

From Diagnosis to Discovery: A Parent's Guide to Autism



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Introduction

An autism diagnosis marks the beginning of a unique journey of discovery for both you and your child. It's a path that unfolds the depths of your child's unique personality, talents, and ways of experiencing the world.

Whether you're just beginning to explore the possibility of autism in your child or adjusting to a new diagnosis, this guide is designed to be a compassionate companion. It offers insights and support through diverse experiences of understanding and nurturing a child with autism.

Embracing this journey is about hope, understanding, and growth. It's a pathway to seeing your child not just for the challenges they face but for the complete, wonderful individual they are.

Remember, you are not alone on this journey. Alongside this guide, a community of parents, caregivers, and professionals are navigating similar paths and are valuable sources of support, understanding, and shared experiences. Together, with the right information and resources, you can provide your child with the love and support they need to thrive.





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Embarking on this journey of understanding autism spectrum disorder (ASD) can be both challenging and rewarding. As a parent or caregiver, your concerns and questions are not only valid but also shared by many others. This guide is crafted to be a comforting companion for you and a source of insight for young minds experiencing life through the lens of ASD.

We begin by exploring what ASD stands for and the nuances of autism tests for children and teens. We'll introduce Applied Behavioral Analysis (ABA) therapy — an effective approach in supporting children with autism. This guide is enriched with autism parenting tips and free autism resources, offering a supportive tool for early autism intervention.

Throughout this guide, we use fictional examples to illustrate various scenarios in the autism diagnosis journey. You are not alone on this path; together, we'll navigate the complexities of ASD, ensuring that every step empowers both you and your child.

Recognizing Early Signs of Autism

Identifying early signs of ASD is a critical step in providing timely support and intervention. Autism, a diverse and multifaceted condition, manifests differently from one child to another. However, some common cues can guide parents in understanding their child's unique needs.



Cognitive Clues

Cognitively, a child may show signs like delayed speech development or challenges in using language effectively. They might have difficulties in imaginative play or exhibit unusual responses to sensory experiences.

Lily is four years old. Her parents started noticing differences when Lily didn't babble as a baby. Now, she speaks a few words but often echoes what she hears rather than initiating her own sentences. Lily spends hours organizing her toy cars by color and size, showing early cognitive signs of ASD that her parents are learning to navigate with her.

Social Cues

Socially, early signs can include limited eye contact, reduced interest in interacting with peers or caregivers, and challenges in understanding and expressing emotions.

Eight-year-old Jack finds the playground overwhelming. While other kids run around making friends, Jack sits quietly in the corner, intensely focused on his sketchbook. His parents recall that he rarely makes eye contact and has never been keen on cuddles or high fives, often seeming to be in his own world — signs they now recognize as part of his social development within the autism spectrum.

Behavioral Clues

Behaviorally, watch for repetitive movements, strict adherence to routines, or intense focus on specific interests. These behaviors are coping mechanisms for the unique way children with ASD perceive and interact with their world.

Maya is six years old and has a deep fascination with clocks. Her room is filled with various timepieces, and she can spend hours watching and listening to them tick. Her parents noticed her distress during unexpected changes, like a sudden switch in meal times, and her habit of rocking back and forth when she feels anxious.

Understanding these signs is not about labeling your child but about acknowledging their unique way of experiencing the world. Recognizing these cues early can pave the way for effective interventions, like ABA therapy, which can significantly enhance your child's development. Remember, noticing these signs doesn't mean your child definitely has autism. However, if you observe these behaviors, it's a step toward seeking professional advice. You're not alone in this; many parents share this journey of discovery and understanding.



Deciding When to Seek Professional Advice

Recognizing when to seek a professional ASD diagnosis for your child is a profound decision. It's a path many parents embark on, driven by love and the desire to understand their child's unique world. When consistent signs of ASD become apparent, it's recommended to consider an autism test for your child.

The first step is usually a conversation with your pediatrician, who can offer initial insights and direct you toward specialists for a more comprehensive autism evaluation. Documenting your observations is invaluable. Whether it's noting your child's social cues, their response to changes, or their communication patterns, these details are crucial for an accurate autism test. This could include instances that highlight both challenges and strengths in areas like social interaction or behavioral responses.

Getting an Autism Diagnosis

The journey to obtaining an autism diagnosis for your child is comprehensive and involves several key steps, each designed to ensure a complete understanding of your child's unique developmental needs. The process typically begins with a basic developmental screening conducted by your child's pediatrician.

If indicators point towards ASD, a referral to specialized professionals, such as developmental psychologists and neurologists, is the next course of action. These specialists play a critical role in the diagnostic process. Through a combination of standardized tests and observational assessments, they work to understand not just the challenges your child faces, but also their strengths and capabilities. This holistic approach is essential in forming a complete picture of your child's developmental journey.

Receiving an autism diagnosis for your child is a significant moment that can bring a mix of emotions – from relief in understanding to concerns about the future. Navigating this new terrain involves both supporting your child and equipping yourself with the knowledge and resources needed for this journey.

For Parents & Caregivers

Give yourself time to process the diagnosis. It's normal to experience a range of emotions. Seek support from professionals, other parents of children with ASD, or support groups. Educating yourself about autism is crucial. Understanding the spectrum and its implications will help you advocate for your child effectively.

For Your Child

Explaining autism to your child in an age-appropriate and positive way is vital. They need to understand their diagnosis in a manner that doesn't make them feel 'less' but rather highlights their unique view of the world. Encourage them to express their feelings and concerns about their diagnosis.

Building a Support Network

A strong support network is invaluable. This includes therapists, educators, family members, and even peer support groups. Different therapies, like occupational therapy and speech therapy, can be beneficial. It's also important to maintain regular communication with your child's school to ensure they receive the necessary support.

Embracing Resources & Therapies

Look into various resources available for parents and children. Organizations often provide free autism resources for parents, early autism intervention programs, and educational materials. While traditional therapies are important, also consider other forms of support like art or music therapy, which can be quite effective for some children.

An autism diagnosis is both a challenge and an opportunity. It's a chance for you to understand, support, and celebrate your child in all their uniqueness. You are not alone on this journey; there is a wealth of knowledge, support, and community available to guide you.

Encourage your child to embrace their unique view of the world, and take every opportunity to celebrate their strengths and individuality. As a parent, your understanding, advocacy, and love are the most powerful tools in supporting your child's growth and development.

At Your Life ABA and within the broader community, resources and support are readily available. Whether it's connecting with other families, accessing professional therapies, or simply finding a listening ear, you are not alone. This journey is not just about navigating challenges; it's about discovering the incredible potential and joy in the world of a child with autism. Together, with patience, love, and the right support, you and your child can embark on a fulfilling and enlightening journey.



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Autism Myths & Truths

Understanding these signs is not about labeling your child but about acknowledging their unique way of experiencing the world. Recognizing these cues early can pave the way for effective interventions, like ABA therapy, which can significantly enhance your child's development. Remember, noticing these signs doesn't mean your child definitely has autism. However, if you observe these behaviors, it's a step toward seeking professional advice. You're not alone in this; many parents share this journey of discovery and understanding.

Myth: People with autism are less intelligent than others.

Truth: Autism is not an intellectual disability. It is a neurological disorder that occurs on a very broad spectrum. While people on this spectrum often share some general characteristics, they are all individuals.

There are people on the autism spectrum with higher than average intelligence, those with lower than average intelligence, and everything in between. Some are able to communicate verbally, and some are not. Some go to college, get jobs, and live independently, while others require various levels of support and care.

There is a very diverse range of abilities, skills, and communication levels among people on the autism spectrum. Therefore, it is best not to assume that someone with autism is any less intelligent than anyone else.

In the words of Dr. Stephen Shore, a professor of special education, "If you've met one person with autism, you've met one person with autism."

This <u>fact sheet</u> created by The National Autism Association is a great resource for learning more about shared characteristics and other facts about autism.

Myth: People with autism don't feel emotion or form relationships.

Truth: This myth can be particularly hurtful to those on the autism spectrum, and like the others, it is untrue. People with autism are entirely capable of feeling all of the same emotions as anyone else. However, since difficulties in communication and interpretation of social cues are of particular difficulty to those with autism, sometimes it can be challenging for them to express, and for others to perceive their emotions. Although this might impact their ability to socialize effectively, it does not reflect on their willingness or interest in doing so.

For example, people with autism may be more bluntly honest and straightforward in social settings, not sugarcoating their words in the way that people who are not on the spectrum typically do. This can sometimes inadvertently upset or offend others. Therapy and professional interventions can be very helpful in allowing those with autism to improve their social interactions and communication skills. As long as those without autism are aware and accommodating of their differences, genuine and long-lasting relationships, including marriages, can (and often do) occur among those with autism.



Only 10% of people with autism display an advanced particular skill.

Myth: All people with autism have a savant skill.

Truth: This major misconception has been egged on by pop culture entertainment, with characters in productions like "Rain Man" and "The Big Bang Theory" exhibiting exceptional mental ability in a specific area, like memory, art, music, or rapid calculation. There actually is something called <u>savant syndrome</u>, and that is not a myth. It is a real thing. However, the myth lies in the assumption that all people with autism have it.

The fact is that 1 in 10 (only 10%) of people with autism display an advanced level of a particular skill. Autistic people often display very focused and specific interest in a single subject or topic, sometimes to such a degree that excludes anything else. For this reason, they may become quite skilled, or experts in this very specific interest.

Some people on the spectrum are excellent at art or writing, some are great at math, and some are skilled at sports. However, assuming that all people with autism are geniuses at something is inaccurate and can cause feelings of inadequacy.



Myth: Autism is becoming an epidemic.

Truth: This myth is also quite common. Many people believe that autism is becoming more and more prevalent, to the point that it should be considered an epidemic. While it is misleading and untrue, this belief is understandable when you consider that the number of people diagnosed with autism has increased over the past few decades.

However, what this myth does not consider is that the increased diagnoses are a reflection of our understanding of the disorder than an actual increase in individuals who have it. This means that more people who would not have been diagnosed before, are now receiving the diagnoses, support, and care that they need.

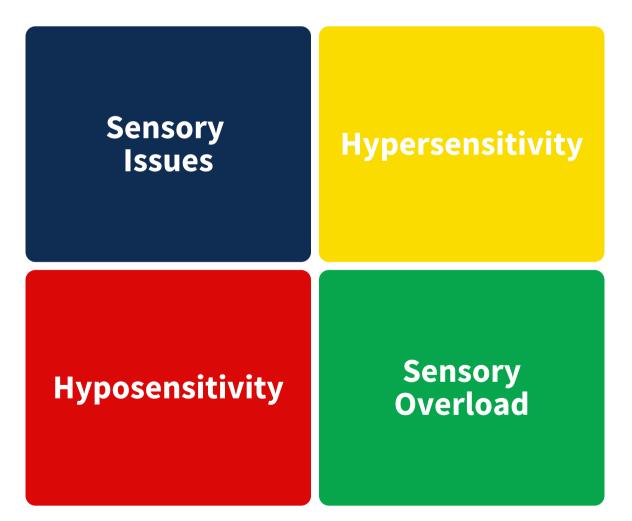
As we learn more about the disorder, we are more readily able to identify it and support it. So, although it seems like more diagnosed cases is a reason for alarm, the opposite is true. It means more people have access to help, support, and understanding that would not have had it before.

Autism and Sensory Issues

When you have a child on the autism spectrum, it can be challenging to understand how the world around them can affect them differently than it affects you. While no two people with autism share the same sensory differences, it helps to know what to look for. Learning to recognize and help minimize sensory issues will make life better for your young one, and in many cases, improve your own life too.

What are sensory issues in people with autism?

People on the autism spectrum commonly experience <u>sensory processing issues</u> that would not typically affect a neurotypical (non-autistic) person. These reactions can cause mild to very profound difficulties which can affect their lives (as well as the lives of those around them) significantly. Let's explore some ways that the senses can be affected, keeping in mind that each person is different, and can experience one, more than one, or any combination of the reactions discussed below.



Hypersensitivity

This is a state of oversensitivity, or over-responsiveness, and it can affect any of the senses. A common hypersensitivity in people on the spectrum can be in reaction to bright lights, particularly fluorescent lighting, but any bright light could cause a sensitivity. For others, certain sounds, smells, tastes, or textures can be overstimulating or overwhelming.

For instance, some people on the spectrum do not tune out certain sounds or background noises as well as neurotypical people. So, something as simple as a loud air conditioner, a low hum of a refrigerator, or people talking quietly on the other side of the room, could be just as loud or intrusive as the person talking directly to them.

Particular clothes or clothing fasteners might rub the wrong way, or the smell of certain perfumes or soaps can be too strong. Signs of hypersensitivity may include pulling away from physical touch, covering ears to avoid sounds, being repulsed by certain foods, becoming agitated in certain lighting, and avoiding certain kinds of clothing.



Hyposensitivity

This is a state of under-sensitivity, or under-responsiveness, and it can also affect any of the senses. This can present itself in various ways, such as difficulty recognizing hunger, pain, illness, or a need to use the restroom.

Someone with hyposensitivity to pain may walk around on a broken ankle for days before anyone notices. Hyposensitivity to smell may cause someone to be unaware of strong smells, like their own body odor. Hyposensitive people may have a constant need for movement, be attracted to brighter light, louder noises, attempt to eat things that aren't food, or seek out more sensory input with <u>behavior called stimming</u>.

Sensory Overload

This can happen when intensity (whether it be from hypersensitivity or from too much stimming) overwhelms a person's ability to cope, or self-regulate. It could be triggered by one event, like a very loud noise, or build up gradually due to the effort it takes to cope with everyday <u>sensory</u> <u>sensitivities</u>. When this happens, it can feel like intense panic or anxiety, a sudden need to escape, difficulty communicating, or exhaustion and shutdown.



What can I do to help with my child's sensory issues?

The first thing you can do is gather information. Keep a close eye on signs of hypersensitivities and hyposensitivities in your child, and do your best to communicate with them about what may be bothering them. From there, you can try accommodating by changing the environment and/or using tools or strategies that help. Here are just a few examples of how to help sensory difficulties.

Helping with Hypersensitivity

- Make a safe, quiet place with dim lighting for calming down
- Visit new places at quiet times, gradually increasing the duration over time
- Try earplugs or noise-canceling headphones to help with sound sensitivities
- Plan for 'calm' days to counteract busy days and reduce anxiety
- Avoid strongly scented products
- Choose soft, comfortable clothing
- Choose foods that avoid aversions to textures, temperatures, or spices
- Ask or tell before you touch, and remember that hugs can be painful

Helping with Hyposensitivity

- Provide fidget toys, chewies, squishy balls, putty, or playdough
- Arrange furniture to allow for safe, open spaces that allow movement
- Take several breaks for movement throughout the day
- Use weighted blankets, stuffed animals, or squeeze vest to provide pressure
- Take frequent restroom breaks for those with reduced body sensation awareness
- Listen to music, bounce on a trampoline, or take walks periodically
- Provide foods with strong tastes or textures as desired

Be sure to partner with your child's school and medical professionals for the best chance at consistency and success. Therapies such as occupational therapy, cognitive behavioral therapy, or other forms of therapy can also be very helpful in some cases. For more in-depth information on sensory issues and ways to help your child handle them, check out these articles by The <u>National Autistic Society</u>, <u>Autism Speaks</u>, and <u>The Spectrum</u>.



Stimming: Helpful Tips for Parents of Children with Autism

Have you noticed your child with autism engaging in repetitive motions or sounds, and you aren't sure why? These behaviors are likely a form of self-stimulatory behaviors, otherwise known as "stimming". <u>Stimming</u> can sometimes cause concern and alarm in parents. Is my child okay? Is something wrong? Will this behavior draw unwanted (or worse, unkind) attention from others? It can be difficult to know how to handle a loved one when stimming occurs. Here are some helpful tips to recognize, understand, and handle stimming in your child.

What is Stimming?

Stimming is the repetitive performance of certain physical movements or vocalizations. Most people (on and off of the autism spectrum) engage in stimming activities to some degree without even realizing it. This could present itself in simple actions such as foot tapping, nail biting, hair twirling, or drumming fingers on a table. However, for some, the actions can be more pronounced and noticeable. Some of these include rocking back and forth, hand flapping, clapping, rubbing surfaces of certain textures, humming, yelling, or repeating certain words, phrases, or sounds. Stimming behaviors are more common among those on the autism spectrum, but can be exhibited by anyone.

Why Is My Child Stimming?

Stimming usually serves one of three purposes: self regulating, expressing feelings, or coping with anxiety. Let's look at each one:

Self Regulating — People (especially kids) with autism can often become overwhelmed or overstimulated in what can feel like a chaotic and out of control world. Stimming can be a soothing and comforting activity to help self-regulate and feel a sense of control in an unpredictable environment. Understimulation (or boredom) can also bring on stimming in some cases.

Expressing Feelings — Stimming can be a way to communicate excitement, joy, frustration, or a variety of other emotions. This is especially true when those feelings are difficult or unable to be conveyed verbally.

Coping with Anxiety — Stimming can be a helpful and calming coping mechanism in order to <u>manage stress or other intense emotions</u> that may be difficult to process. This is due to the repetitive and familiar nature of stimming activity, which can bring feelings of safety and reassurance.

How Should I Handle My Child's Stimming?

There are a few questions parents should ask themselves about their child's stimming behaviors. First, is my child harming his or herself with this behavior?

If the answer is yes, visit this article for more information on self-injurious behaviors and autism.

If the answer is no, it is important to avoid punishing or shaming your child in any way for his or her stimming. Stimming is a natural behavior that serves an important purpose. Trying to suppress it can be harmful and counterproductive.

The second question to ask is what purpose the behavior is serving for your child. This may take some practice, trial, and error, but knowing why your child is stimming can help you provide the best support.

For instance, if you can tell the stimming is due to overstimulation, you can take a break or move to a less chaotic environment. If it's to express an emotion, you can share in the joy or provide reassurance in times of anxiety or frustration.

What If My Child's Stimming Is Affecting Others?

The last question to ask is whether a child's stimming is affecting others in a negative way. While it's not a good idea to punish a child for stimming, it can be helpful to encourage appropriate times and places for the behaviors, or even provide opportunities for more fitting behaviors that serve the same purpose.

Perhaps your child's repeated clapping isn't harming them, but it might be very disruptive to others in public. Giving them something else to do that is quiet (such as rolling and unrolling a towel, using a fidget device, or squeezing a stress ball) could serve the same purpose without causing a disruption. The more you know about why the behavior is happening, the easier it will be to determine an effective replacement behavior.

"If the behaviors are not harmful or obscene, the public doesn't need an explanation."

Cole Dunlevy Director, Community Partnerships New Story Schools



What Will People Think?

Many parents worry about their child's stimming behavior appearing odd, socially unacceptable, or "weird." While it may be understandably tempting to discourage these behaviors for this reason alone, if no one is being harmed or disrupted, it is best to accept that all children are unique individuals with their own mannerisms, and support them as best you can.

In public settings, this may require some extra communication. A good way to do this is to introduce your child in a friendly way to anyone who might be looking, and then simply explain their behavior. Don't be afraid to reach out to your child's school staff, a therapist, or support groups for more guidance on how to appropriately handle your child's stimming. You are not in this alone.



ABCs of ABA

Applied Behavior Analysis (ABA): Applied Behavior Analysis is a scientific approach to understanding and improving behavior. It is based on the principles of behaviorism, which emphasize the relationship between behavior and its environmental factors. ABA is widely used in various fields, including psychology, education, and healthcare, to bring about positive behavioral changes in individuals.

The seven dimensions of ABA are:

1. Applied

The behavior targeted for change should have social significance and importance to the individual or society. The goal is to address real-world issues and improve the individual's daily life.

2. Behavioral

The behavior targeted for change should have social significance and importance to the individual or society. The goal is to address real-world issues and improve the individual's daily life.

3. Analytic

The analysis of behavior invovles a systematic and scientific approach. The cause-and-effect relationship between interventions and behavior change should be demonstrated. This dimension ensures that interventions are evidence-based and can be replicated.

4. Technological

Interventions should be precisely and clearly defined, providing a step-by-step description of the procedures used. This ensures that the interventions are replicable and can be accurately implemented by others.

5. Conceptually Systematic

The principles of behavior that underlie interventions should be based on the science of behavior analysis. This dimension emphasizes the importance of grounding interventions in well-established principles and theories.

6. Effective

Interventions should result in a significant and socially meaningful improvement in the behavior targeted for change. The goal is to achieve practical and positive outcomes.

7. Generality

Behavior change should occur in various relevant settings and should be maintained over time. The intervention's effects should generalize to other behaviors not specifically targeted, and the individual should be able to apply learned skills in different environments.