



# Introduction for Kids

Have you ever sensed you're different somehow? Maybe you don't seem to fit in with the kids at school or in your neighborhood. You look around and see them talking, laughing, messaging, and living life at a different speed than you are. Perhaps you even feel out of step within your own family.

Or, maybe you don't feel so different but other kids treat you as if you are. They may tease you, stare, shy away from you, or tell on you for behaving in ways you didn't even know were "wrong." What's going on? You're special in some way, but how?

This book is about discovering why you're different. Like many people, you have some special skills and gifts. But you also have some special needs. More specifically, you have a condition known as autism spectrum disorder, or ASD. The definition on the next page will explain it more.



# Introduction for Adults

*"If you've met one person with autism,  
you've met one person with autism."*

What a great quote. It's often repeated, and for good reason—people with autism spectrum disorder are complex and unique. They're *individuals*. They can't all be lumped together, because there are vast differences in how they think, learn, feel, behave, and communicate. It's why this popular quote is important for parents, educators, doctors, and experts to always keep in mind.

Sometimes autism is referred to as an invisible disability. In other words, the person isn't in a wheelchair or may not have an obvious physical impairment—so people might assume there's nothing different, nothing "wrong." But autism does affect how someone communicates, socializes, and learns. People with autism spectrum disorder (ASD) behave differently from what is considered "typical" or *neurotypical* (a term sometimes preferred by the autism community; it means "neurologically normal"). Someone with autism isn't typical, yet the person cannot be defined only in terms of the diagnosis.

You're probably reading this book because someone you love (or teach) has autism spectrum disorder. You want to help. Chances are, this young person in your life is now old enough to begin learning about the diagnosis. *The Survival Guide for Kids with Autism Spectrum Disorder (And Their Parents)* is a handbook to help children through the questions, challenges, frustrations, tears, mysteries, successes—the journey. We recommend this book mainly for kids ages eight to thirteen, although older kids may also find it useful. Depending on age and ability, some children may be able to read the book independently. However, we suggest that you and the child share and discuss it together. Even a child who is an adept reader will benefit from having a grown-up read alongside for support, empathy, and further explanation of the issues discussed. As a parent, you may also find that reading together is a chance to strengthen your relationship with your child and keep the door open to questions and issues that arise.

This book is designed to help a child with ASD through many ages and stages, from learning about the diagnosis to facing physical and emotional challenges to improving communication and social skills at home, at school, and in the wider world. Use the book as an everyday tool or guide, or as a way

to introduce a new topic or skill. You may find it helpful to come back to the book during times when the child is asking questions, facing changes at home or school, reaching a milestone, or struggling. Because children grow and change—and because their ASD changes too—they need a book that keeps them informed and helps them achieve to the best of their abilities and at their own pace.

As you may know, the autism community is growing larger by the day. More kids are being diagnosed, more parents are becoming advocates, and more educators are being trained to understand the autism spectrum. There are many voices, many points of view—so many stories of hardship and hope. And we've been a part of the story ourselves. Both of us are mothers of sons who have autism, and one of us is a doctor who works with children and adults with autism spectrum disorder. At times, the two of us wondered how this one book could possibly meet the needs of such a wide and varied audience of passionate, questioning advocates.

In the end, we kept coming back to these questions: What do the *kids* need? What are *their* issues, questions, and experiences? We wrote this book to help kids with autism spectrum disorder get answers to the questions that are important to them, learn more about issues they struggle with, and find out what it's like for other kids who have ASD.

*The Survival Guide* is divided into three parts:

- **Part 1: A Look into Autism Spectrum Disorder** is a kids' primer on the symptoms, the sensory issues, famous people with the condition, questions that arise, and building a team of helpers.
- **Part 2: Home, School, Community** is about improving daily life at home, at school, and in the wider world. We want kids and families to know that everything you do can make a difference. Some days, you may want to give up, or you'll think "This is just too hard" and "Why even try?" Daily life with ASD can be frustrating—but it also can be full of great humor, acceptance, and gratitude for the little things. Part 2 offers tips for making everyday life easier, as well as for setting short- and long-term goals for improving social skills or school performance. What you do for your child matters. Our aim with Part 2 is to help both your child and you keep moving forward, even when it's hard to do.
- **Part 3: Body and Brain Basics** looks into the physical and emotional issues that are such a big part of life with ASD. Readers will learn about exercise, nutrition, sleep, relaxation, handling intense emotions, and more. Here we emphasize the importance of good self-care—because it's a huge step toward better health and greater confidence.

All three parts of the book contain real-life stories of kids with autism spectrum disorder (names and details have been changed to protect their privacy).

## 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*

