

THE **SURVIVAL GUIDE** FOR

Kids with

Autism Spectrum Disorder

(And Their Parents)

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UPDATED EDITION



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Part 1

A look into Autism Spectrum Disorder



Chapter 1

What Is ASD?

ASD stands for autism spectrum disorder. But *disorder* isn't a very friendly word. If you want, you can think of ASD as a brain difference.

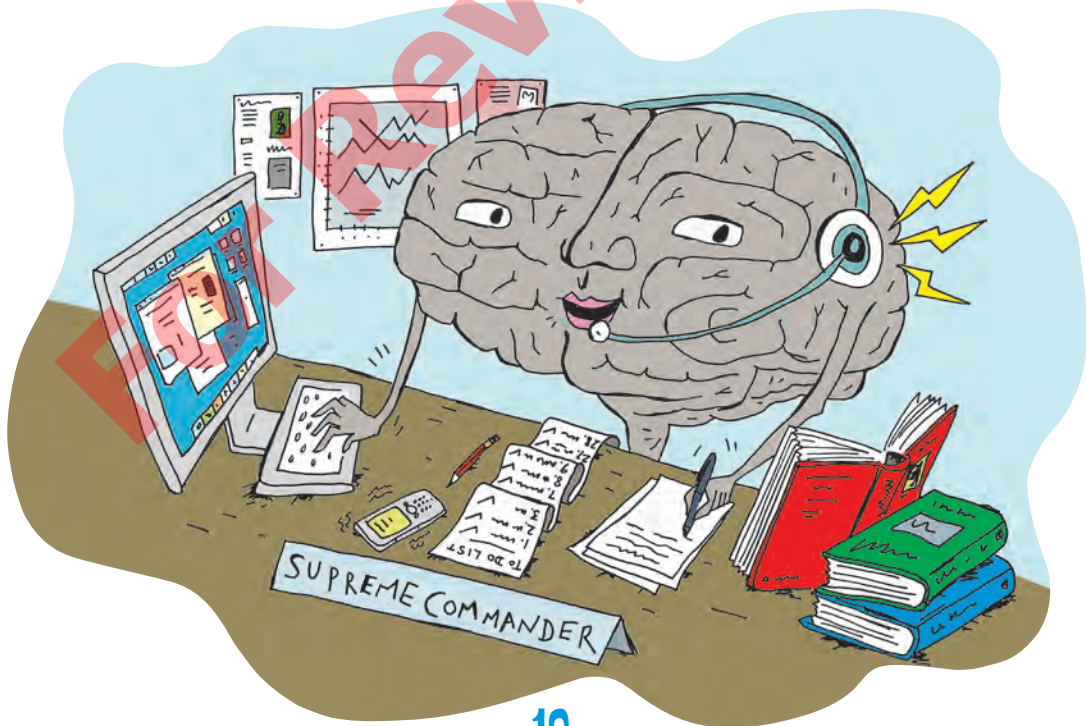
Because the difference starts in the brain, ASD has an effect on your body too. Your brain is like your command center. It sends billions of messages 24/7 to all areas of your body. Messages like:

"Legs, run!"

"Hey, what's that noise?"

"Ouch, that bright sun hurts my eyes."

"Mmmm, I smell lunch. Time to eat."



Your brain plays an important role in three areas having to do with autism spectrum disorder:

1. **Communication:** This is about how you listen, speak, write, or get messages across to others.
2. **Socialization:** *Socializing* is doing things with other people. Your brain affects how you socialize with others and how much you want to socialize with them. It affects how you fit into a group, like your family, friends, or community.
3. **Interests and behaviors:** Interests are the things you think about and the activities you enjoy. Behaviors are the things you do and how you act. Your brain plays a role in how often you think or do things, and how much you enjoy them.



If you have ASD, your brain has to work harder when it comes to communicating and socializing. All this hard work might make you feel tired or frustrated, but you can do it! This book will tell you how.

On pages 16–24, you’ll learn more about each of the three key areas mentioned above. But first, a word about rainbows . . .

The Many Colors of ASD

Rainbows? What do rainbows have to do with the autism spectrum? You might have seen the word *spectrum* if you’ve read about rainbows. The spectrum refers to the colors of light in a rainbow (red, orange, yellow, green, blue, indigo, and violet). Just like the rainbow, autism comes in many colors, including your special color! The “spectrum” part of ASD means that each and every person with this condition is different and unique.



ASD and Y-O-U

Maybe your doctor and parents (or caregivers) have explained your condition to you already. Or maybe they're still in the process of figuring things out. Coming up with the diagnosis of ASD takes time.

To do so, your doctor looks at your medical history, your habits and behaviors, and information about you from your school. Lots of questions come up, like:

- How do you communicate?
- What are your interests?
- How do you play?
- Do you have friends? How do you get along together?
- How do you do in school?
- What do you like to eat?
- What are your sleeping habits?
- Do you have trouble handling your feelings?

To understand you even better, the doctor takes your answers to the questions and compares them to the list of autism symptoms (problems) in a special book.* This can be tricky because every person with autism is so unique. The “magic number” of symptoms the doctor looks for is five. A person with ASD must have at least five symptoms that include difficulties with:

- communication
- socialization
- limited interests and/or repetitive behaviors



Your doctor will also take a look at your childhood history, especially at what age you learned to speak. Some kids who have a diagnosis of autism had a hard time learning to talk

*The book is called *The Diagnostic and Statistical Manual of Mental Disorders Fifth Edition* (or *DSM-5*).

when they were young. They may have been late to start talking, and might have needed speech therapy to start getting the words out. Some people with autism never learn how to speak. They may use special communication tools.

Sam's Story

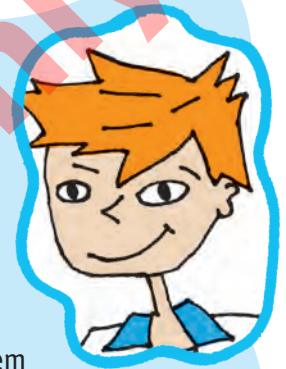
Sam is 10 years old and has autism. He looks like any other 10-year-old boy—unless something exciting is happening. Then Sam starts rocking back and forth in his chair and flapping his arms like a baby bird ready for its first flight. This is one of the things Sam doesn't like about his autism—he can't keep himself from "flapping" when he's happy or excited.

When Sam was younger, the kids at school didn't seem to mind his flapping. But now that he's older, the kids don't seem as accepting of his behaviors. These days, he feels really embarrassed when he flaps.

Another problem for Sam at school is his voice. People say he talks too loud. His teacher reminds him to use his "indoor voice." Sam tries to talk more softly, but this only lasts a short time. Pretty soon he's speaking loudly again, and he gets the same reminder about using his indoor voice.

Sometimes Sam feels sad or frustrated about what's hard for him. Then he tries to stop and think about the good things in his life. Sam is the best speller in his class, and he has lots of energy and enthusiasm. He loves to learn new things, and he knows more knock-knock jokes than anyone else in his whole school! Many kids at school and in Sam's neighborhood know him, and they always say hello. All of this makes Sam feel better about himself.

For now, he thinks, maybe a little flapping and loud talking aren't so bad—especially when he thinks of all the good things in his life.



ASD Is Not . . .

- your fault
- something you “caught” like a germ
- something you can “give others” (autism is not contagious)
- a sign that you are stupid, bad, sick, crazy, lazy, flawed, or weird

ASD Is . . .

A medical condition. You have symptoms, but with help from experts, family members, and teachers, you can work on improving those symptoms. ASD is also a way of being—it’s how you experience the world.

You may have ASD, but you’re still **you**. You’re a whole person, head to toe, inside and out. You have the potential to live a healthy, unique, and remarkable life.



I have what some people would call a disability but I call a gift. . . . I am not your average child. I like to think of myself as the ‘new and improved model.’

—Luke Jackson, from his book *Freaks, Geeks & Asperger Syndrome*



Chapter 2

Symptoms of ASD

In many ways, autism spectrum disorder is a mystery. There's no simple test (like a blood test) to show that a person has autism. Instead, it's a matter of looking for symptoms and seeing whether they match up with the diagnosis of ASD.

This chapter is all about understanding the symptoms you may have. You can imagine that you're a detective, looking for clues to the mystery. Detectives almost always have partners. Ask a parent or another adult you trust to study the clues with you, so you can figure out things together.



Detectives take good notes. **Get a pen or pencil and some paper.** Whenever you read about a symptom that sounds familiar, write it down. These notes are clues about areas you might need help with.

Symptom 1: Communication Difficulties

Most people with autism spectrum disorder can talk, although it may be hard for them to find the right words to express what they want to say. Do you ever feel like other people are watching you too closely or hurrying you to say something? Or do you sometimes use words that are correct but sound odd to your friends? Sometimes, you might have trouble understanding what others are saying. Maybe it seems like they talk too fast. Perhaps they tell jokes that don't seem funny to you, or use slang words you haven't heard before.

Some people who have ASD may misunderstand common expressions. For example, you might hear your mom say she's "fed up" and think she's full from eating too much. But what "fed up" really means is *frustrated*. Or, someone might say "Take a hike." You might think the person means "Put on some hiking boots and find the nearest trail." The expression "Take a hike" said in an annoyed tone of voice usually means "Go away!"

Understanding words that you read may also be hard, even if you love reading! Some people with ASD are super spellers and fast readers but may have trouble making sense of the story or information. Do you sometimes read a section nearly perfectly, even when it's full of long words? And then find that you're unable to explain to someone else what you just read? If so, this is because your brain is good at decoding (figuring out) the *sounds* of words, but not their *meanings*.

Problems understanding the meaning of language happen when parts of your brain don't communicate with each other. Think of it this way: Part of your brain has the job of making words. Another part has the job of understanding feelings. Both parts of your brain may be doing their jobs—but they're not talking to each other! Messages are lost along the way or take a while to get there.

Because of your ASD, your brain tends to focus on one thing at a time. For example, imagine someone is angry at you. That person may look something like the girl at the top of the next page.



Your brain might not **see** the “whole picture” that someone without ASD sees. What do you **see** instead? *Pieces* of the picture. You may hear an angry voice but not be able to focus on what the words mean. You may see an angry face but not notice the person shaking her foot. You may be focused **on listening** for words, and then miss the person’s facial expression.

People use a combination of words, actions, and facial expressions to let **others** know what they think and feel. For you, it’s harder to see, hear, and understand that combination.

