

THE SURVIVAL GUIDE FOR

Kids with Autism Spectrum Disorder

(And Their Parents)

Elizabeth Verdick &
Elizabeth Reeve, M.D.

UPDATED EDITION

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PUBLISHING®

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“Pick it up for its emphasis on self-acceptance and its A-to-Z nature.”

—Scholastic Parent & Child

“[T]he authors lay a strong foundation in giving kids the ultimate skill of self-advocacy.”

—Booklist

“Useful and easily readable . . . with lots of practical advice.”

—Kirkus Reviews

“Should be one of the first books a family buys after a diagnosis . . .
it will be invaluable to so many children and their families.”

—Claire LaZebnik, author of *Things I Should Have Known* and *Growing Up on the Spectrum*

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Kids with Autism Spectrum Disorder (And Their Parents)

UPDATED EDITION

Elizabeth Verdick & Elizabeth Reeve, M.D.

Illustrated by Nick Kobyluch



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PUBLISHING®



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Note: The names of some children described in this book have been changed to protect their privacy.

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Dedication

To Nancy, Cara, and Trish: You were there in the beginning and you helped bring us further than we imagined possible. Forever grateful, EV

To all the patients and families I have worked with over the past 30 years. You have each taught me something! ER

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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.



ASD—What Do These Initials Mean?

ASD is the short and simple way to say **autism spectrum disorder**. But ASD is far from simple.

You probably noticed that the word *autism* is part of ASD. So, what is autism? Doctors and other professionals use this word to describe brain disorders that affect how you think, learn, communicate, and behave.

The word *spectrum* in autism spectrum disorder means “wide range.” This is a good word to use because the term *autism* can describe a wide range of different symptoms. All people with autism have some type of difficulty with:

- communication
- social skills
- how they enjoy activities and interests

These difficulties may be mild or more serious—and every person with autism is unique. People with autism have a “spectrum” of differences.

Because people with the symptoms of autism are now mainly referred to as being “on the spectrum,” we use that language in this book. We talk about **autism**, **autism spectrum disorder**, and **ASD**. We like to use phrases like “kids with autism” rather than “kids who are autistic” or “autistic kids.” Some people use terms like “autistic person” freely. Others don’t. We used language we prefer—hope that’s A-OK with you!

In the past, other terms were sometimes used to describe people on the spectrum. Maybe you’ve heard of “Asperger’s” or “Asperger’s syndrome.” This term applied to those who had the symptoms of autism but who didn’t have difficulties in learning to talk or in the speed of their learning when they were young. The word *Asperger’s* comes from Johann (“Hans”) Asperger, a doctor who studied mental disorders in children in the 1930s and 1940s. Today, doctors and other experts do not use his name to describe people with ASD—they use the term “autism spectrum disorder.”

If you've been diagnosed with Asperger's in the past and prefer that term, that's fine too. Lots of people still use it. In fact, if you turn to "Where to Go for More Info" (pages 233–234), you'll see book titles about Asperger's and "Aspies." *Aspie* is a short form, a nickname. You're free to use whatever term you like to describe *you*.

Learning that you have ASD can be a confusing experience—and we'd like to make it easier for you. We want to tell you "It's going to be okay." And it *is*. That doesn't mean it's going to be "super simple" or "problem free," though. We wish it could be. But life is hardly ever super simple and problem free.



We wrote this book to help you better understand your needs and differences. We hope it will help you with daily issues, such as your feelings, behavior, and communication with other people. We recommend that you **read the book with an adult**, even if you're already a strong reader. Why? Because reading with a parent or another grown-up who cares about you is an important way to get support. An adult can answer your questions and help you try out the ideas and tips.

Another reason we wrote this book is because we have a special place in our hearts for kids who have ASD. Both of us are mothers whose sons are on the spectrum. While raising our sons, we've heard comments like:

"People with autism can't live in the 'real' world—they're in their own little world."

or

"People with ASD never have many friends or want to be social."

We don't believe in can't or never. If you have ASD, there are some differences between you and other people. But your life can be about *can*. You *can*

- make friends
- succeed to the best of your ability in school
- be an awesome son, daughter, sister, brother, or friend
- learn, grow, and connect with others

Never Say never. Life is about trying your best and learning from each new experience. We believe in you and want you to grow up healthy, strong, and proud of who you are! The power to do that is in your hands—with help from your family, your school, and the experts you work with.

Let this book help you along the way. We know it's a long book. But learning about ASD and facing its challenges can be a long process—one that takes time and effort. The book is not meant to be read all at once. Use it in a way that works for you, focusing on chapters or sections that are useful at a given time. Think of it as a handbook you can go to when you need help with a certain issue or have a question about ASD. You and your parents can turn to it again and again over the years.

The table of contents and the index can guide you to topics of interest. Look at the stories of kids with autism: you may find inspiration or shared experiences. Try some of the book's tips to see what helps you right now. But remember that learning new skills takes time, patience, and practice. Give yourself the time you need.

If you have questions that the book doesn't answer or if you want to tell us about yourself, email us at: help4kids@freespirit.com. We can't wait to hear from you!

Elizabeth & Elizabeth

P.S. On the next page is a section for adults, written for any grown-ups who are reading this book with you. If you'd like, you can go straight to Chapter 1 (page 10) to find out more about the question "What Is ASD?"

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).

These stories give a glimpse into the range of challenges our children face each day. The book also includes quotes from real kids who have shared thoughts and insights that may help others with ASD realize they're not alone.

After Part 3, you'll find additional information for you and your child, including a section for parents and caregivers called "Sharing the Diagnosis with Your Child." We hope it helps you feel more confident about—and ready for—this special conversation.

Your role as a parent is unique and complex, just as your child is unique and complex. You need added support from relatives, friends, neighbors, teachers, therapists, doctors, experts, and local organizations focused on autism spectrum disorder. If you're struggling to juggle all that's required of you, ask for help. Even if you're not struggling, ask for help. Reaching out can be an enlightening, rewarding experience. You'll likely find a community of people with amazing stories, invaluable knowledge, strong bonds, and exceptional openness and tolerance.

Being a parent to a special-needs child takes a unique kind of knowledge, courage, and dedication. There's no map to point the way—no expert who can tell you exactly what's best for your child now or in the future. You'll learn by trying new things, seeing what works and what doesn't, and gathering all the support and resources you can. Autism spectrum disorder teaches you. Your child teaches you. Other families living with ASD teach you. Together, you and your child grow stronger with every new challenge you face.

We wrote this book because we care a lot about young people on the spectrum. We believe they can succeed at home, at school, and in their communities. We want them to enjoy life, set goals within their reach, make friends, keep friends, learn, grow, achieve, know who they are, and feel a sense of belonging in the world. We hope to give readers (both young and not so young) a sense of optimism and positive direction. However, we're not suggesting that you should be relentlessly upbeat about your child's condition or expect miracles—after all, autism spectrum disorder is a very real and challenging condition. Let's put it this way: Don't think of ASD as a life sentence . . . it's a life difference. People with autism spectrum disorder can have rich, fulfilling lives.

You teach them how. You lead the way. Let this book be one of the many tools you turn to for help on the journey.

For more information, we recommend looking into the Autism Society: autism-society.org. You can also check out the American Academy of Child and Adolescent Psychiatry at aacap.org (search for autism) or visit the autism section of the Mayo Clinic's website: mayoclinic.org.

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.

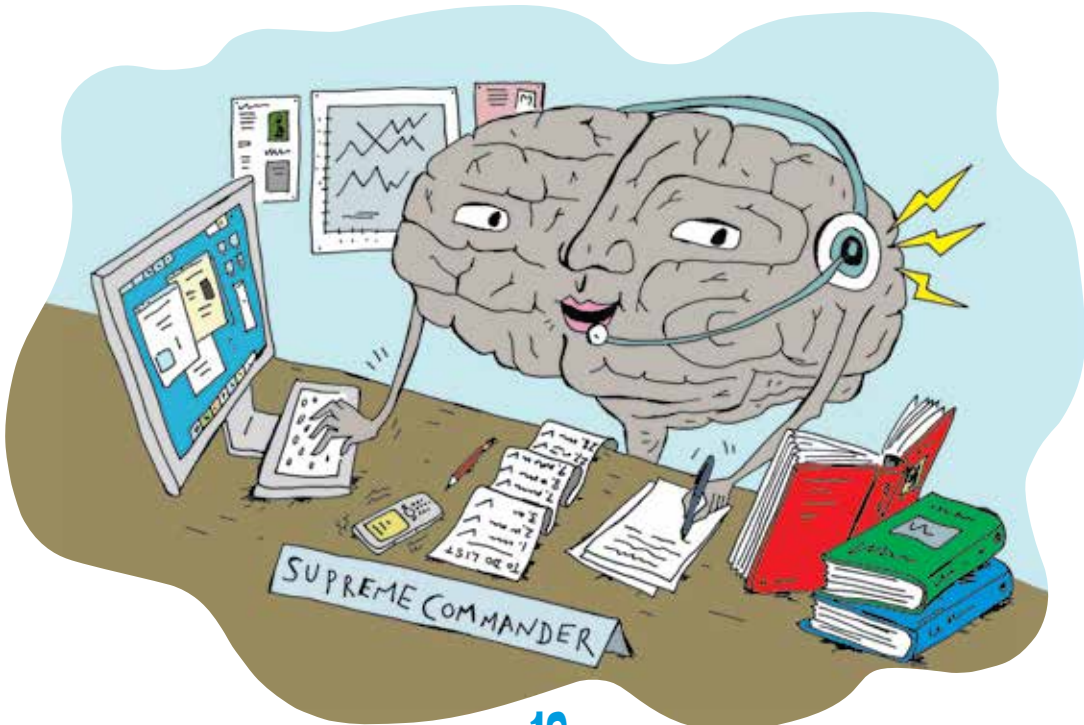
Because the difference starts in the brain, ASD has an effect on your body too. Your brain is like your command center. It sends billions of messages 24/7 to all areas of your body. Messages like:

"Legs, run!"

"Hey, what's that noise?"

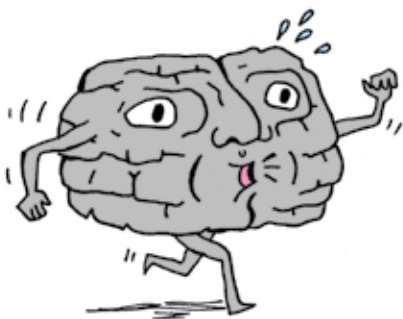
"Ouch, that bright sun hurts my eyes."

"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*

