time to find the right provider for your family.

Start by sitting down and really thinking about what is important in both the short and long-term for your family. Would you prefer to be very involved at every step, or would you prefer a provider who can make some smaller day-to-day decisions? Do you like a slower, more play-based approach, or a more clinical approach? Would your child respond better to providers within your home, or would it be better to have ABA sessions in a clinic or school? Are there any cultural considerations? Once you have this list, you can begin the interview process.







# Interviewing a potential ABA provider

Schedule a few new client conversations with potential providers either in person or over the phone (it's best to avoid email or text messages, as it can be hard to get a good feel for providers via written communication).

Most companies will make time to have these conversations with new clients and answer their questions. A good guideline for these initial interview conversations is about 15-20 minutes.

## 10 best questions to ask during the initial interview include:

### 1. Are all of your providers credentialed through the BACB (both direct-service staff and supervisory staff)?

It is sometimes OK for direct-service staff to not be credentialed, but it is never OK for supervisory staff to lack credentials. RBTs are direct-service staff and BCBAs are supervisory staff.

### 2. How frequently do your client's teams change (both direct-service staff and supervisory staff)?

Some turn-over on teams is normal, but clients shouldn't go through more than 2-3 direct service staff or more than 1-2 supervisory staff in a year, as this may be a red flag in their company, service delivery, or something else.

### 3. Where do you provide services (home, school, clinic, community)?

Find a provider that can serve your child where you think is best, or that serves clients in a variety of settings to allow for flexibility over time.

### 4. What teaching methods do you employ (discrete trial, naturalistic methods, incidental teaching, functional communication training, etc.)?

The best providers use a variety of teaching methods based on individual clients instead of only 1 or 2.

### 5. In what ways do you use reinforcement?

Providers should be able to label many instances in which they use reinforcement, and should talk about how reinforcement changes over time.





### **6. In what ways do you use punishment?**

Providers should have an open conversation about punishment during treatment. There should never be any cruel or unusual punishment, and they should say the focus is always on reinforcement for replacement behaviors and that punishment is never used in isolation. Note: “punishment” in typical language usually has a negative connotation, but this may be different within the context of ABA or behavioral language.

### **7. How do you work with stimming behaviors?**

Providers should understand that stimming may be part of who your child is, and should only target stimming behaviors for reduction if they are impeding your child’s ability to learn, function, or experience their environments.

### **8. Do you use planned ignoring program for eye contact, or work on compliance?**

All of these practices can be seen as unethical when provided incorrectly, or not alongside other practices like differential reinforcement, so it’s important your provider is aware of this.

### **9. What can I expect from the first few sessions?**

Experienced providers should have a typical routine they follow in the first sessions in order to make their clients comfortable, build rapport, and learn about the client’s interests.

### **10. What kind of continuing education is provided to direct-service staff?**

Supervisory staff have a minimum requirement of CEs to maintain their credential, but it’s very important that the direct-service staff get regular training and support, even outside of the ongoing supervision provided during client sessions.



# 10 things to look for when choosing an ABA provider

These 10 items are “green flags” to look for when choosing an ABA provider for the first time. Some companies might not have all of them, but you should try to find a provider in your area that has as many as possible. Look for:

- 1 Flexibility in scheduling** - morning, afternoon, and evening availability and schedules that can change over time as your needs do. Typical client schedules change twice per year, following the school calendar.
- 2 Strong collaboration** - ABA providers should actively seek out collaboration with you, your child’s teacher, and any other professionals (like SLPs) your child works with.
- 3 Ethical awareness** - companies should have ongoing training on ethics in ABA, be aware of ethical concerns in the field, and be open to talking about them.
- 4 Solid procedures** - the company should have processes for onboarding new clients, handling problems, and reviewing clinical data (assessments, programming, etc.).
- 5 Experienced mentors** - while newly credentialed providers can be great assets to your child’s team, there should also be experienced providers within the company who give regular support, guidance, and mentorship to all other team members.

- 6** **Variety of teaching modalities** - providers should be utilizing a variety of different teaching methods and modalities, rather than one set structure, so that they can fit their teaching style to each client.
- 7** **Individualized treatment and goal planning** - while some goals are considered typical for all same-aged children with autism, each client's treatment plan and specific goals should be completely individualized.
- 8** **Parent participation policies** - because long-term success and effectiveness of ABA is so closely tied to parent participation, the best ABA companies have a policy for parent involvement that is given to parents at the onset of treatment, and then referenced regularly.
- 9** **Easy communication** - it should not be difficult to reach out to members of your child's ABA team. Emails should be answered in 1-3 working days, and phone calls returned as needed.
- 10** **Happy employees** - as with most fields, happy employees usually perform the best on the job. Look for companies with low staff turnover, good benefits, and employees who are generally happy.



# Test providers, communicate, and don't be afraid of change

In the end, the best way to decide if a provider is right for you or not is to try them out. See how they interact with you and your child, and watch how your child responds. Ask for frequent check-ins and bi-weekly coaching at the start, and determine how comfortable you are with the provider. Are they able to listen and answer your questions? Do they seem competent? Does your child seem to enjoy their ABA sessions? If any of these answers are “no” or if it just doesn't feel right, despite talking and attempting to problem-solve, it may be that you need a different provider.

Before you switch, it's important to communicate with your current provider. They may be able to make changes that will make ABA sessions

more comfortable and meet your needs better, but they won't know there's a problem unless you bring it up. Because ABA therapy is an ever-changing process, most providers are used to making changes and are pretty flexible.

If communication doesn't help, you might need to request a switch. Most companies have several different providers (both at the direct-service and supervisory levels), so consider requesting a different provider at the same company. It could just be that you need a fresh perspective or that another provider might have more similar interests to you. If this still doesn't solve the issues, the final step would be to look for a different agency or company.

# In-home vs. clinic-based ABA

ABA therapy can really be provided to children in any setting they're in- at home, in their gymnastics camp, at school, in a clinic, and more.

## When deciding which setting is best for your child, there are several factors to consider:

### **Age and comfort level of your**

**child** - if they are young or fearful, it may be best to have ABA sessions in the home where they are most comfortable.

allow ABA. If you have a company chosen, it may be best to hold sessions in a less-than-perfect setting in order to work with the provider you like.

### **Your child's strengths and needs -**

ABA should be provided in whatever environment they need the most support in. So, if your child has very strong skills when at home, but is struggling at school, sessions should ideally take place at school.

**Distractibility of your child** - if your child is easily distracted, you will want to choose a setting for ABA therapy that is the least overwhelming to set them up for success.

### **Availability and regulations** - not all

ABA companies provide services in every setting, and not all settings





**Parent involvement** - some parents prefer to observe a large percentage of ABA sessions with their child, where others prefer strong communication with the team outside of sessions. Both are great ways to stay involved, but you will need to choose a setting that works with your preference.



There are many benefits to holding ABA therapy sessions in both the home (or community) and the clinic, so it's important for families to review these in order to make decisions about where their child will be most successful. It is also common for children new to ABA therapy to begin sessions in a clinic where the environment can be controlled, making success easier, and then transition later to home sessions where those skills can be generalized to other environments.

## Chapter 13

Benefit	In-home sessions	Clinic sessions
Easy parent observation	▼	
Structured environment		▼
Clear “time to learn” expectation		▼
Easy generalization of skills	▼	
Communication with ABA team	▼	▼
No need for family member supervision		▼
Skills taught in the natural environment	▼	
Easy to get to know the providers	▼	
Easy to prevent multiple relationships		▼
Availability of peer models		▼
Easy access to teaching materials/programming	▼	▼
Employee access to mentors		▼
Access to parent coaching	▼	▼



# Paying for ABA therapy & insurance

## What your options are for financing ABA and how insurance coverage works

Insurance-reform initiatives, driven by organizations like Autism Speaks, successfully lobbied for legislative reforms mandating insurance companies to cover ABA. Demand for ABA intensified due to the increased incidence rates, good outcomes, and cost savings involved with ABA therapy compared to the traditional costs of raising a child with ASD.

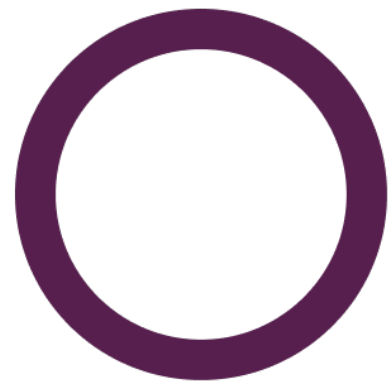
Coverage for autism therapy is mandated in most states. Depending on the mandate, coverage may be limited to a specified age range, the number of visits, spending limit, or other restrictions. You will find more detailed information about private health coverage of autism-related services, your rights, steps to obtaining coverage, Essential Health Benefits, and filing internal and external appeals in this informational [Guide for Individuals and Families](#) provided by the Autistic Self Advocacy Network.





# Requirements for insurance-covered ABA treatment

A medical need is required for most insurance companies to reimburse the cost of ABA therapy in most cases. You need to verify with your insurance company to see precisely what they consider medically necessary and be aware of the importance of prior authorization. Before therapy begins, ensure that all necessary documentation has been completed. You might end up footing the entire expense if you neglect this step. Generally, formal autism diagnosis and authorization for a functional behavior assessment are prerequisites for ABA.



# Figuring out if your plan covers ABA



Determine whether or if your company's health insurance is self-funded or fully insured. Federal law governs self-funded plans, whereas state mandates govern fully funded plans. If there is no government

mandate in place, employers can choose whether to include ABA services in their self-funded health plans. Your company's health insurance plan may or may not cover ABA therapy.

### Fully-insured plans

Fully insured plans entail the employer purchasing employee health insurance from a third-party provider. Your employer has no say in the structure of your insurance plan if you have one that is fully insured. A change in state law will usually initiate a shift in policy.

### Self-funded plans

Instead of relying on their employer to provide them with insurance, many people purchase their own policies. Individual insurance is frequently purchased by those who are self-employed or do not have access to health insurance via their place of employment.

Benefits are determined by the employer in self-funded plans but by the insurance company with fully insured plans. These decisions are also subject to state or federal law. State insurance rules apply to all types of private insurance policies, including those purchased by people on their own.


Autism coverage mandates, for example, may only apply to group plans under some state insurance laws. The 2010 Affordable Care Act also applies to individual health insurance policies.

Sometimes, private insurance carriers will cover ABA members in a medical emergency. However, it is advisable to check with your medical insurance provider to see if ABA therapy is covered under your policy.

### The health insurance marketplace

Consumers in the United States can purchase private individual or family health insurance plans and obtain income-based financial support to make insurance and treatment more cost-effective in a health insurance marketplace, also known as an insurance exchange. There is only one recognized health insurance marketplace in each state, which might be controlled by the state and/or the federal government; however, HealthCare.gov acts as the available marketplace in most regions.

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As a result of the Affordable Care Act (ACA), individuals and families began to have the opportunity to purchase health insurance starting in 2014.

Medicaid is a government program that serves as a critical safety net for those who need health care but can't afford to pay for it. Medicaid offers coverage on par with, if not better than, that of private insurance. You may have to verify that a member of your family is disabled to get Medicaid. Medicaid guidelines define autism as a disability. If you are accepted, you will be able to receive financial assistance for the therapies you require under your state's mandate.

The statewide marketplaces provide a variety of health insurance plans, some of which are not private. Many states require that people who qualify for Medicaid but do not qualify for a commercial insurance plan must enroll in a Medicaid plan, even if they do so through the marketplace.

Medicaid programs are required by law to fund the costs of autism treatment. Services deemed medically necessary are determined by each state on a case-by-case basis. Autism therapies, such as ABA, are medically recommended and, thus, covered by each state's Medicaid program. This means that treatment must fulfill the standard practices of medicine in each state to be considered medically essential.

In these plans, states have the last say on distributing health care. Use of Medicaid-accepting providers is often required. Medicaid isn't accepted by every doctor, hospital, or health center. If you go outside the Medicaid network in your state, you may be responsible for some or all of the costs.

# ABA coverage: insurance specifics

## **Premium vs. out-of-pocket maximum**

Your premium is the monthly price you pay for your health insurance. Your out-of-pocket maximum is the most you'll have to spend out-of-pocket for covered services per year. Copays, deductibles, and coinsurance are all included, but premiums are not.

## **Copayment vs. deductible**

After the insurance company has paid a bill, depending on the plan you possess, you are responsible for the remaining percentage of the bill, which is your copayment or coinsurance amount. Before receiving any benefits, you must pay a certain amount as a deductible (again, this depends on your specific plan). Some services, like wellness screenings, usually don't qualify

to count towards your deductible.

These services are accessible even if you haven't reached your deductible.

## **In-network providers vs. out-of-network providers**

A health maintenance organization (HMO) is a kind of insurance delivery. In most cases, you must use a network of providers (a pre-selected group of covered professionals) to receive insurance coverage. In a preferred provider organization (PPO), a network of specialists is available to you, but you can still gain some advantages if you go outside of it.







**When considering a change in your coverage or looking to find out how or if ABA is included in your health plan, consider the following:**

- The cost of your premium
- Your total copay/coinsurance amount
- Your total deductible amount
- Any expected out-of-pocket expenses
- Any benefit maximums concerning ABA
- Using in-network providers vs. out-of-network providers
- If your plan requires specific qualifications from service providers  
If a pre-authorization is needed from your insurance company before services can be reimbursed

# Common insurance providers for ABA



## Healthcare literature and policy information

### UnitedHealthcare

Cover the costs for ABA therapy as a standard benefit. New and renewing fully insured small and large group plans in the few remaining states where ABA coverage is not mandated will get ABA benefits. Coverage is offered in the states of Connecticut, New Jersey, and New York. For more specific information, please see [their PDF](#).

[Autism Spectrum Disorder and Developmental Disabilities](#)

[Intensive Behavioral Therapy for Autism Spectrum Disorder](#)

### Anthem Inc.

Anthem's medical plans provide mental health coverage as standard, ensuring that their members receive comprehensive, well-coordinated care. Coverage is offered in the states of [California](#), [Colorado](#), [Connecticut](#), [Georgia](#), [Indiana](#), [Kentucky](#), [Maine](#), [Missouri](#), [New Hampshire](#), [Nevada](#), [New York](#), [Ohio](#), [Virginia](#), and [Wisconsin](#). If you do not see your state listed here, please visit <https://www.bcbs.com>.

[Adaptive Behavioral Treatment Guidelines](#)

[Behavioral Health Provider Services](#)





Kaiser Foundation
<p>Individuals with autism spectrum disorder (ASD), developmental disabilities, or other conditions for which ABA therapy has been proven to be effective are covered by Kaiser Permanente for ABA treatment. Plan coverage varies from state to state. Coverage is offered in the states of California, Colorado, Georgia, Hawaii, Maryland, Oregon, Virginia, Washington, and Washington, D.C. Choose your region <a href="#">here</a> to find out specific information for your area.</p>
<p><a href="#">Applied Behavioral Analysis Provider Information</a></p> <p><a href="#">Learning about Autism Spectrum Disorder Screening</a></p>
Cigna
<p>Cigna will cover some services and treatment for individuals with ASD with specific criteria in place. Before you may begin therapy, your doctor must submit an official diagnosis of ASD. Cigna does not provide general location information on ABA coverage. Contact Cigna directly to see how your coverage affects access to ABA treatment.</p>
<p><a href="#">Autism Spectrum Disorders/Pervasive Developmental Disorders: Assessment and Treatment</a></p>
Aetna
<p>Medical need for an ASD assessment and diagnosis by a certified/licensed health care expert is considered by Aetna in cases where developmental delays or persistent deficiencies in social communication and social interaction have been established. There are many Aetna policies that exclude educational services from coverage. These plans do not cover speech therapy or ABA services during class. Please verify the exclusions in your benefit plan. Aetna does not provide general location information on ABA coverage. Contact <a href="#">Aetna</a> directly to see how your coverage affects access to ABA treatment.</p>
<p><a href="#">Autism Spectrum Disorders</a></p> <p><a href="#">ABA Provider FAQs</a></p> <p><a href="#">ABA Medical Necessity Guide</a></p>







It is tough to stay current in today's fast-paced medical insurance world, where things change regularly. The availability of ABA insurance coverage and the number of people claiming their rights to the advantages of ABA therapy are increasing. To get the most up-to-date information regarding ABA insurance coverage, you should always contact your own insurance provider.



**As a consumer, you are ultimately responsible for conducting your own research before deciding whether or not to enroll in a health insurance plan based on this information. Ensure you're consulting the most current health insurance material available in your state.**



# State by state information



It's crucial to check with your state's insurance provider to see if there are any restrictions or rules that apply to your situation within your state. Additionally, knowing the limitations of your state's autism mandates will aid in avoiding denials of claims for ASD care. All 50 states in the United States currently mandate some degree of autism insurance coverage.

## States that require ABA coverage in all marketplace plans:

Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Georgia, Hawaii, Idaho, Illinois, Indiana, Kentucky, Louisiana, Maine, Maryland, Massachusetts, Michigan, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Dakota, Ohio, Oregon, South Dakota, Tennessee, Texas, Vermont, Washington, West Virginia, Wisconsin, and Wyoming.

## States that do NOT require ABA coverage in all marketplace plans:

Alabama, Florida, Iowa, Kansas, Minnesota, Mississippi, North Carolina, Nebraska, Oklahoma, Pennsylvania, Rhode Island, or Virginia.



# Specific state autism mandate information

## Alabama

For more information on ABA provisions and autism mandate specifics in this state, please see [Ala. Code §10A-20-6.16 and 27-21A-23](#) (as amended by [H.B. 284](#) [2017])

## Alaska

For more information on ABA provisions and autism mandate specifics in this state, please see [Alaska Stat. §21.42.397](#) (as created by S.B. 74 [2012]) and [AS 21.42.397](#)

## Arizona

For more information on ABA provisions and autism mandate specifics in this state, please see [Ariz. Rev. Stat. Ann. §20-826.04](#)

## Arkansas

For more information on ABA provisions and autism mandate specifics in this state, please see [Ark. Code Ann. §23-99-418](#) (as created by HB 1315 [2011])

## California

For more information on ABA provisions and autism mandate specifics in this state, please see [Cal. Health & Safety Code §1374.73](#) (as amended by S.B. 946 [2011]) and Disability Rights California's informational article on [Access to ABA Therapy](#)

## Colorado

For more information on ABA provisions and autism mandate specifics in this state, please see [C.R.S. 10-16-104](#)

## Connecticut

For more information on ABA provisions and autism mandate specifics in this state, please see [Conn. Gen. Stat. §38a-514b](#) (as amended by S.B. 301 (2009))

## Delaware

For more information on ABA provisions and autism mandate specifics in this state, please see [18 DE Code § 3366](#). (2021)

### District of Colombia (Federal District)

For more information on ABA provisions and autism mandate specifics in this state, please see [Fla. Stat. Ann. §627.6686](#)

### Georgia

For more information on ABA provisions and autism mandate specifics in this state, please see [Ga. Code Ann. 33-24-59.10](#) (as amended by HB 429 [2015])

### Hawaii

For more information on ABA provisions and autism mandate specifics in this state, please see [Haw. Rev. Stat. §431:10A](#) (as created by SB 791(2015))

### Idaho

For more information on ABA provisions and autism mandate specifics in this state, please see [BULLETIN NO. 18-02](#)

### Illinois

For more information on ABA provisions and autism mandate specifics in this state, please see [Ill. Comp. Stat. ch. 215, § 5/356z.14](#)

### Indiana

For more information on ABA provisions and autism mandate specifics in this state, please see [Indiana's Health Insurance Mandate for Autism Spectrum Disorders \(ASDs\)](#) and [IC 27-13-7-14.7](#)

### Iowa

For more information on ABA provisions and autism mandate specifics in this state, please see [IAC Rule 191.35.40](#)

### Kansas

For more information on ABA provisions and autism mandate specifics in this state, please see [Kan. Stat. Ann. §75-6524](#); [Kan. Stat. Ann. §40-2,103](#) and [40-19C09](#)

### Kentucky

For more information on ABA provisions and autism mandate specifics in this state, please see [House Bill 159](#) and Kentucky's [Insurance Benefit for Children with Autism](#)

### Louisiana

For more information on ABA provisions and autism mandate specifics in this state, please see [LA Rev Stat § 46:1301 \(2018\)](#)



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### Maine

For more information on ABA provisions and autism mandate specifics in this state, please see [Me. Rev. Stat. Ann. tit. 24A §2768](#); [24A §2847-T](#); [24A §4259](#)

### Maryland

For more information on ABA provisions and autism mandate specifics in this state, please see [Md. INSURANCE Code Ann. § 15-835](#)

### Massachusetts

For more information on ABA provisions and autism mandate specifics in this state, please see [Mass. Gen. Laws. ch. 32A §25](#); [ch. 175 §47AA](#); [ch. 176A §8DD](#); [ch. 176B §4DD](#); [ch. 176G §4V](#)

### Michigan

For more information on ABA provisions and autism mandate specifics in this state, please see [S.B. 414](#); [S.B. 415](#); [S.B. 981](#)

### Minnesota

For more information on ABA provisions and autism mandate specifics in this state, please see [Minn. Stat. §62A-3094](#)

### Mississippi

For more information on ABA provisions and autism mandate specifics in this state, please see [Miss. Code Ann. §83-9](#)

### Missouri

For more information on ABA provisions and autism mandate specifics in this state, please see [HOUSE BILL NOS. 1311 & 1341](#) and the [Missouri Department of Insurance](#)

### Montana

For more information on ABA provisions and autism mandate specifics in this state, please see [MT Code § 33-22-515 \(2019\)](#)

### Nebraska

For more information on ABA provisions and autism mandate specifics in this state, please see [Neb. Rev. Stat. §44-7,106](#)

### Nevada

For more information on ABA provisions and autism mandate specifics in this state, please see [Ne. Rev. Stat. §689A.0435](#)



### New Hampshire

For more information on ABA provisions and autism mandate specifics in this state, please see [N.H. Rev. Stat. Ann. §417-E:2](#)

### New Jersey

For more information on ABA provisions and autism mandate specifics in this state, please see [Bulletin No: 10-02](#)

### New Mexico

For more information on ABA provisions and autism mandate specifics in this state, please see [Reconciling Autism Spectrum Disorder Coverage in Federal and State Law](#) and the [New Mexico Department of Health](#)

### New York

For more information on ABA provisions and autism mandate specifics in this state, please see [Insurance Law §§ 3216\(i\) \(25\), 3221\(l\) \(17\), and 4303\(ee\)](#)

### North Carolina

For more information on ABA provisions and autism mandate specifics in this state, please see [N.C. Gen. Stat. §58-3-192, as added by SB 676 \(2015\)](#)

### North Dakota

For more information on ABA provisions and autism mandate specifics in this state, please see [N.D. Cent. Code §26.1-36-09](#) and [Bulletin 2018-1 Coverage of Treatments for Autism Spectrum Disorder](#)

### Ohio

For more information on ABA provisions and autism mandate specifics in this state, please see [H.B. No. 350](#)

### Oklahoma

For more information on ABA provisions and autism mandate specifics in this state, please see [Okla. Stat. tit. 36 §6060.21](#)

### Oregon

For more information on ABA provisions and autism mandate specifics in this state, please see [OREGON INSURANCE DIVISION BULLETIN INS 2014-2](#)

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### Pennsylvania

For more information on ABA provisions and autism mandate specifics in this state, please see [Pa. Cons. Stat. tit. 40 §764h](#)

### Rhode Island

For more information on ABA provisions and autism mandate specifics in this state, please see [RI Gen L § 16-24.1-2 \(2015\)](#) and Rhode Island's fully comprehensive [Resource Guide: for Families of Children with Autism Spectrum Disorders](#)

### South Carolina

For more information on ABA provisions and autism mandate specifics in this state, please see [S.C. Code Ann. §38-71-280](#)

### South Dakota

For more information on ABA provisions and autism mandate specifics in this state, please see [58-17-157](#) and [An Analysis of Treatment Coverage for Children with Autism Spectrum Disorder in South Dakota](#)

### Tennessee

For more information on ABA provisions and autism mandate specifics in this state, please see [Bulletin 19-01](#), [56-7-2367](#) and [SUMMARY OF AMENDMENTS \(003081, 003489, 003852\)](#)

### Texas

For more information on ABA provisions and autism mandate specifics in this state, please see [Tex. Ins. Code Ann. §1355.015](#)

### Utah

For more information on ABA provisions and autism mandate specifics in this state, please see [Utah Code Ann. §31A-22-642](#) [as created by S.B. 57 (2014)]

### Vermont

For more information on ABA provisions and autism mandate specifics in this state, please see [8 V.S.A. § 4088i](#)

### Virginia

For more information on ABA provisions and autism mandate specifics in this state, please see [§38.2-3418.17. Coverage for autism spectrum disorder](#)



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### Washington

For more information on ABA provisions and autism mandate specifics in this state, please see [SUBSTITUTE SENATE BILL 6743](#), [Autism Statewide Resources for the State of Washington](#), and [Washington's Autism Advocacy's Autism Insurance Benefits legislation \(Shayan's Law\)](#).

### West Virginia

For more information on ABA provisions and autism mandate specifics in this state, please see [HB 2693 Text - West Virginia Legislature](#)

### Wisconsin

For more information on ABA provisions and autism mandate specifics in this state, please see [Wis. Stat. §632.895 \(12m\)](#)

### Wyoming

For more information on ABA provisions and autism mandate specifics in this state, please see [Wyoming Governor's Council on Developmental Disabilities State Resource Page](#)







# What to do if your insurance carrier does not cover ABA

ABA therapy can teach your child how to thrive in the outside world. If you don't have insurance, you don't have to give up this therapy option for your child. ABA therapy can be paid for in various ways, including through government programs, private grants and scholarships, and various other means. Be sure to research these topics to make sure you are not already eligible for ABA through these services:

## ABA services in an academic setting

Schools will sometimes contract with ABA providers. Contact your school's district office and Special Education services for more information.

## Community-Based Services

The programs can be held by churches, child/teen centers, and clinics to address functional skills.

## Supplemental Security Income (SSI)

Individuals with impairments of any age or employment history are eligible for this federal income program, as long as they fulfill the medical and financial requirements. It is a program that is tailored to meet the individual's specific needs.

## Grants

There are a number of grants you can apply for to access ABA therapy. Autism Speaks has an abundant list of grants available [here](#).

# Navigating autism & special education

## What to expect in your child's academic journey and how to be prepared

Recently, the number of children with autism attending public schools has increased significantly. Instructors, administrators, and other school team members still often lack the education and experience necessary to work with students who have autism spectrum disorders effectively. Usually, the responsibility will fall on the shoulder of the parents to ensure that their child's difficulties in social relationships, communication, or

conduct are addressed through research-based treatments in the school context. To implement and maintain this, parents must have a basic grasp of special education services and their child's rights, as well as their own.



## The transition to elementary school: how a BCBA can help

The success of a student's transfer from an ABA program to a school depends on various things, including skills the child has acquired, any transition preparation, and how (or if) the school is ready to support the child. Schools will sometimes contract with ABA providers. Contact your school's district office and Special Education services for more information.

A BCBA can assist your child with this transition by identifying and tackling everyday life and school routines to improve academic performance (such as working with a group of peers or walking in line) and independent skill development. The ABA program should strive to resemble a classroom's physical layout and the ratio of teachers to students. Your child's BCBA will utilize social stories, visual aids, and other resources that may be used in

the school context (like a sign chart, picture schedule, and others) to prepare the child for the transition and provide coaching to school personnel on how to use the materials.

Before the transition, you and your school district will get a report from your ABA program after it has completed a current assessment, documented progress on goals, and provided documentation. Information on how your child learns, their communication methods, and their behavior program will be summarized. They'll also make it easier for schools to restructure the wording when outlining goals in accordance with state standards, which is a necessity within your child's individual education plan (IEP). In contrast to state standards, the aims of an ABA treatment plan are based on medical necessities.

# Navigating the public and special education system

All children, including those with special needs, are entitled to a free and adequate public education. When early intervention programs end at age 3, special education services take their place. Your district's special education department provides these services. Early intervention and special education usually have different goals. Understanding your child's rights will ensure that your child is treated fairly and have access to all services and supports to which they are eligible. Contact your local school district for special education information.





### **Individual education plans (IEPs)**

Your child's local school system can provide extra support by creating an individualized education plan (IEP) for your child if they have been diagnosed with ASD. You can help your child realize their full potential with the appropriate education plan. However, education isn't only about learning but also navigating friendships and social settings with peers. Your child's strengths and limitations are described in the IEP, as well as the specifics of how they can be achieved. The IEP, in contrast to the IFSP (learning plan with early intervention), is almost exclusively concerned with how your child's needs will be addressed within the school system's boundaries.

IEPs may involve speech/language, behavioral treatment, or sensory considerations. The use of a classroom aide, «lunch bunch,» or social skills group may help children build social skills in school. A child's needs are determined by an IEP team, which will consist of teachers that work with your child and various administrative members. Some children with autism do not require an IEP. Those who don't qualify for an IEP can seek help through a 504 Education Plan, which offers classroom accommodations to enhance learning.



### **Inclusion and your child's rights**

Also, the «least restrictive environment» is something your child has a right to. Your child should be put in an environment where they are able to interact with neurotypical classmates and engage in the general education setting. This is known as mainstreaming or inclusion. In general education, modifications like an autism-trained one-on-one assistant can help provide the least restrictive atmosphere. Working with the school system to identify your child's needs and adjustments can

be difficult. This is a collaborative approach that may need negotiation with the school.

With oversight from Autism Speaks, the legal firm Goodwin Procter LLP created a guide on your child's educational rights and privileges. You can appeal if the IEP doesn't satisfy your child's requirements. Your child's IEP is reviewed and updated annually, but you can request updates to ensure your child is reaching their goals.



# About the authors



# Julie Sheard

## Special Education Teacher

Julie Sheard worked for over 15 years with children, adolescents, and adults with autism spectrum disorder to build meaningful relationships and implement research-based methods to improve their quality of life. She graduated from the University of California, Santa Cruz. Julie lives in California with her husband and son.



# Katelyn Morris



## Board Certified Behavior Analyst

Katelyn became a BCBA in 2017, after spending several years working with children and families across the US. Her primary focus is to include clients in their goal-planning using frameworks like ACT and on family and parent coaching. She loves meeting new people, crocheting, and spending time with her family and pets in their rural Pennsylvania home.



# Miriam

## Forta Parent Ambassador



Miriam spent ten years working in the non-profit industry in various roles where she provided her expertise in fundraising and advocating for children's causes. After expanding her family, two of her children, twins, were diagnosed with autism - she then focused her efforts on becoming the best advocate and parent she could for her five children.

Miriam joined Forta in April 2022 as Parent Ambassador and provides her experience as the parent voice - hoping families receive the very best care that they deserve.



# About Forta

## Who we are, how we got started, and our mission

Forta is set to revolutionize ABA therapy for children on the autism spectrum by training parents in our expert-developed Parent Training course to provide care to their children at home. We strive to provide families with the very best support and tools they need to help their child thrive.

By taking our free 40-hour online course, you will be certified to work as an RBT for your child and beyond. With support from Forta's world-class clinical and training team, you can become the care your child needs. Reduce meltdowns, develop new ways to communicate and achieve your goals with your child with our program's guidance.





### How Forta was started

Forta was founded by Ritankar Das, PhD and his team in 2021.

The inspiration for Forta came to Ritankar after he saw firsthand how challenging it was for his cousin with autism to receive the quality care he required.

Ritankar recognized that the autism community has a strong need for greater access to treatment, and stepped up, knowing he could really help. He soon put together a team of highly skilled and customer-obsessed professionals, who began working on building our training course, support platform and as a result, expanding access to ABA therapy. This is how Forta was born.

### Our mission

Our mission is to clear the pathway to quality care for all families affected by autism. Equipped with a team of expert clinicians and modernized by its proprietary clinical platform, Forta is uniquely positioned to train every parent to deliver a high standard of care.

From the very beginning of the company, it has always been about the customer. Forta's leadership and teams have all been carefully screened for cultural fit so that only the most customer obsessed and mission aligned members come together to create a real impact within the autism community.



# Acronym glossary

## AAP

American Academy of Pediatrics.

## AAPD

American Association of People with Disabilities.

## ABA

Applied Behavior Analysis: a science dedicated to the understanding and improvement of human behavior. ABA differs from other fields in its focus, aim, and methods.

## ABC

Autism Behavior Checklist: is a checklist of non-adaptive behaviors; capable of providing how an individual “Looks” in comparison to others. This checklist reflects an individual’s challenges to respond appropriately to daily life situations.

Babbling - Typically by six to nine months, a child begins to vocalize repeated consonant-vowel combinations, like “ba-ba-ba,” “da-da-da,” called babbling. As vocal development continues, babbling sounds take on the characteristics of adult speech even though the child may not have specific meanings in mind. Babbling precedes real speech, and is necessary in the process of learning to talk.

## ABLLS

Assessment of Basic Language and Learning Skills: the assessment of basic language and learning skills (ABLLS, often pronounced «ables») is an educational tool used frequently with applied behavior analysis (ABA) to measure the basic linguistic and functional skills of an individual with developmental delays or disabilities.

**ACA**

Affordable Care Act.

**ADA**

American with Disabilities Act.

**ADOS**

Autism Diagnostic Observation Schedule : the instrument considered to be the current gold standard for diagnosing ASD and, along with information from parents, should be incorporated into a child's evaluation. Although a diagnosis of ASD is not necessary to get intervention, in some states the differences in the services provided to children with and without a diagnosis of ASD can be huge. Once a child has had a diagnostic evaluation and is determined eligible for services, additional assessments may be completed to better understand the child's strengths and needs to plan intervention goals and strategies.

**ASD**

Autism Spectrum Disorder (s).

**BCaBA**

Board Certified Associate Behavior Analyst: this level of certification requires an undergraduate degree, several courses related to Behavior Analysis, less than a year of supervised practice, and passing an International Exam in behavior analysis. BCaBAs who wish to provide supervision must complete additional training and continuing education requirements.

**BCAT**

Board Certified Autism Technician.



**BCBA**

Board Certified Behavior Analyst: individual with a graduate-level certification in behavior analysis, who is trained to provide and supervise behavior analysis. Often it is a BCBA who supervises individuals providing ABA. Neither ABA nor BCBA, by definition, is Autism specific.

**BCBA-D**

Board Certified Behavior Analyst - Doctorate: a doctoral designation for Board Certified Behavior Analysts with doctoral training in behavior analysis — Board Certified Behavior Analyst-Doctoral (BCBA-D). It is not a separate credential, and it does not grant any special privileges above or beyond the BCBA credential. Professionals who are credentialed at the BCBA-D level function in the same capacity as a BCBA.

**BIP**

Behavior Intervention Plan.

**BMP**

Behavior Management Plan.

**CARS-2**


Childhood Autism Rating Scale, Second Edition: a behavior rating scale intended to help diagnose autism. The childhood-autism rating scale was designed to help differentiate children with autism from those with other developmental delays, such as intellectual disability. It helps to identify children with autism and determine symptom severity through quantifiable ratings based on direct observation for ages 2 years and up.

**CDC**

Center for Disease Control and Prevention.

**CHIP**

Individual's Health Insurance Program.



<b>CMS</b>	Centers for Medicare and Medicaid Services.
<b>DD</b>	Developmental Disabilities.
<b>DSM-V</b>	Diagnostic and Statistical Manual of Mental Disorders (5th edition) by the American Psychiatric Association.
<b>DTT</b>	Discrete Trial Training.
<b>ECI/EI</b>	Early Childhood Intervention/Early Intervention: a support system designed for children with developmental delays or disabilities and their families. It is a system of coordinated services designed to promote a child's developmental growth and the ability to cope with disabilities.
<b>EHB</b>	Essential Health Benefits.
<b>EIBI</b>	Early Intensive Behavioral Intervention: is a treatment approach that is based upon the principles of applied behavior analysis (ABA) and the research of Ivar Lovaas and colleagues at the UCLA Young Autism Project. Typically involves 20-40 hours of individual ABA instruction per week, beginning at age 4 years or younger and lasting 2-3 years.
<b>EPO</b>	Exclusive Provider Organization.
<b>FBA</b>	Functional Behavioral Assessment.
<b>HMO</b>	Health Maintenance Organization.



## HIPPA

Health Insurance Portability and Accountability Act is a law that protects a patient's privacy.

## IEP

An Individualized Education Plan is the individualized curriculum plan that school age children have if they are in special education. An IEP is a legal document, and the IEP process should be taken very seriously and with much consideration for the child's future. If the child is under 3 years old and receiving services they may have an IFSP, which is an Individual Family Services Plan.

## IFSP

Individualized Family Service Plan is the birth to 3-year-old equivalent to the Individualized Education Plan. A document created between the parent(s) of a child with special needs and early intervention professionals to outline goals for the child's development.

## IPOS/ISP

Individual Plan of Service (IPOS) or Individual Service Plans (ISP): provide enhanced and detailed information that facilitates methodical and concise individual plan-building. Agencies can use ISPs to plan, organize and implement the Individual Plan of Service for everyone in a HIPAA compliant manner. The ISP module includes program definition, data collection and report generation which offers an effective tool for goal tracking.

## M-CHAT-RT

Modified Checklist for Autism in Toddlers: a scientifically validated tool for screening children between 16 and 30 months of age that assesses risk for autism spectrum disorder (ASD).

**MOOP**

Maximum Out-of-Pocket.

**MSEL**

Mullen Scales of Early Learning: for assessing cognitive and motor ability. Five scales - Gross Motor, Visual Reception, Fine Motor, Expressive Language, and Receptive Language - are used for targeting strengths and weaknesses in children.

**NCD**

National Council on Disability.

**NET**

Natural Environment Teaching: is a type of ABA where learning occurs incidentally in the natural environment, such as at the bus stop, in the tub, or during dinner. NET is more meaningful and a higher quality teaching approach because it occurs around natural events, such as play.

**NT**

“Neurotypical” is a term used by many individuals with autism to describe people who do not have autism. It basically refers to someone who does not have neurological difficulties.

**OEP**

Open Enrollment Period.

**OT**

Occupational Therapy: Professional services offered to assist with self-help skills, adaptive behavior, and sensory, motor, and postural development.

**PDD**

Pervasive Developmental Disorder.

**PDD-NOS**

Pervasive Developmental Disorder – Not Otherwise Specified.





## PEAK

Promoting the Emergence of Advanced Knowledge: PEAK module contains an assessment for evaluating the presence or absence of 184 skills that serve as the foundations for language and cognition. The latter two modules also contain pre-assessments which are designed to evaluate abstract relational abilities.

## PECS

Picture Exchange Communication System (PECS): is a communication system for functionally non-verbal individuals. The approach is designed to help young children with autism learn to initiate requests and communicate their needs. PEG is an ABA-based method.

## POS

Point of Service.

## PPO

Preferred Provider Organization: in a preferred provider organization (PPO), a list of a network of specialists is available to you, but you can still gain some advantages if you go outside of it.

## PT

Physical Therapy: professional services that help enable bodily movement and helps prevent onset of mobility difficulties.

## RBT

Registered Behavior Technician: a paraprofessional who practices under the close, ongoing supervision of a BCBA, BCaBA, or FL-CBA. The RBT is primarily responsible for the direct implementation of behavior-analytic services. The RBT does not design intervention or assessment plans.

<b>SLP</b>	Speech-Language Pathology: the specialized practice of analyzing communication disorders as well as disabilities pertaining to the mouth, such as swallowing disorders.
<b>SPED or SE</b>	Special Education.
<b>VB-MAPP</b>	Verbal Behavior Milestones Assessment and Placement Program: is an assessment, skills-tracking system, and curriculum guide to assess the language, learning and social skills of children with autism or other developmental disabilities. A strong focus of the VB-MAPP is language and social interaction, which are the predominant areas of weakness in children with autism.
<b>Vineland-11</b>	Vineland Adaptive Behavior Scales, Second Edition: measures the personal and social skills of individuals from birth through adulthood.

