

Getting an Autism Diagnosis

A Step-by-Step Guide for Parents



**ACTION
BEHAVIOR
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Introduction

Have you noticed your child having trouble with things like talking, playing with others, or making eye contact? These behaviors could be early signs of autism. Recognizing these signs is important because it is the first step toward helping your child get an autism diagnosis.

An autism diagnosis can give parents clarity and open doors to resources that better address their child's needs. The earlier a child receives an autism diagnosis, the sooner they can begin life-changing interventions like applied behavior analysis (ABA) therapy.

This guide is here to help you make the best decisions for your child. At Action Behavior Centers, we're committed to empowering families with the knowledge, tools, and expert support they need to confidently navigate this journey.



Overview of autism spectrum disorder (ASD)

Autism spectrum disorder is a developmental condition that affects how people learn, behave, and interact with others. Children with ASD may have challenges with social interactions, such as making eye contact, communicating verbally and nonverbally, and understanding social cues. They may also have specific, intense interests or engage in repetitive behaviors. In some cases, children with ASD may unintentionally hurt themselves.

Autism spectrum disorder is an umbrella term that includes a diverse range of signs and symptoms and can affect people differently. Some people with autism may require significant, daily support. However, many people with autism can live independent lives with minimal support.

Autism signs & behaviors

Autism can show up in different ways, often becoming noticeable when a child is still very young. Spotting early signs can help families get the support they need sooner.



According to the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*, a manual that healthcare providers use to diagnose certain conditions, common signs and behaviors of autism may also include:¹

- Difficulty understanding social cues or nonverbal communication, such as facial expressions and gestures
- Echolalia (*repeating words or phrases*)
- Intense focus on specific topics or objects, often to the exclusion of other interests
- Hypersensitivity or hyposensitivity to certain sensory inputs, such as loud noises and bright lights
- Preference for specific sensory experiences, like particular textures or sounds

Developmental milestones by age

Autism might look different depending on your child's age. How your child communicates, behaves, learns, and moves says a lot about whether they are meeting appropriate developmental milestones.

Developmental milestones: Skills or abilities that most children can do by a certain age. They help parents and doctors understand how a child is progressing compared to the majority of children their age.



(1) American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Publishing, 2013.

The following are typical developmental milestones by age, according to the Centers for Disease Control and Prevention (CDC):²

18 months

- Looks to see if a caregiver is nearby, helps with getting dressed, and points at objects.
- Uses a few words and follows simple directions, like "Give it to me."
- Imitates chores and engages in basic play, like pushing a toy car.
- Walks independently, scribbles, and tries to feed themselves with fingers or a spoon.



2 years

- Notices when others are upset and looks to adults for guidance in new situations.
- Uses simple two-word phrases, like "More milk."
- Points to objects in books, waves, and blows kisses.
- Holds objects with both hands, runs, kicks a ball, and walks up stairs.



3 years

- Notices and joins other children in play.
- Engages in two-way conversations, asks "who," "what," "where," "when," and "why" questions, says their first name, and speaks clearly most of the time.
- Draws circles, strings items together, dresses partially, and uses a fork.
- Calms down within 10 minutes after separation from a caregiver.



(2) Centers for Disease Control and Prevention. "Developmental Milestones." Last modified May 8, 2024. <https://www.cdc.gov/ncbddd/actearly/milestones/index.html>.

4 years

- Engages in pretend play, seeks out playmates, comforts others, and adapts behavior based on the setting.
- Forms sentences of four or more words, repeats parts of songs or stories, discusses daily activities, and answers simple questions.
- Recognizes colors, predicts story outcomes, and draws a person with three or more body parts.
- Catches a ball, serves food with supervision, unbuttons buttons, and holds writing tools properly.



5 years

- Follows game rules, takes turns, answers questions about books, and recognizes simple rhymes.
- Helps with simple chores like matching socks.
- Counts to 10, uses words to talk about time, and writes or recognizes letters.
- Buttons clothing.
- Hops on one foot.



How common is autism?

Autism is relatively common. According to the CDC, approximately 1 in 36 children in the United States age 8 and younger are diagnosed with autism spectrum disorder. Boys are four times more likely to be diagnosed with autism than girls. Autism rates are consistent across racial, ethnic, and socioeconomic groups.³

The number of autism diagnoses has grown over the years. This is partly because people are more aware, doctors have better tools to diagnose, and the definition of autism has expanded. As a result, more children are being identified and getting the support they need!

<3> M. J. Maenner et al. "Prevalence and Characteristics of Autism Spectrum Disorder among Children Aged 8 Years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020." *Morbidity and Mortality Weekly Report Surveillance Summaries* 72, no. SS-2 (2023): 1–14. <https://doi.org/10.15585/mmwr.ss7202a1>.

Step 1: Talk to your child's pediatrician

Your pediatrician is usually the first person to talk to if you're concerned about your child's development. During your visit, share the behaviors you've noticed. They can look for early signs of autism and may suggest seeing a specialist if needed.

It might feel intimidating to bring up concerns, but your pediatrician is there to help! Before your appointment, write down specific behaviors you've observed and ask about an autism evaluation.

On **page 16**, you'll find a list of helpful questions to ask your pediatrician.



Autism screening tools & questionnaires

A developmental screening is one of the first steps in helping to evaluate if a child might have autism. The American Academy of Pediatrics (AAP) recommends screening all children for ASD during regular well-child visits at 18 and 24 months.⁴ During these visits, your pediatrician may use a special test to screen your child, watch how they behave, and ask you questions about their development.

Doctors often use tools like the Modified Checklist for Autism in Toddlers (M-CHAT) for toddlers or the Childhood Autism Spectrum Test (CAST) for older children. These tools can help identify children who might be at risk for autism and guide the next steps for further evaluation and intervention.

For Toddlers – **Take The M-CHAT**

For Older Children – **Take The CAST**

(4) American Academy of Pediatrics. "Autism." Last modified April 5, 2023. https://www.aap.org/en/patient-care/autism/?srsltid=AfmBOoozbGjKjU_w_CIPMVOqkq5QjLtd-jbE7r8Bbzh19w6Y0vnUYwkW.

The earlier, the better

Research shows that identifying and treating autism early can help a child's behaviors and skills development over time.⁵ Early diagnosis is crucial for accessing important services, like ABA therapy.

In some cases, doctors can diagnose autism before a child turns 2 years old. Early intervention programs, such as ABA, speech therapy, and occupational therapy, can sometimes start before age 2. At this age, a child's brain is still developing and can adapt more quickly, making early treatment especially effective. Early intervention gives children a better chance to learn and grow!⁶

Early intervention for autism can help children build foundational life skills and reach important developmental milestones. It can also improve their chances of starting school on time with their peers. In fact, some children progress so well with early treatment that by the time they reach school age, they are functioning at the same level as their neurotypical classmates.

These children often have the following in common: **they were diagnosed and treated early.**

Step 2: The autism diagnostic process

If your pediatrician notices signs of autism during an initial screening, they may refer your child to a specialist for a more in-depth evaluation. Specialists are professionals with advanced training who can assess your child's development in greater detail.



(5) L. Zwaigenbaum et al. "Early Intervention for Children with Autism Spectrum Disorder under 3 Years of Age: Recommendations for Practice and Research." *Pediatrics* 136, Suppl. 1 (2015): S60–S81. <https://doi.org/10.1542/peds.2014-3667E>.

(6) Catherine Lord et al. "Autism from 2 to 9 Years of Age." *Archives of General Psychiatry* 63, no. 6 (2006): 694–701, <https://doi.org/10.1001/archpsyc.63.6.694>.

At Action Behavior Centers, we partner with a trusted network of specialists who are experts in diagnosing autism spectrum disorder. Some of the specialists your pediatrician may refer you to include:

- **Developmental pediatrician:** A physician who specializes in children's neurodevelopmental disorders, such as autism, ADHD, and other learning or behavioral challenges.
- **Psychologist:** A doctorate-level mental health professional who evaluates a child's emotional, social, and behavioral development.
- **Pediatric neurologist:** A physician who focuses on brain and nervous system disorders in children, which can sometimes be linked to autism.
- **Psychiatrist:** A medical doctor who diagnoses and treats mental health conditions such as autism, and is able to prescribe medications for conditions such as ADHD and anxiety.

Types of autism evaluations

There are several types of tests that specialists use to figure out if a child has autism. These tests measure important areas of a child's development, like communication, interactions with others, and behavior. The assessments typically involve activities with the child and observations from parents, which helps specialists gain a deeper understanding of the child's strengths and challenges.



Action Behavior Centers offers the following autism diagnostic tests across our regions:

Autism Diagnostic Observation Schedule, Second Edition (ADOS-2)

The ADOS-2 is one of the most trusted tools for helping providers identify autism. It uses a natural, play-based approach—making it feel less like a doctor’s appointment and more like playtime!

Action Behavior Centers provides the ADOS-2 as a **no-cost** service to the community.



A Gold Standard

The ADOS-2 is considered a “gold standard” method for helping determine if a child has autism spectrum disorder. This tool is backed by research and helps clinicians reliably and accurately identify autism symptoms regardless of the child’s age or developmental level.



Play-based

Children have fun participating in the ADOS-2—it’s not like going to the doctor! During the 40- to 60-minute assessment, our clinicians engage in play and activities tailored to your child’s age and developmental abilities.



Scoring

After the assessment, scores are calculated to indicate how closely the child’s behaviors in key areas align with autism characteristics. These scores, along with a summary, are sent to the child’s pediatrician or referring provider to support their diagnostic process and recommendations.

Initial Diagnostic Evaluation (IDE)

This evaluation, led by a psychologist, typically involves a developmental interview, parent-report questionnaires, and direct observation of your child’s behaviors. The evaluation lasts approximately 2 to 3 hours.

Contact us to learn more about the diagnostic evaluations offered in your region.

Common steps involved in the diagnostic process

A typical evaluation to see if a child has autism includes several important steps:

- **Observation:** Specialists watch how your child plays and interacts with you and others. This helps them understand your child's social skills and behavior patterns.
- **Medical history and physical exam:** Your medical doctor or team will ask about your child's medical history and do a physical exam to make sure there are no medical issues affecting their development.
- **Behavioral history:** Specialists will gather information about when the behaviors of concern started. Signs of autism are usually present early on, but they might not be clear until your child gets older.⁷
- **Review of records:** Your medical doctor or team will look at past medical records, school evaluations, and other assessments to see what type of support your child has already received.
- **Developmental assessment:** Your child's development will be checked in areas like language, social skills, and thinking abilities. This helps specialists evaluate how your child is progressing in these important areas.
- **Hearing test:** If your child has any speech or language delays, or if there are concerns about ASD, a hearing test may be done to rule out hearing problems.
- **Language and communication evaluation:** Specialists will check how well your child understands and uses language. They will also observe how your child communicates in social situations and how clear their speech is.

After the evaluation, the specialist will discuss the results with you. A diagnosis of autism can be made based on how your child's behaviors align with the criteria outlined in the *DSM-5* and whether these behaviors significantly impact their daily life.

(7) American Academy of Pediatrics. "Identification, Evaluation, and Management of Children with Autism Spectrum Disorder." *Pediatrics* 145, no. 1 (2020): e20193447, <https://doi.org/10.1542/peds.2019-3447>.

Step 3: After diagnosis

Hearing that your child has a lifelong developmental disorder can be challenging. It's normal for you, other caregivers, and family members to feel sad or worried about what the future may hold.



However, it's important to remember that many children with ASD make great progress. Many thrive in regular classrooms, build close relationships with family and friends, and gain independence as adults.

Although a diagnosis of autism might change your expectations of parenting, children with ASD can achieve so much with the right support and opportunities.

- 72.4% of students with ASD complete high school and receive a diploma.⁸
- 60% of autistic youth who received vocational rehabilitation training in high school have a job upon graduation.⁹
- Some of the most influential people in the world have autism, including: Albert Einstein, Andy Warhol, Elon Musk, Satoshi Tajiri, Sia, Mozart, Charles Schulz, and Jerry Seinfeld.

Early intervention can significantly boost the development of a child with autism. Research shows developmental therapies or services through their school often help children improve in areas like IQ, communication, and social skills.

If your child is already receiving early intervention but a screening shows a possible risk for autism, it's important to get a full evaluation. A diagnosis can open the door to more autism-specific services. Be sure to share the diagnosis with your early intervention provider or your child's school.

(8) National Autism Data Center, A.J. Drexel Autism Institute. "How Often Do Students (Receiving Special Education for Autism) Leave High School with a Diploma?" *Autism by the Numbers*. Last modified February 2024. <https://nationalautismdatacenter.org/exit-status/>.

(9) Autism Speaks. "Executive Summary: Autism by the Numbers," Last modified 2023. https://www.autismspeaks.org/sites/default/files/ABN_Executive_Summary_2023.pdf.

Finding the right autism care providers

Choosing the right specialists is an important step in your child's autism journey. Look for providers who have lots of experience with autism spectrum disorder and who are highly recommended by other parents or professionals. Feeling confident and comfortable with your child's care team can make a big difference in your child's progress.

At Action Behavior Centers, our dedicated team is passionate about helping children with autism grow and thrive. Our team includes Board Certified Behavior Analysts (BCBAs), Registered Behavior Technicians (RBTs), and other professionals specializing in applied behavior analysis therapy. Every member of our team is committed to helping children with autism live happy, fulfilling lives.



Board Certified Behavior Analyst (BCBA): A professional trained in applied behavior analysis (ABA) who assesses behavioral patterns and designs personalized strategies to help children with autism learn new skills and make positive changes in their lives.



Registered Behavior Technician (RBT): A highly-trained paraprofessional who works directly with autistic children to implement personalized therapy plans under the supervision of a BCBA. They play a critical, hands-on role in creating an engaging environment for learning and growth.



ABA therapy: the best therapy for autism

Applied behavior analysis therapy is a gold standard in behavioral therapy for children on the spectrum. It uses play-based techniques and positive reinforcement to teach children practical skills for everyday life. ABA therapy can help children with autism develop communication, social, and other essential skills while addressing challenging behaviors, such as aggression, that might make learning harder.

Your child's designated BCBA will work closely with your family to determine which skills to focus on and set specific goals based on your child's unique needs. Research shows that younger children who participate in more ABA therapy hours each week tend to reach their goals more quickly.

Our ABA programs are individualized because every child with autism is different. Your child's BCBA will provide a clinical recommendation for the number of hours of ABA therapy they believe your child needs to make the most progress.

Step 4: Insurance coverage for autism early intervention

Many insurance plans cover diagnostic evaluations and therapy services for autism, including ABA therapy. Before scheduling evaluations or therapies, contact your insurance provider to check what is covered under your plan. Be sure to ask about coverage for ABA therapy, speech therapy, and occupational therapy.

Because the *DSM-5* classifies all autism diagnoses under one umbrella condition (autism spectrum disorder, or ASD), insurance billing practices may vary.

At Action Behavior Centers, our insurance specialists are here to assist you in verifying your benefits, understanding copays, and managing out-of-pocket expenses so that you can focus on your child's needs.



Your child's future is **bright**.

After receiving an autism diagnosis, it's important to begin planning for your child's future. This involves setting goals, building a support network, and finding helpful resources.

Being your child's advocate is a lifelong commitment. As you move forward, create a plan that prioritizes their specific needs. Always remember that you are their strongest voice and biggest supporter.

At Action Behavior Centers, we are more than just an autism therapy center—we're a supportive community. We welcome you and your child with open arms and are here for every milestone, every challenge, and every success.

We promise to **celebrate** your child's individuality

We promise to **help** your child reach milestone moments

We promise to **advocate** for your child in everything we do

We promise to **honor** your family's dynamics and values



Resources

Checklist for parents

- ☐ Watch and write down your child's behaviors and milestones.
- ☐ Make an appointment with your child's doctor to talk about your concerns.
- ☐ Follow through with any screenings and tests the doctor recommends.
- ☐ Get referrals to specialists if needed.
- ☐ Check your insurance coverage to make sure early intervention services for autism are covered.
- ☐ Find diagnostic assessment services to help formally evaluate for autism.
- ☐ Join a support group or connect with other parents to exchange advice and resources.
- ☐ Research therapy options such as ABA therapy.
- ☐ Set up a schedule of regular follow-ups with your child's doctor or specialists.
- ☐ Keep a folder or binder with important medical and educational records to ensure easy access when needed.

Questions to ask the pediatrician:

- How do I know if my child is reaching developmental milestones?
- How can I tell if my child needs a full autism evaluation?
- What happens during the diagnostic process?
- Do we need to see any specialists?
- What early intervention options are available if my child has autism?
- How can I plan for my child's care and support in the future?
- How often should we schedule check-ups or follow-ups?
- Are there any resources or support groups for families in our situation?
- How can I work with my child's school or teachers to support them?

Autism tips for parents

As you move forward, remember that you're not alone! Staying informed and connected with other autism families in your community is a great way to share experiences and learn about valuable autism resources near you.

- **Reach out to local resources:** Contact your health care provider, local health department, school, or autism advocacy group to learn about special programs and services in your area.
- **Join an autism support group:** Sharing experiences with others can help you learn about treatment options, programs, and resources for people with autism and their caregivers.
- **Stay organized:** Keep copies of health care reports and evaluations. These documents can be important when applying for programs or services for your child.
- **Document important conversations:** When meeting with healthcare providers or teachers, it's a good idea to take notes. This helps you review the details later and make the most informed decisions about your child's care.

Continue learning



**ABA and
school-readiness**



**Simple tips for
teaching hygiene
skills**



**Autism-friendly
travel hacks**

** No ABC patients or families are featured in this e-book.*