



# Autism Spectrum Disorder

A Basic Introduction  
for Families



# INTRODUCTION

Your child has been diagnosed with an autism spectrum disorder (ASD). You may have mixed feelings ... relieved to know that the concerns you have had for your child are valid, yet perhaps sad, confused, or overwhelmed about what the future holds. Whatever you are feeling, know that you are not alone. Thousands of parents share this unexpected journey with you. Remember, your child is the same unique, lovable person that he was before the diagnosis.

This booklet will give you a better understanding of ASD and provide you with some tips as you and your family begin your journey.

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## WHAT IS ASD?

ASD is a term that covers a group of developmental disorders that begin in the early years and lasts throughout a person's lifetime. It affects how a person communicates, interacts with others, and behaves. It is considered a "spectrum" because each person is unique: characteristics can be hardly noticeable in one individual, while more complex in others.

Individuals with ASD ...

- Have challenges with communication and social interaction.
- Demonstrate repetitive behaviors and/or difficulty with any change in daily routines.

# WHAT ARE THE CHARACTERISTICS OF ASD?

## Communication

Some individuals with ASD have large vocabularies, yet may not understand what others are saying and thinking; others with limited vocabulary may understand everything. For every child with ASD, communication skills develop differently.

You may notice your child having difficulty:

- Using language like you do. His words may seem unusual, out of place, or have a special meaning only to him and your family.
- Understanding that words have more than one meaning. For example, "it's raining cats and dogs" does not mean that animals are falling from the sky.
- Letting others know what he needs and wants using words. Some children point, scream, or grab.
- Understanding what others are thinking and feeling. For example, you may sigh when upset, but your child may not understand why you are sighing.
- Using words. Instead, your child may use a speech device, pictures, or signs to communicate.
- Beginning and keeping a conversation going. Your child may talk only about a favorite subject or repeat the same phrase over and over.

*No matter what path your child's language development takes, remember that people with ASD do want to communicate and can.*

**TIP**

**Make sure that your child can “tell” you what he wants or needs.** Help your child find the best way for him to communicate – whether words, sign language, a communication device, or pictures.

**TIP**

**Communicate your message clearly.** Use words or phrases that have meaning to your child. Drawing and writing what you want to say can also help.

**TIP**

**Give choices.** Ask questions that offer a choice. Instead of asking a general question such as, “What do you want?,” ask, “Do you want a snack or a toy?”

## Social Interaction

From the earliest age, ASD can impact how a child interacts with others. You may notice your child having difficulty:

- Making eye contact.
- Responding to her name or other attempts to get her attention.
- Accepting hugs and showing affection for or interest in others.
- Knowing how to play with others, often preferring to be alone.
- Participating in pretend play.
- Seeking comfort.
- Understanding the facial expressions and tone of voice of others.

*Children with ASD want to have friends. They enjoy interacting with family members and can be loyal friends, good colleagues, and responsible coworkers.*

**TIP**

**Teach your child how to be a friend.** Show your child how to play with others and practice playing at home, with neighbors, and peers.

**TIP**

**Follow their lead.** Join your child in what he is doing or showing interest in.

## Restricted, Repetitive Patterns of Behavior and Need for Routines

You may notice that your child uses unique behaviors, such as flapping hands, rocking back and forth, walking on toes, suddenly freezing in a position, or having extreme difficulty when a routine is changed. Parents often report that their child with ASD lines up toys in a certain way rather than “playing” with them, and becomes upset if someone moves a toy out of place. These are referred to as restricted, repetitive patterns of behavior.

Your child may:

- Play with toys differently than peers. For example, he might sit tirelessly spinning the wheels of a toy car.
- Have a hard time predicting what will happen next. He may not figure out that after reading a bedtime story, it’s time to go to bed.
- Like things to be the same, such as eating the same foods, playing with the same toys, or following the same routines. A slight change may be very upsetting for the child.

**TIP**

**Create daily routines.** Your child will do best when daily routines are in place. Help your child understand the steps to complete daily routines, such as bathing, putting away toys, doing homework, and going to bed.

**TIP**

**Prepare your child.** Try to prepare your child to move from activity to activity and understand what will happen next. Using something visual, such as a card with a list of steps and maybe pictures he can follow, is often helpful.



## Special Interests

Sometimes a child has a strong interest in a particular object or topic and may spend a great deal of time playing with or talking about it. Topics may include trains, dinosaurs, vacuum cleaners, video games, numbers, letters, science, and more. This interest may seem unusual to you or your child's peers because of what your child is interested in or how much she knows about the topic.

**"My daughter was really interested in animals starting when she was about 7. She is now finishing her degree as a veterinary assistant."**

**– Parent of a child with ASD**

**TIP**

**Use special interests whenever possible.** Use special interests to motivate your child to learn new things, help calm your child when upset, and make playing and interacting with you and peers fun.



## Sensory

You may observe that your child reacts to sounds, smells, textures, tastes, and sights differently than you do.

You may find that your child:

- Finds certain lighting (e.g., fluorescent lights, blinking lights, direct sunlight) distressing.
- Responds negatively to certain sounds (e.g., fire alarms, vacuums, sirens, volume in a movie theater).
- Eats only certain foods because of the texture, smell, or taste.
- Wears only one type of clothing because of how it feels on his body.
- Finds the smell of an object (e.g., perfume, toothpaste) appealing or upsetting.
- Walks a bit awkwardly, has difficulty with balance, or does not understand when he is standing too close to someone.
- Has an unusual reaction to pain and may not sense the feelings of hot or cold.

**“It was tricky trying to figure out if my child was not feeling well or if something was hurting. When he broke his arm, he didn’t complain at all, however, when he got a hangnail, he cried hysterically.”**

**– Parent of a child with ASD**

### TIP

**Understand your child’s sensory needs.** He may seek out and be comforted by sensations like the feel of a certain blanket or swinging on the swing set.

### TIP

**Turn down the noise and lights.** Try to eliminate multiple sounds and be aware of lighting that may bother your child. Headphones might help, as needed. You may consider using lamps instead of fluorescent lighting.

### TIP

**Provide space.** Move slowly into your child’s personal space. When possible, let your child choose where he wants to sit, stand, or walk.

## Self-Regulation

Many children with ASD have difficulty with self-regulation. This means that they have challenges controlling their emotions and behavior and may not automatically know how to stay calm and relaxed. They may tend to “lose control,” particularly when in a strange or overwhelming place. While these “meltdowns” often seem inappropriate to others, they often are the only way a child with ASD has to express how she feels. On the other hand, the child may also have a large reaction to positive situations, spinning out of control with glee.

A child might express challenges with self-regulation by:

- Showing high levels of anxiety, happiness, depression, or excitement.
- Responding to a situation by over- or under-reacting.
- Not recognizing her feelings, such as not understanding how her body feels when excited, happy, or angry (e.g., “butterflies in your stomach,” heart racing).

“My anxiety will come out as being bossy, or whatever, because I will tell people what to do even under my breath. Or I will just start talking and telling people, ‘We’re going to be late; we’ve got to go. Keep moving.’ This could come out as bossy, but really I’m just trying to hold it all together.”

– Young adult with ASD

**TIP**

**All behavior is communication.** For the child who has meltdowns, remember that all behavior is communication and that teaching and showing the child what to do, rather than punishing, is important.

**TIP**

**Listen or look for the message behind the behavior.** Consider the possible “hidden message” in your child’s behavior before you respond.

**TIP**

**Be patient.** Try to avoid rushing. Provide time. A quiet, calm moment is a place to begin.



## Learning Style

Every child – whether or not he has ASD – learns differently. As you understand the unique ways your child learns, you will see new ways to help him develop skills.

Your child may learn in a particular way. He may:

- Learn best when he can see what he is supposed to do. He may follow directions better if you write or draw a checklist of what to do.
- Do best in fact-based or creative subjects, including math, science, history, art, and music.
- Have a great memory. He may learn things in detail and remember them for a long time.
- Have difficulty organizing, keeping track of belongings, and managing time.

**TIP**

**Use positive statements.** Your child will probably learn best if told or shown, in a positive, calm way, what to do rather than what not to do. For example, “The door stays shut,” instead of, “Don’t open the door.”

**TIP**

**Provide time.** Do your best to give your child enough time to respond, as he may require a longer time to think and process information.

**TIP**

**Use praise.** Tell your child when he has done something right. Celebrate accomplishments and progress – no matter how large or small!



## ANOTHER THING TO THINK ABOUT

Sometimes, a child has ASD combined with other medical, mental health, or physical issues. These are called co-occurring conditions, and they can range from mild to severe and can affect how your child feels, acts, or learns.

“One of the biggest challenges for our family was figuring out a sleeping schedule for our son. After talking with our child’s doctor, we learned that our child had problems sleeping. The doctor helped us figure out things we could do to make our night times better for our son and family.”

– Parent of a child with ASD

**TIP**

**You know your child best.** Don’t hesitate to bring up any concerns you may have with your child’s doctors, specialists, or any other professionals working with your child.

**TIP**

**Take time to notice and appreciate your child’s strengths.** Share this with others.



## AFTER THE DIAGNOSIS, WHAT NEXT?

Along your family's journey, you may receive a lot of information and hear complex terms and opinions from professionals. While intended to be helpful, this may be overwhelming, especially at first. It is important to identify the top needs of your family and your child because no one-size-fits-all when deciding what to do next. The following may be helpful:

- 1. Share with family and friends.** Help family members and close friends understand your child and her ASD. To begin the discussion, you might talk about the way your child interacts, her specific behaviors and how they are related to ASD. You might also want to offer some simple things that family members and friends can do with your child to have a positive experience.

# *ASD does not impact just the child; it impacts the entire family.*

- 2. Give yourself time.** Give yourself and your family time to adjust. It will take some time for everyone to understand your child's ASD and its impact on your family. Your other children may have questions and may want extra time with you. In addition, take care of yourself, your health, and your relationships with significant adults, such as a spouse and long-time friends. It may feel like you do not have time for this; however, it is important. Find time for laughter, rest, and exercise!
- 3. Develop relationships.** As you identify the needs of your child and family, know that there are many people who can help your child learn and grow. You may find that a team can assist, including speech/language pathologist, occupational therapist, doctor, teachers, autism family support group members, childcare provider, member of your faith community, neighbor, community center employee, and others. Focus your efforts on solving problems together. Guide your team in setting goals, creating expectations, and sharing information.
- 4. Find out what services and supports are available.** Your child will have different needs at different points in her life. One of your first steps is to explore what is available in your community. No matter how old your child is when she is diagnosed, services and supports can make a difference. If your child is diagnosed under the age of 3, early intervention programs are available. Early intervention is support provided before the child is 3 years old and typically includes the entire family and is meant to help your child and you get a good start. If your child is diagnosed after the age of 3, work closely with your local school district to make sure that your child has what she needs to learn.
- 5. Be a part of the community.** It is easy for your child and you to become isolated if the focus on ASD consumes every waking moment. Try to have some sort of adult life, while allowing your child to develop the skills to have one of her own. Brief, yet ongoing activities in your community, together and apart from your child, can refresh and energize you. These early experiences can pave the way for your child to be a lifelong active and welcome member of the community.

*“Parent-to-parent support is essential. I thought no one else could be experiencing the stress and chaos that I was feeling when my son was first showing signs of autism. I thought no one else had a child who behaved like mine. I was wrong.*

*I met two moms who talked openly about their children and families. Their honesty brought me great relief. We laughed about the many times our boys would take their clothes off, and the endless hours of trying to guess what they were saying because they did not have words yet. Our kids were similar, but yet unique. Years later, we still laugh, cry, and support one another. I am thankful I met them early in my journey. They make all the difference.”*

*– Parent of a child with ASD*



*Find opportunities in the community: a parent support group, parks and playgrounds, community centers, libraries, community theater, church, neighborhood gatherings, summer camps, book clubs, and others.*

- 6. Keep records about your child with ASD.** Organizing the information and records that you collect is an important part of managing your child's care and progress. Many parents find that binders – hard copies or digital – are great for organizing and sharing paperwork.
- 7. Dream big.** It is never too early or too late to think about your child's future. As your child grows, try to not simply focus on what your child cannot do. Continue to discover strengths and understand what she needs to know and do to be successful. Try to find opportunities for your child to learn important skills and be proud of the accomplishments of your child and yourself – both small and large.

*The potential of individuals with ASD is unlimited. The child with ASD who experiences multiple challenges at age 3 can become the 25-year-old with ASD who has friends, a job, and lives a full and happy life.*



## CONCLUSION

Along the journey with your child, refer back to this booklet as a guide. This information is meant as a simple introduction as you continue to learn about the unique characteristics, strengths, and needs of your child with ASD. Always keep in mind that your child is the same wonderful person he was before the diagnosis and that his potential is unlimited!

**“One of the hardest things for me to learn was not to do it all alone. I had to learn to ask for and accept help from others. I learned that there are family members, friends, and others who want to help but don’t know what to do.”**

**– Parent of a child with ASD**

# **ASD STRATEGIES** IN ACTION

autism certification center

One of the best places to learn more about autism is ASD Strategies in Action, a set of easy-to-use videos. The videos provide everyone in your family, as well as your child's teachers, your friends, relatives, and community members with practical information, real-life examples, and strategies that can be useful across your child's life ([www.autismstrategies.org](http://www.autismstrategies.org)).

**For additional resources  
visit [www.ocali.org](http://www.ocali.org) or call 614.410.0321**

*Content for this publication was developed using resources from OCALI's ASD Strategies in Action, the Center for Disease Control and Prevention, the National Institute of Mental Health, the U.S. Department of Health and Human Services, Indiana Resources Center for Autism, Autism Speaks, and the Autism Society of America.*

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