

First Signs, Next Steps: A Guide for Parents Concerned with their Child's Development

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What is Autism?

Autism Spectrum Disorder (ASD) is characterized by social-interaction difficulties, cognitive impairments, communication difficulties, and repetitive behaviors. Because Autism is a spectrum disorder, it can range from very mild to very severe and occur in all ethnic, socioeconomic and age groups. Males are four times more likely to have autism than females. Some children with autism appear to develop typically before age 1 or 2 and then plateau or suddenly regress, losing language or social skills they had previously gained. ASD can sometimes be detected at 18 months or younger. By age 2, a diagnosis by an experienced professional can be considered very reliable.



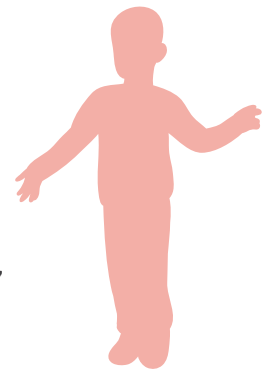
First Signs

Early signs of ASD may vary by individual. Some individuals may:

- not respond to their name or appear deaf
- not point at objects of interest
- not play “pretend” games
- avoid eye contact
- want to be alone
- show difficulty understanding other people’s feelings or their own
- have no speech or delayed speech
- reverse pronouns (e.g., says “you” instead of “I”)
- give unrelated answers to question
- repeat words or phrases over and over (echolalia)
- give unrelated answers to questions
- become upset by minor changes
- have obsessive interests
- flap their hands, rock their body, or spin in circles (stimming)
- have hyper or hypo-sensitivity to sound, smell, taste, look or feel
- have low to no social interest
- avoid or resist physical contact
- demonstrate little awareness of danger

TIP

The M-CHAT checklist is a good resource to help assess your child’s development. It is a modified checklist for autism in toddlers available at m-chat.org. It is important to note that the checklist may not detect early signs of autism and developmental delay in all children.



Next Steps

If your child is showing signs of ASD, or you are still concerned about your child's development, you are ready to take the next steps in confirming or ruling out a diagnosis.

Step 1: Call your Pediatrician

Set up an appointment with your child's doctor to discuss your concerns. Bring your M-CHAT results to your appointment and discuss any other concerns you may have.

You know your child best. Your pediatrician may have experience and expertise; however, it may be difficult for them to pick up on developmental issues as they are only observing your child for a short time. If your pediatrician doesn't notice or agree with your concerns, you can ask for a referral for a full developmental assessment. In a situation when a pediatrician will not agree, you can always contact your state health department to request a free developmental screening.

Step 2: Get an Evaluation

Once the need for an evaluation is determined by either a pediatrician, Department of Special Education in your public school system, or by the state Department of Health, be sure to have all relevant multi-disciplinary assessments

conducted (cognitive function, speech and communication, gross and fine motor, social and emotional, physical, visual and auditory) so that you can see the greatest areas of strengths and need, which will be helpful in developing a therapy plan and tracking progress. This means that several areas may be assessed by different professionals to obtain a complete, full picture of your child's development. Your child should be observed in a number of settings with different people. It is common for doctors and school systems to recommend and conduct an Autism Diagnostic Observation Schedule (ADOS), which is an instrument for diagnosing and assessing autism. The protocol consists of a series of structured and semi-structured tasks that involve social interaction between the examiner and the subject. This serves as a diagnostic tool, and helps define the need for additional assessments and intervention.



You can also get in touch with your community's early intervention (EI) program and ask to have your child evaluated. This evaluation is free of charge, won't hurt your child, and looks at his or her basic skills. Based on that evaluation, your child may be eligible for early intervention services, which will be designed to address your child's needs or delays. There are several ways to connect with the EI program in your community. You can:

- Contact the Pediatrics branch in a local hospital and ask where you should call to find out about early intervention services in your area.
- Ask your pediatrician for a referral to the local early intervention system.
- Visit the Early Childhood Technical Assistance Center's page at ectacenter.org. Click on contacts, then click "Part C Contacts" for a state listing.
- Be sure to explain that you are concerned about your child's development. Say that you think your child may need early intervention services. Explain that you would like to have your child evaluated under Part C of IDEA.



If an ASD diagnosis or developmental delay is confirmed, you are ready to join a community of caring fellow parents who understand and want to help.

Step 3: Remember These Four Words

Your child will progress. He or she is the same beautiful, amazing child you've always had and will progress in their own way, in their own time.

Step 4: Find a Support Group

It's important to know that you are not alone. Reach out to local support groups or rely on family and friends to help. Be open with them about what you are going through. Find local resources and support groups at yellowpagesforkids.com.

Step 5. Develop a Working Plan

If your child is under 3 and qualifies based on testing results and observations, he/she will receive early intervention services through the state. A family coordinator or liaison from your local Early Intervention Agency will work with you to develop an Individual Family Service Plan (IFSP). If your child is over 3 years of age, your public school district is responsible for working with you to develop an Individualized Education Program (IEP) and provide services and therapies specified in the IEP to help your child reach his/her outlined goals. Work together with your providers to develop goals based on your child's areas of needs.

If your child receives therapies at school, it is helpful to ask for consistent reports daily, weekly, or monthly, so that you are always aware of what they are working on, your child's current level of performance, and any changes being made. Every child has the right to a free and appropriate education (FAPE). The Individuals with Disabilities Education Act (IDEA) mandates a public education for all eligible children and makes the schools responsible for providing the supports and services that will allow this to happen.

IDEA specifies that children with various disabilities, including autism, are entitled to early intervention services and special education. In addition, it establishes an important team approach and role for parents as equal partners in planning for their child. It also promotes an education in the least restrictive environment. As a parent, you are entitled to be treated as an equal partner with the school district in deciding on an education plan to meet your child's needs. This enables you to be a powerful advocate for your child. It also means that you must be an informed, active participant in planning and monitoring your child's educational program and legal rights. A great resource to help you understand your legal rights and what your child is entitled to is wrightslaw.org.



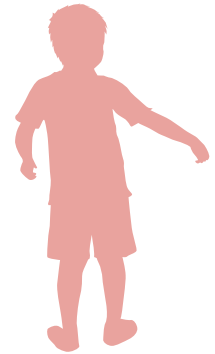
Who pays for the services?

Whether or not you, as parents, will have to pay for any services for your child depends on the policies of your state. Check with your service coordinator. Your state's system of payments must be available in writing and given to you, so there are no surprises or unexpected bills later. Under Part C of IDEA, the following services must be provided at no cost to families: Child Find services, evaluations and assessments, the development and review of the IFSP, and service coordination. Depending on your state's policies, you may have to pay for certain other services. You may be charged a "sliding-scale" fee, meaning the fees are based on what you earn. Some services may be covered by your health insurance, by Medicaid, or by Indian Health Services.

Services cannot be denied to a child just because his or her family is not able to pay for them.

Step 6. Stay Organized

Utilize a worksheet to track assessment appointments, assessments administered, and results. This will be vital in measuring progress and advocating for the services your child needs. It is also very helpful to ask for copies of all assessments and results, as well as written correspondence with schools, therapists, and doctors. Many parents find it useful to keep an e-mail folder with all electronic communications, and a 3-ring binder for paper copies of IEPs, assessments, doctor reports, etc., for easy referencing.



Sample Record-keeping Worksheet

Use the spaces below to keep a record of the conversations you have with service agencies and others regarding your child.

Problem/Topic:

Name of person or agency you talked to:

Name of your contact person (may be same as above):

Date you called: _____

Phone #: _____

Email: _____

Results of discussion: _____

Action taken (if any):

Person not helpful on this topic, but may be helpful regarding (list topics/areas/issues):

Next steps (Follow up needed):

Step 7. Find a Means of Communication

Your child may be experiencing a world where light, sound, touch, taste, and scent are amplified, leaving them feeling overwhelmed. He or she may not be able to communicate basic needs/wants such as hunger, thirst, pain, or if something is very bothersome or frightening. Behavior is a form of communication for our children. Compassion, patience, and attempting to understand what our children are trying to communicate is key. Pay attention to their environment, and what precedes any behaviors. Individuals with ASD often have significant language and communication delays. Many families find the Picture Exchange Communication System (PECS) helpful as a first step. Work with your child's Speech and Language therapist to determine whether an assistive technology device such as an iPad with communication software may be useful in helping your child to communicate. You can request an assistive technology evaluation through your school district. The evaluation should include information and recommendations for applications that best fit your child's needs. The device, apps, and training can be written into your child's IEP (Individualized Education Program).



Picture Exchange Communication System (PECS)



iPad with Communication Software

TIP

According to the Individuals with Disabilities Education Act (IDEA) Sec. 300.105 Assistive Technology:

(a) Each public agency must ensure that assistive technology devices or assistive technology services, or both, as those terms are defined in Sec. 300.5 and 300.6, respectively, are made available to a child with a disability if required as a part of the child's –

- (1) Special education under Sec. 300.36;
- (2) Related services under Sec. 300.34; or
- (3) Supplementary aides and services under Sec. 300.38 and 300.114(a)(2)(ii)

(b) On a case-by-case basis, the use of school-purchased assistive technology devices in a child's home or in other settings is required if the child's individualized education program (IEP) Team determines that the child needs access to those devices in order to receive FAPE.

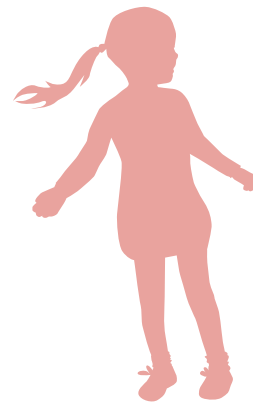
Step 8. Develop a Safety Plan

Many individuals with ASD have an impaired sense of safety and cannot effectively communicate when they need or want to go somewhere, or are feeling overwhelmed and need to get away from a certain environment. There are several key steps you can take to help prevent a wandering or bolting incident.

Some key steps:

- Safeguard your home by installing door/window chimes, a home security system, fencing
- Use visual prompts like stop signs on windows and doors
- Put identification on your child, especially for those who are non-verbal or minimally verbal

You will also want to contact your local law enforcement agency to make them aware of your child's lack of safety awareness and wandering risk. Become aware and sensitive to your child's triggers (new environments, loud noises, bright lights, fears, crowds at picnics or holiday parties, etc.), and teach safety skills, such as swimming. In the event your child does go missing, remain calm and always call 911 immediately. Law enforcement should treat each case as "critical." Immediately search areas that pose the highest threat first, such as nearby water, busy streets, train tracks and parked cars.



Safety Resources

Free personalized ID's are available through MedicAlert. Visit medicalert.org/autism.

Visit awaare.org and nationalautismassociation.org for information and free wandering-prevention tools and resources.

TOOL

Important Numbers to Customize & Keep

Doctor(s)

State Protection & Advocacy Agency: ndrn.org or 202-408-9514

Autism Information & Referral Center: 1-855-828-8476

Pharmacy

If a child with autism is missing, Dial 911, then call the National Center for Missing & Exploited Children at 1-800-THE LOST (1-800-843-5678)

School

Local Resources: yellowpagesforkids.com

Other

Poison Control: 1-800-222-1222

Step 9. Do Your Research

Become familiar with all different types of therapy and programs available in your area so that you can decide what will work best for your child. Even though you will have professionals guiding you and telling you what's available, you know your child better than anyone else. Therapies include:

Behavior Intervention: Many professionals feel that early intervention is key in treating autism, and that behavior modification techniques are crucial in a child's early years. There are several types of behavior therapy techniques, including:

- Applied Behavioral Analysis (ABA)
- Verbal Behavior (VB)
- Floortime
- TEACCH
- Son-Rise
- Relationship Development Intervention
- SCERTS

Occupational Therapy: Occupational Therapy (OT) is a health service that is concerned with an individual's ability to participate in desired daily life tasks, or "occupations," which give one's life meaning. If a person's ability to perform these tasks, which include caring for one's self or others, working, going to school, playing, and living independently is impacted by an illness, disease, and/or disability, OT can be important. OT is often paired with Sensory Integration. Have your child evaluated by an occupational therapist that is trained in sensory integration therapy and certified to perform diagnostic testing such as the SIPT (Sensory Integration and Praxis Test).

Also consider having your child evaluated by the school occupational therapist and request sensory integration support in his/her IEP.

Physical Therapy: An individual with autism spectrum disorder may benefit from Physical Therapy if they have any of the following indicators: muscle stiffness or tightness; Delay in obtaining motor skills milestones; Poor balance and coordination; Difficulty in moving through the environment; postural abnormalities; muscle weakness; pain.

Speech Therapy: Speech therapy services focus on enhancing or restoring limited or lost communicative skills or oral motor skills like swallowing. Since autism often affects speech and communication, many will need Speech Therapy to help facilitate language. Some individuals may do well with a Picture Exchange Communication System (PECS) and others may do well with augmentative communication devices.

Vision Therapy: Vision therapy is based on the fact that vision is learned. The ability to see and correctly interpret what is seen does not appear automatically at birth. It develops over a lifetime and is shaped by the experiences a person has.

Music Therapy: Music Therapy is the use of music and its elements (such as; sound, rhythm, melody and harmony) by a qualified music therapist. It can be provided in an individual or group setting.

To search for local therapists and service providers, visit: providersearch.com and yellowpagesforkids.com.

TIP

Getting ABA paid for is a challenge many families face. Look into applying for medicaid programs offered in your state for children with special needs. Contact your state's Developmental Disability Council for guidance, and remember, you can appeal insurance denials.

Step 10. Be Aware of Co-occurring Medical Issues

Research shows that many individuals with ASD have medical issues that frequently go undiagnosed and can cause or exacerbate symptoms of ASD.

These medical conditions include epilepsy, allergies, eczema, sleeping disorders, asthma, chronic diarrhea and/or constipation, feeding issues, obsessive compulsive disorder, pica (eating non-food materials), anxiety, tics, among others.

Treating these underlying medical issues can improve some of the behaviors and symptoms associated with ASD.

Patients should undergo diagnostic testing and consult with a licensed physician to develop an individualized treatment plan.

Find a physician who will not ignore medical conditions that may be contributing to the symptoms and severity of autism. There are a number of physicians in the U.S. who specialize in treating children and adults with ASD. Visit medmaps.org for a physician directory.



Gluten Free/Casein Free Diet

The Gluten Free/Casein Free Diet is the removal of all wheat protein (gluten), and milk protein (casein) from the diet.

Many parents and physicians have found that implementing the GF/CF diet relieves some symptoms associated with ASD.

For more information about the GF/CF Diet, visit gfcfdiet.com.



What is Comorbidity?

Comorbidity refers to the existence of two or more diseases or conditions in the same individual at the same time. A detailed assessment conducted by CDC demonstrated that children with autism had much higher than expected rates of all of comorbid medical conditions studied, including: eczema, allergies, asthma, ear and respiratory infections, gastrointestinal problems, severe headaches, migraines, and seizures (Kohane et al., 2012).

Last step... Stay Balanced!

The challenges of raising a child with special needs can be overwhelming. Remember it is important to set aside time to take care of yourself.

It is also important to set aside special time for siblings of your child with special needs. They may sometimes feel that attention has been shifted away from them, and it's nice for both you and your other children to set aside special time together.

