

## IDENTIFYING AUTISM

An informational guide for parents of children suspected to have Autism Spectrum

Disorder



If you've received this packet, that means you or your child's pediatrician suspect they may have Autism Spectrum Disorder. Contained in this packet you will find helpful resources, answers to common questions, and, we hope, peace of mind as you navigate this journey.



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### **WHAT IS AUTISM?**

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition of varying severity levels with lifelong effects impacting many facets of life. Individuals with ASD may have challenges in social situations, with communication, and display restrictive and repetitive behaviors. Autism is a spectrum disorder, meaning symptoms can present in a wide variety of ways and severity.

According to the Centers for Disease Control and Prevention (CDC) report in 2020, 1 in 36 children are diagnosed with Autism. It is four times more common among boys than among girls and occurs across all racial, ethnic, and socioeconomic groups.





# WHAT ARE THE SIGNS OF AUTISM?

Autism Spectrum Disorder (ASD) looks different from person to person and affects communication, behavior, and social interactions. Recognizing the early signs of Autism can lead to earlier diagnosis and intervention, which can significantly improve outcomes for children with Autism. If you have a concern that your child may have Autism, it is important to speak with your pediatrician for the appropriate screenings and referrals for testing and evaluation.

- Delayed speech or language skills
- Lack of eye contact
- Not responding to their name
- Preferring to play alone
- Difficulty understanding personal space or "stranger danger"
- Difficulty interpreting facial expressions or other social cues
- Repetitive movements such as rocking, spinning, or hand-flapping
- Difficulty with transition or changes in routine
- Very focused or intense interests
- Over or underreacting to sensory stimuli
- Motor skill delays
- Lack of pretend play or imitation skills

This is not a complete list of signs and even if your child exhibits some of these concerns, does not mean they have Autism. Speak to your pediatrician about your concerns and screening for Autism.



### **AUTISM LEVELS**

The current edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) breaks Autism Spectrum Disorder into three severity levels. These levels are meant to identify the level of support the individual may require. Most diagnostic evaluators today assign a level to the Autism diagnosis.

### **Requiring Support**

Children with Level 1 Autism often have many skills that are near or at the same level as their peers, but may also face challenges in making friends, understanding social rules, handling changes in their routine, or managing their own schedule. These children can do many things on their own, and can do even more with some supports in place.





## Requiring Substantial Support

Children with Level 2 Autism experience challenges in their communication and social skills. They may become upset if they become overwhelmed and may experience sensitivity to loud sounds or bright lights. They require substantial support to navigate these challenges and learn new skills.

## Requiring Very Substantial Support

Children with Level 3 Autism require the most support to be successful. They likely have significant delays in their communication and social skills, may experience frequent or high-magnitude behavior challenges, and likely require a lot of support throughout the day.



### HOW IS AUTISM DIAGNOSED?



- Your child will begin receiving screenings at 18 months old as part of your state's Early and Periodic Screening, Diagnostic, and Treatment benefits or as part of their well-child visits.

  Your child's pediatrician may use a tool like the M-CHAT, ASQ, or STAT.
- If the screening tool indicates your child has symptoms associated with Autism, your child's pediatrician will refer you to a specialist who can complete the comprehensive evaluation for Autism Spectrum Disorders. This could be a Developmental Pediatrician, Clinical Psychologist or Psychiatrist, or Child Neurologist.
- The evaluation will occur with the specialist, typically over a series of appointments. During these appointments the evaluator will ask you questions about your child's developmental history, will spend some 1:1 time with your child, and review their findings with you.



## SCREENING FOR AUTISM RISK

Some families may not want to wait until they can schedule a visit with their pediatrician to discuss their concerns. If your child is missing certain milestones, losing skills they once had, or is displaying characteristics of Autism Spectrum Disorder, you can take an online screening yourself!

### **The Modified Checklist for Autism in Toddlers** *M-CHAT*

The M-CHAT is a parent-completed questionnaire that assesses a child's potential risk for Autism Spectrum Disorder. You will be prompted to answer a series of 20 questions about your child's development and behavior. Once completed, these results should always be shared and discussed with your child's pediatrician who will determine what next steps to take. These next steps may include referring you to a specialized provider who can conduct further evaluations for Autism.



#### **Limitations of the M-CHAT**

While the M-CHAT and other similar screening tools are instrumental parts of the diagnostic process, it has a couple of limitations to keep in mind.

- 1 The M-CHAT is NOT a diagnosis.
- The M-CHAT is only intended for toddlers between 16 and 30 months of age.



## EDUCATIONAL VS. MEDICAL AUTISM



#### **MEDICAL**

A medical diagnosis of Autism Spectrum Disorder means the evaluation, testing, and conclusions were conducted by a medical or behavioral health professional. This is typically a Developmental Pediatrician, Licensed Child Psychologist, Neurologist, or similar provider who has been trained in conducting evaluations and diagnosing using the criteria found in the DSM-5. These type of diagnoses are important if you wish to have Autism Services like ABA Therapy through your health insurance or Medicaid plan.

#### **EDUCATIONAL**

Educational "diagnoses" are conducted by school professionals in order to qualify a child for Special Education and related services in public school under the Individuals with Disabilities Education Act (IDEA). These school professionals are qualified to conduct educational assessments as they relate to school-based eligibility and services. This type of evaluation is important if your child needs extra supports and accommodations during their school day or if you feel they require an Individualized Education Plan (IEP) or 504 Plan. These type of evaluations are not accepted by your insurance or Medicaid for medical services outside of the school system like ABA Therapy.







# WHAT TO DO POST-DIAGNOSIS



#### **Breathe**

Whether this information is a surprise or something you suspected for a while, it is normal to feel a range of emotions and need a few days to process. So take a few deep breaths and take it one day at a time! When you are ready, consider some of the following next steps.

- Join an online or in-person Autism parent group
- Research different therapies including ABA, Speech, and OT.

#### **Communicate**

Autism support is a team effort, so share your child's Autism Diagnosis information with the other providers on their team. This includes doctors, daycare, school, therapists, and anyone else who provides supports to your child.

### **Get Organized**

The diagnostic report will be an important document for you to have. There are many providers who may need a copy of the report including doctors, teachers, and therapists. If you were given a paper copy of the report, we recommend scanning a clear PDF of the document and digitally storing it somewhere you can easily access it.

#### **Reach Out**

Be this to a trusted friend or family member, a support group, or to Inner Circle Autism Network for ABA Therapy, connecting with those around you will ensure you feel supported as a parent. There are many in-person and online groups of parents who have been through this before, so remember - you are NOT alone!



Does my child need a diagnosis to get services?

What services are available if my child is diagnosed with Autism?

If I am unsure about the diagnosis, should I get a second opinion?

How long does the diagnosis process take?

## FAQ

Answers to common questions regarding Autism diagnoses.

Some services, like ABA Therapy, will require your child to have received a medical diagnosis of Autism while other therapies like Speech and OT may be able to provide services without one. An official diagnosis can be the key to opening the door to many types of services and resources.

An Autism diagnosis is often a medical necessity requirement for services like ABA Therapy. It may also help guide the conversation with your child's school district in accessing Special Education services. Depending on your state, it may also grant you access to waivers, grants, or other resources.

Getting a second opinion after an Autism diagnosis is a very personal decision. Parents unsure about their child's evaluation results should reach out to their child's pediatrician or the person who conducted the evaluation for clarification on anything they do not understand.

Many providers have waitlists for Autism evaluation appointments and these waitlists can often be months long. The actual evaluation typically takes place over 2-3 different appointments, which can be spread out over many weeks. From first appointment to receiving a report could take anywhere from a few weeks to a few months depending on the evaluator.



## What about virtual diagnosing?

# Does my child need an "updated" diagnosis?

## **FAQ CONTINUED**

In the last few years, many telehealth providers have begun providing virtual diagnosis appointments. These providers often have very short waitlists and offer evaluations in the comfort of your home in most cases. While convenient, not all insurance plans work with virtual evaluators and some do not accept the diagnosis for things like prior authorization for ABA Therapy. Reach out to your insurance plan prior to scheduling with a virtual evaluator.

There are many scenarios in which you may be asked to have your child re-evaluated for Autism. While Autism is a lifelong diagnosis, you may encounter a request from your provider to update the diagnosis. Some of these instances include:

- Some insurance plans have time limits on how recently the child needs to be evaluated. Most commonly this could be anywhere from every 24-48 months.
- Diagnosis was done in a state with different requirements than where you currently reside and an updated evaluation is needed to secure therapy services.
- Your child's needs or symptoms have changed and your provider feels your child needs to be re-evaluated.
- You have changed to a new insurance plan that has different requirements for diagnosis.



### **NEXT STEPS**

If your child is evaluated and diagnosed with Autism Spectrum Disorder, there are many resources and supports available to you. Don't go through the journey alone and reach out to Inner Circle Autism Network or another provider of your choosing to learn about services in your area.

Read More Here





### **Contact us today!**

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