

**PACT**

Autism Resource Guide for Parents/Caregivers

As a parent, it can be overwhelming with the amount of information available when it comes to autism. You may not know where to start or who to contact, so we put together this resource guide. We encourage you to use this guide as your starting place. This guide focuses on the basics of autism, developmental milestones, who to contact for a diagnosis, different therapies offered, types of support offered in school/college/workplace, and how you can advocate for your child. If you have any further questions or need help with this process, please reach out! The team at PACT is more than happy to help you through this journey.



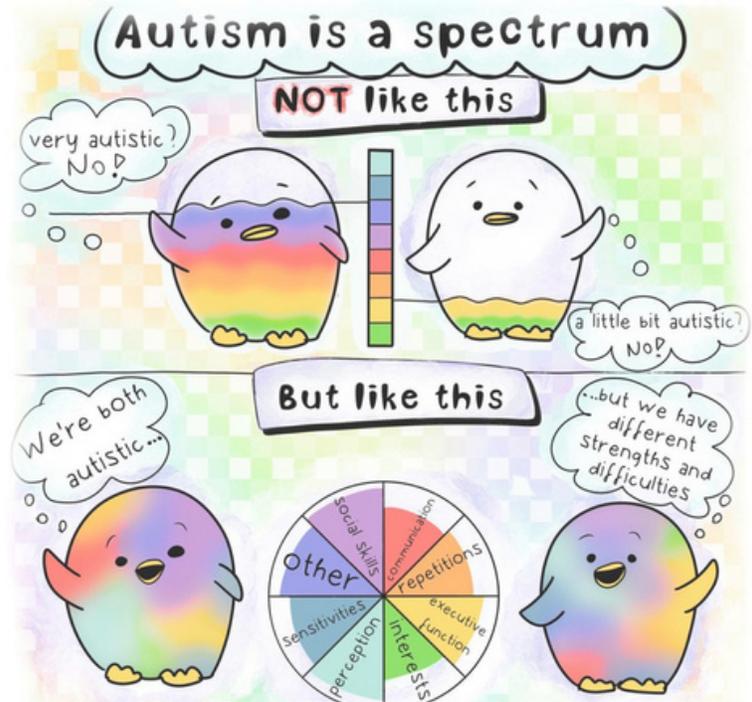
What is Autism?

Autism, or **Autism spectrum disorder (ASD)**, is a lifelong developmental journey that reflects neurodevelopment differences in the brain. While all autistic individuals are unique, they often have differences in the way they communicate, socially interact, and commonly demonstrate restricted and repetitive behaviors. Autism is present in all ages, races, ethnicities, and genders. Characteristics are presented prior to three years of age, but diagnosis can happen at any age. Many people embrace autism as an identity and celebrate unique ways of thinking.

While there is not a singular cause for autism, many environmental, biological, and genetic factors may act together to change how people develop.

Signs to look out for

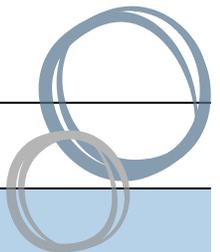
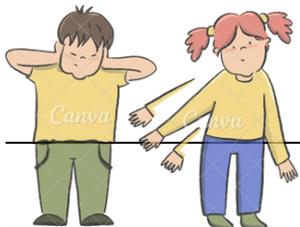
Autistic individuals embrace their differences in social communication, interactions, and interests. It is important to look at developmental milestones if you are concerned for your child. Remember, not all autistic children show all the signs. Those without autism may even show a few signs.



@autism_happy_place

You can follow your child's developmental journey by checking out these resources developed by the Florida State University Autism Institute:

- [1 - 24 months Growth Chart](#)
- [Red Flags of ASD in Toddlers](#)



Should I get a diagnosis for my child?

Although it is difficult to recognize whether a child is autistic until they are 18 to 24 months, diagnosing earlier means that they receive support in schools to reach their full potential. Many children don't receive a final diagnosis until much older, with the average age of diagnosis being 4.5 years. The American Academy of Pediatrics (AAP) recommends screening all children for ASD at the 18 and 24-month well-child visits. It is important to note that screening is not a diagnosis. Parents are encouraged to ask for a referral to a specialist (Developmental pediatricians, child neurologists, child psychologists, or child psychiatrists) for a more in-depth evaluation.

Providing a formal diagnosis for autism is based on a set of characteristics, observations, and interactions rather than a biological, genetic, or physiological test. The most commonly used diagnosis tool is **developmental monitoring**, in which an active and ongoing process of watching a child's growth takes place in addition to encouraging conversations between parents and providers about the child's skills and abilities. More information on the process can be found [here](#).

Note: A doctor referral may not be needed to get an evaluation. Parents can call the state's public early childhood system to request a free evaluation or contact the local public school system and speak to someone who can help get your child evaluated. However, it should be noted that an assessment through the school system is not equivalent to seeking an outside medical diagnosis. Professionals who may assess and diagnosis autism include psychologists and developmental-behavioral pediatricians.

Response to diagnosis

After learning that your child is on the autism spectrum, it may feel as if your life took a sudden turn. Each family's reaction to the diagnosis will be different. Reach out to other parents and caregivers through local community groups and events.



Therapies and Support



Therapies aim to support autistic individuals in their daily lives by strengthening their communication and social skills. Therapy centers often require prescriptions for therapy from providers, such as pediatricians and/or psychologists. After an initial evaluation, a comprehensive therapy plan is developed that involves multiple professionals who are catered toward the individual's needs. Therapy can take place at a school, home, community, or clinic setting. Talk to the your child's pediatrician, psychologist, or teacher about which therapy is best suited for your child.

Support in Schools



All children have the right to seek out additional support if they are having difficulties in schools. As a parent of an autistic child, you can contact your child's school district for a free comprehensive evaluation to start out. From there, the team may suggest a **504 Plan** or an **Individualized Education Plan (IEP)**. It is important that families understand the differences between a 504 Plan and an IEP. It is also recommended that you read your local/state Department of Education's guidelines about these supports.

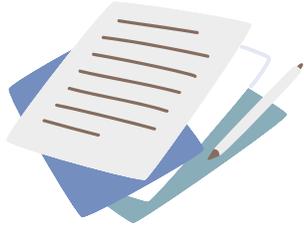
504 Plan: Governed by Section 504 of the Rehabilitation Act of 1973 (the Civil Rights law), this plan includes how the school will provide support to the student, such as providing a service or changing the learning environment so they can learn alongside their peers. There is no cost to this and can be used in school, college, and work. In sum, this law ensures that individuals with disabilities are fully included and able to participate in daily activities to the greatest extent possible.

Individualized Education Plan (IEP): Governed by a special education law, this written legal documentation provides individualized special education and related services to meet a student's needs. Unlike the 504 plan, the IEP contains measurable learning goals and describes the services that the school will provide. The IEP is at no cost to families and is only used in schools up to the 12th grade. In college, families are encouraged to reach out to the college's disability resource center for support. Information on accommodations in the workplace can be found [here](#).



For more information on either one of these plans:

- [IEP](#)
- [504 Plan](#)
- [IEP vs 504](#)



Advocating for your child

When you first learn that your child is on the autism spectrum, you will be likely be taking on many roles: parent, teacher, care coordinator, and therapist. However, the most important role will be being your child's advocate. Advocating for your child will be a lifelong journey and as a parent, it is important to make sure that your child is receiving the support that they are entitled to, speaking up for their needs, teaching your other children and/or family members about autism, and being heard and respected.

Along the way, it is also key for your child to learn to advocate for themselves to get the support from others. Although communication may be more difficult for some people than others, it is good to start out with speaking up on their current preferences. For example, what clothes to wear, videos to watch, or if they want to wear a hat to school.

Check out these advocacy resources for more ways to advocate for your child as well as ways you can teach your child to self-advocate for themselves:

- [Self-advocate](#)
- [What is advocacy](#)

Give yourself time to adjust and be patient with yourself as it will take some time to understand your child's needs. Reach out to family and friends for comfort and support. Get back into your creative outlets and take the time to realize that your well-being is as important as your child's.

It takes a village to raise a child! Throughout this journey, you must remember that if you are tired, then you cannot help to your fullest potential. It is okay to ask for support from family or friends! You are also not alone! You can find amazing support groups through social media (Facebook groups, blogs, etc.) or the community (school, autism events, etc.)!



More Resources and Materials



- [PACT's Family Resource Guide](#) for more information on what to expect and how to prepare for a first responder encounter in addition to other safety resources.
- PACT has created a Safety and Wandering Prevention Checklist for parents and caregivers and can be found on our website under the "Families" section. This checklist highlights the importance of safety for autistic individuals and to guide parents/caregivers who are facing these challenges for the first time.
- Sensory Kits containing fidget spinners or pop-its can be a great tool for parents to help individuals to self-regulate during a stressful situation. See more ideas for your sensory kit [here](#).
- [Autism Society Bluegrass](#) in Lexington, Kentucky is an example of an organization that holds events for the autistic community. Search for events held in your local area to meet parents/caregivers and families in your own community!
- The [Organization for Autism Research \(OAR\)](#) has many other resources, including self-advocacy, education, family, and spanish language materials.

What to know more? PACT members are more than happy to answer any questions you may have! Feel free to fill out [our contact form](#) and we will reach out to you!