

1

What Is High-Functioning Autism Spectrum Disorder?

Joseph had always seemed like a brilliant child. He began talking before his first birthday, much earlier than his older sister and brother. He expressed himself in an adult way and was always very polite. When his mother offered to buy him a treat at the movies, for example, Joseph said, “No, thank you, M&M’s are not my preferred mode of snacking.” He showed a very early interest in letters and by 18 months could recite the whole alphabet. He taught himself to read before his third birthday. Joseph wasn’t much interested in typical toys, like balls and bicycles, preferring instead what his proud parents considered “grown-up” pursuits, like geography and science. Starting at age 2, he spent many hours lying on the living-room floor, looking at maps in the family’s world atlas. By age 5, he could name anywhere in the world from a description of its geographical location (“What is the northern-most coastal city in Brazil?”). Just as his parents suspected, Joseph is brilliant. He also has autism spectrum disorder.

Nine-year-old Seth was playing video games in the family room while his mother bustled about the house cleaning up for the guests who would soon arrive. As she climbed a step-ladder in the living room to change a light bulb, she lost her

balance and fell backward. While she lay on the floor gasping for breath, Seth walked by on his way to the kitchen for a snack, stepped over her, and said “Hi, Mom.” Seth has autism spectrum disorder.

Clint turns 30 soon. He graduated from college with a degree in engineering, lives in an apartment in a nice section of town, recently bought a used car, and enjoys going to the movies. He is troubled, however, by his difficulty finding and keeping a job. Time and again, supervisors have gotten frustrated by his slower work pace and difficulty getting along with coworkers. Clint gets stuck on details and finds it hard to set goals that eventually lead to completion of his projects. After finishing a seasonal job cleaning hotel rooms at a ski resort, he tells prospective employers that he was “let go” without realizing that this term means “fired” to most people. Unable to find work for months, he visits a vocational counselor, who suggests a psychological evaluation. Testing reveals that Clint has autism spectrum disorder, which was never diagnosed.

Lauren is a teenager with the looks of a model. Despite her beauty, she has no friends, nor does she seem particularly interested in having any. She still loves Barbie dolls at age 17 and collects every new model and outfit that comes on the market. At school, Lauren often appears to be daydreaming; when the teacher presents directions to the class, she does not respond as she sits smiling and occasionally talking softly to herself. Despite this apparent inattention, she is a straight-A student who excels in mathematics and physics. When other kids greet her in the hallways, she sometimes does not notice and other times looks away while mumbling a quick “Hi.” Now the school psychologist has mentioned to Lauren’s parents that she may have autism spectrum disorder.

Joseph, Seth, Clint, and Lauren all have what is referred to as *autism spectrum disorder* or ASD. If your child resembles them in any way, you may also have heard the labels “high-functioning

autism,” “Asperger syndrome,” or “pervasive developmental disorder” (often abbreviated as PDD). And you probably have many questions: What is ASD? What causes ASD? How is it that my unique and interesting child, who has so many strengths, could also have such challenges? What will the future bring for my child and us? This book will answer these questions and many more.

In this chapter we define some important terms to help you decide whether this book is relevant to you and whether it may help the person in your life who has similar strengths and similar challenges. We’ll also tell you what we know about who has these disorders and what the future may bring to these children and their families.

The word *autism* was coined from the Greek word *autos*, meaning “self.” The term was first used to describe a specific set of behaviors in 1943 by Leo Kanner, a child psychiatrist at Johns Hopkins University in Baltimore. In his landmark paper, Dr. Kanner described 11 children who showed little interest in other people, insisted on routines, and displayed unusual body movements, like flapping their hands. Many of the children could talk: some could name things in their environment, others could count or say the alphabet, still others could recite whole books, word for word, from memory. However, they rarely used their speech to communicate with others. The children had a variety of learning problems in addition to their unusual behaviors.

For many years after Dr. Kanner’s initial description, only those children whose behaviors were very similar in type and severity to those of the original cases were diagnosed with autism. Slowly, however, we began to recognize that autism has a wide variety of faces and can be found in children with good communication skills, who are of normal intelligence, who have few learning problems, and who show milder versions of the behaviors Dr. Kanner described. These are so-called *high-functioning* individuals; this term has been defined in different ways but generally means having normal intelligence and a fairly good command of language. We now know that autism is not a narrowly defined condi-

tion, but rather a spectrum that varies in severity from the classic picture described by Leo Kanner to milder variants associated with good language and cognitive (thinking) skills. For this reason, we now use the term *autism spectrum disorder* (or ASD). The subject of this book is the high-functioning end of the spectrum.

Good language and cognitive skills mean that many children with ASD, like Joseph and Lauren, often do just fine in school and tend to get along well with adults. But in other ways, Joseph's unusual behaviors make life challenging. Joseph's intense interests often disrupt family activities; his parents are often unable to persuade him to leave his science projects to use the bathroom or come to the dinner table. On a recent trip to Disneyland, he insisted on taking along his globe, which had to be transported in a baby stroller throughout the park. Joseph's professor-like speech makes him stand out among his peers, who delight in teasing him and rarely accept his invitations to come over and play. Joseph has begun to make negative comments about himself ("Nobody likes me"), and his parents worry about depression. Lauren, on the other hand, doesn't seem to mind being virtually friendless, but her parents are worried about her social isolation and the social life that she is missing. A boy invited her to the junior prom, and her mother bought her a dress, but Lauren refused to go; her mother spent prom evening worrying whether her daughter would ever make any friends. Clint certainly has the intelligence to be successful, but his social awkwardness and blunt comments to coworkers ("It's too bad you broke up with your boyfriend, but we're here to work, not talk") mean that he has never kept a job for longer than a few weeks. He is also underemployed: despite a degree in engineering, Clint has held a variety of manual labor and store clerk positions. And Seth illustrates another problem that some people with high-functioning ASD have: difficulty reading other people's emotions and thus understanding empathy. Until her son was diagnosed with ASD, Seth's mother was convinced that it was something she did that had led to her son's difficulty with responding appropriately to others and their feelings. When he was young,

Seth would talk so loudly and behave so unusually in restaurants (for example, by taking food that appealed to him off other diners' plates) that the family was sometimes asked to leave. Seth's mother remembered sympathizing with a neighbor whose daughter was in a wheelchair about the restrictions their children placed on their families. The neighbor listed several things her family couldn't do, such as go hiking together, and then asked in astonishment, "What can't you do?" And Seth's mother, taken aback, said, "Why, we can't do anything! Seth's behavior is so active and difficult in public, but he seems so normal, that everyone gives us terrible looks. It's just too hard on us, especially Seth's siblings." These conditions can be stressful not only for the individuals who have them, but also for their families.

At about the same time that scientists began to realize that autism was a spectrum disorder and that there were high-functioning forms of it, Dr. Lorna Wing, an eminent British researcher at the Institute of Psychiatry in London, brought something called Asperger syndrome to the attention of the English-speaking world. Dr. Hans Asperger, an Austrian pediatrician, had first described children with the condition in 1944, apparently without any knowledge of Leo Kanner's work. Because Asperger's paper was written in German and published during World War II, it was not widely read. Until Dr. Wing's paper was published in 1981, the condition remained virtually unknown in the United States and other non-German-speaking countries. In her paper, Dr. Wing summarized Asperger's original publication, but she also noted the similarities between Asperger syndrome and autism, raising for the first time a question that is still with us today: Are Asperger syndrome and high-functioning autism the same disorder or two separate ones?

Asperger syndrome was first included in the manual used by doctors to make psychiatric diagnoses, the *Diagnostic and Statistical Manual of Mental Disorders* (or DSM), in 1994. People began being diagnosed with Asperger syndrome shortly afterward, and it rapidly became a popular diagnosis to describe individuals with

milder forms of ASD, who had good language and cognitive skills. The question of whether it was different from autism remained, and many researchers conducted studies to try to answer this question. Over the next 20 years, dozens of investigations were carried out and research evidence accrued that, in fact, there were virtually no reliable differences between Asperger syndrome and high-functioning autism. People with the syndromes share the same challenges and the same strengths in their learning profile. They require the same treatments, respond equally well to those interventions, and have similar outcomes later in life. Their brains look similar in brain-imaging studies. And perhaps most telling, Asperger syndrome and autism seem to have the same causes. It is common for families who have two children on the spectrum to have one with Asperger syndrome and one with autism. Even within identical twin pairs, who share the exact same genetic profile, one can be diagnosed with Asperger syndrome and the other one with autism. It began to look more and more to both researchers and clinicians like high-functioning autism and Asperger syndrome were two names for the same condition. Therefore, when the diagnostic manual used by all psychiatrists and psychologists to make clinical diagnoses was revised in 2013 (abbreviated as DSM-5), Asperger syndrome and high-functioning autism were wrapped up into a single diagnosis called autism spectrum disorder (ASD). Children who would previously have met criteria for either Asperger syndrome or high-functioning autism will now meet criteria for ASD. Chapter 2 goes into more detail on diagnostic procedures, recent changes in the newest version of the DSM, and how they may affect your child and you. What is important for parents to know is that whatever the conditions are called (high-functioning autism, Asperger syndrome, ASD, or the broader term *pervasive developmental disorder*, or PDD), they present many of the same strengths and challenges and similar treatments will help individuals who have been given any of these diagnoses. The practical guidance in this book will help those with any of these diag-

noses. We will use the term *high-functioning autism spectrum disorder*, or simply ASD, throughout this book to include *all* conditions.

What Does High-Functioning Autism Spectrum Disorder Look Like?

No one will display all the features that characterize ASD; some individuals will exhibit fewer features than others. Just as no two people without ASD, even identical twins, are absolutely alike, no two individuals with ASD behave in exactly the same way. All, however, have some difficulties socially interacting and communicating with other people and show some odd or repetitive behaviors.

Problems with Social Interaction and Communication

The core feature of ASD is difficulty with socially interacting and communicating with others. Challenges in this area span a wide range. The striking social impairments of more classic autism, such as social remoteness and avoidance of other people, rarely appear in higher-functioning children like those we focus on in this book, but difficulties nonetheless exist. Some children, like Lauren, don't go out of their way to start conversations or interact with others but do respond if other people approach them. Other individuals show interest in people and enjoy their company; they may even want to join groups and make friends. However, their ability to do so successfully is limited by their difficulty knowing what to do or say in social situations. They may be awkward and unsure during interactions. They may give the impression that they are not interested in the person they are talking to because they don't follow the "rules" of social interaction. Most of us naturally know that we should look at the person we're talking to, smile, and nod occasionally to signify that we are paying attention. People with ASD,

however, don't seem to appreciate these unwritten rules of social engagement. Their behavior while out in public may sometimes be inappropriate or embarrassing when, in addition to failing to use these social niceties, they violate clear social conventions, such as refraining from asking overly personal questions or keeping certain opinions to themselves. It may indeed be true that your neighbor's upper arms look like "fat sausages," but this is information best kept to yourself.

People with ASD often appear not to understand other people's feelings or points of view, which makes their social interactions even more difficult. Often these abilities, natural to the rest of us, are delayed or do not develop fully even as the child gets older. Empathy usually begins emerging in infancy, when young children start to show an interest in and a concern about the feelings of others. It's not uncommon in day care centers to see babies break into sympathetic wails when another infant cries or to see toddlers take a toy or an adult to a crying child in an attempt to comfort their peer. Preschoolers are fascinated by the moods of others and often talk about friends being angry or sad. In their pretend play, young children enact scenes in which characters are sick or upset, grappling with understanding such states and how to respond to them.

In contrast, many children with ASD have basic difficulty appreciating the emotions of others (and often their own as well). As Seth's mother could attest, some, but not all, children with ASD don't notice when parents, siblings, or other children are hurt, sick, or sad, and even when they do they rarely offer comfort. Or they may horribly misunderstand others' feelings. One boy burst into laughter after his father fell down the stairs, tearing ligaments in his ankle. When his horrified mother asked why he was laughing, he explained, "Dad is jumping around and making funny faces like a clown." Clint described an interaction with a coworker who made "a strange face" after he told a joke. He didn't think much about it until later, when he saw a photograph of a woman bearing the exact same facial expression. He showed the picture to

his mother and asked how the woman felt. She said, “Offended, I think.” Clint has felt bad about insulting his coworker ever since, but says, “If someone is insinuating something through their face or body, without being direct, I just can’t grasp it.”

While most children with ASD establish warm, loving relationships and secure bonds with parents, siblings, and understanding adults, most, if not all, individuals with ASD experience difficulty relating to peers of approximately the same age. Some children are teased or bullied, others are ignored by kids, and still others, like Lauren, seem perfectly content to have no friends. Some develop friendships that revolve around shared interests (such as video games). Many children with ASD report feeling lonely and socially isolated because of such peer difficulties. They are hurt by teasing and often unaware of their unusual behavior or social responses that may contribute to the situation. In later childhood or adolescence, they can become painfully aware of their differences from others and their inability to understand the fundamentals of interaction that others accomplish naturally. One teen stated, “I know I’m supposed to look people in the eye—my parents are constantly reminding me—but it doesn’t help me understand them, so I just don’t do it.” This can lead to low self-esteem and low self-confidence that, in a vicious cycle, perpetuate the problems. As the child loses hope of social success, he or she gives up trying to interact with others. This only increases social isolation, which may further compound the awkwardness or outright oddity of the child’s social behavior. In the most extreme cases, the cycle may lead to serious bouts of depression that require treatment. Fortunately, as we will discuss later in the book, children with ASD are capable of learning how to interact socially and even interpret other people’s emotions. With “social skills training,” most if not all children make significant improvements, and many go on to have rewarding and successful relationships with their peers and others.

ASD also involves communication problems. A prominent feature of classic autism, at least in the minds of many people,

is an inability to talk or very significant delays in speech. What is less well appreciated is that even high-functioning individuals on the autism spectrum experience difficulties with communication. This, it turns out, is one of the most confusing parts of the diagnostic puzzle and often leads to misdiagnosis when the child is young. You may have had autism raised as a possibility at some point in your child's life, only to have it "ruled out" or to be told later that he or she couldn't possibly have autism because the child speaks so well. It is now clear, however, that some children on the spectrum have very good language skills. Some children show initial speech delays and begin talking late, but soon catch up and speak fluently and articulately later on. A smaller, but not insignificant, number of children develop speech on time or even early and parents may first believe their child is gifted based on precocious language skills. Yet there are virtually always differences in the way language is used, particularly in social contexts, that can cause problems. The child, adolescent, or adult with ASD may dominate conversations, talking on and on without giving others the chance to say anything. The pedantic or overly formal manner of speaking that Joseph uses is common. At age 7, Joseph begins many statements the way a professor might, saying, "Actually . . ." or "I do believe. . . ." He has a vast vocabulary and loves to use unusual words—the bigger the better. When asked his favorite color, he pointed to a yellow balloon and said with a smile "chartreuse." Clint defines terms that don't need defining. He readily tells people that he is autistic, hastening to add, "Autistic is the adjective for the noun *autism*" as if we would not know what the word meant without this explanation. While there is nothing technically wrong with phrasing things so formally, it certainly makes Clint and Joseph stand out from their peers and often makes them the target of teasing. Joseph's mother likens his speech patterns to someone who speaks English as a second language: other people can figure out what he is trying to say, but the way he phrases even simple statements makes it seem as if English is not his native tongue.

Another communication challenge for children with ASD is their *literal interpretation* of what is said. As we all know, often what we say is not exactly what we mean. When his mother sarcastically commented that Seth, who had ignored her request to clean his room, “was doing a really good job,” he nodded and continued playing video games. He didn’t appreciate his mother’s frustration, conveyed by her tone of voice and facial expression, or notice the mismatch between her statement and the context. Another boy, when someone called his house and asked if his mother was home, answered “Yes” and then hung up the phone. He took the question literally, rather than understanding it as a polite but indirect way of asking to speak to his mother.

Still another common communication difference shown by people with ASD is *how* they speak. Children with these disorders may speak very loudly or, conversely, too softly to be heard well. Words may tumble out of their mouths at breakneck speed or crawl out as if on a recording played at the wrong speed. Or their speech may have an unusual rhythm, with emphasis placed on the wrong words in sentences, a rising conclusion to a statement, making it sound like a question, or little inflection, giving their voice a flat tone. There may be fewer of the natural pauses we usually make in conversation, resulting in run-on speech. Or they may take breaths at unusual points during speaking, such as in the middle of a word or phrase. Often children with ASD are unaware of how different from others they sound. Like social challenges, communication challenges can be addressed with interventions that focus on conversational skills.

Unusual Interests and Repetitive or Ritualized Behaviors

The second area in which high-functioning people on the autism spectrum differ is in terms of their repetitive or ritualized behavior. You will probably have noticed that your child’s range of activities is relatively focused and that he can do the same thing over and over again without getting bored. He may have very specific

interests that verge on obsessions. These kids have the favorite pastimes that many children have—computers, video games, dinosaurs, astronomy—but pursue them to the exclusion of almost everything else. Many parents report that their child will stay at the computer for hours, not breaking to go to the toilet, to eat, or to sleep unless pressured, and even then with much resistance. The intensity of the child's interests seems odd to others and may contribute to the child's social isolation. So does the child's choice of interests. Few children (or adults) not on the autism spectrum appreciate the intricacies of the stock market, astronomy, sprinkler systems, or botanical classification, but these are the types of things that children with ASD tend to favor. Their interests often revolve around topics about which the child can amass a great deal of facts and information. Sometimes these children also form unusual collections. One teenage girl with ASD saved the little sticker from every banana and apple she had ever eaten, keeping them in a treasured scrapbook that she carried with her everywhere.

What many onlookers find even more puzzling about children with ASD is that, despite all the time they spend on these interests, they often do not have good commonsense knowledge of their favorite subjects. They zero in on the details but are often unable to see “the big picture.” One young man with ASD was very interested in vacuum cleaners. He knew everything there was to know about vacuums: the cost, color, repair record, and number and kinds of attachments for every brand on the market. He correctly identified my (S. O.) home vacuum as “tan with chocolate-brown trim” with two attachments, one hose-like and one with a brush. Its repair record was not good, he explained to me, since most of the internal parts were made of plastic rather than metal (in fact, it did not seem to work too well!). But when asked for advice about replacing it with a better one, the boy became agitated and eventually advised me to purchase a Royal, justifying this choice by explaining that it has a blue bag. Like many individuals with ASD, he seemed unable to distinguish important

details from irrelevant ones and to weigh the multiple details he had memorized. If your child has ASD, you may notice that she has the same problem with thinking in general, demonstrating an excellent memory for facts but more difficulty understanding abstract concepts and using common sense. If you give your child a rule, she may have trouble generalizing it to a slightly different situation. Your child may want to solve problems the exact same way each time and may get very frustrated when you try to help her see new solutions or ways of doing things. The difficulty with seeing relationships among pieces of information, identifying central patterns or themes, and figuring out what things *mean* can make learning challenging for children with ASD, as we discuss in Chapter 7.

Many children with ASD not only engage in repetitive behavior but also use repetitive language. For example, some children memorize things that other people say (or phrases or dialogue from videos and books) and then incorporate them into their own speech. This memorized speech is called *delayed echolalia* and, while idiosyncratic, does indicate that the child has a well-developed verbal memory. Sometimes the echoed phrases are used in an appropriate context and make sense, as when Joseph exclaimed, “Oh no, it’s my worst nightmare!” (dialogue from a Disney movie) after spilling milk on one of his treasured maps. Other times the link between the phrase and the context is less clear. Seth’s mother reported that as a small child he would say “He’s a happy man right there” whenever he put on or took off a hat. For years, she and Seth’s dad had no idea where this comment came from or what it meant. Then one day they happened to be watching an old golf video they had taped several years earlier. They were astounded to see one of the golfers make a hole-in-one and then tip his cap to the audience as the announcer said, “He’s a happy man right there.” Seth had associated this phrase with hats, and the two remained linked in his mind, although the phrase made little sense to others and didn’t help him communicate his wants or needs.

The Strengths That Accompany the Challenges

Having ASD comes with challenges but also many strengths. In this book, we focus on both aspects of ASD and help parents learn how to minimize the challenges while capitalizing on their child's strengths. In this way, people with ASD can become happy, successful members of society who have rewarding and meaningful lives. ASD is associated with many special gifts, talents, and inclinations that come along with the challenges and make your child a very special, unique, and interesting person. Many children and teens with ASD have excellent memories. They remember details of family trips, routes around their city, or spelling lists effortlessly. Many also excel in reading. Like Joseph, they may teach themselves to read at an early age and later be able to read words aloud and spell well above grade level. Others are very advanced in visual-spatial skills, putting together complex jigsaw puzzles, reading maps, or working electronic equipment far better than their peers. We will describe ways to apply your child's special interests to the "real world," so that his incredible abilities to focus, memorize, and spend long hours immersed in a topic become invaluable strengths. You may have heard of Dr. Temple Grandin, a professor of animal science at Colorado State University, who has ASD. She combined a strong interest in animals with her visual-spatial strengths to revolutionize the design of animal slaughterhouses, making them more humane as well as more efficient. She has become an international expert on the topic, giving lectures around the world. For careers that rely on detail orientation, such as library administration, engineering, or computer science, having ASD might be an asset. Your child thinks, views the world, processes information, and has a personality style that is different but not inferior. Great strengths come with the challenges. *Our* challenge is to harness those strengths and use them to overcome the hurdles that stand in the way. Chapter 5 offers practical suggestions for meeting that challenge.

What Lies Ahead?

The combination of challenges and talents seen in children with ASD strikes fear in the hearts of many parents. Which will prevail, the child's deficiencies or the child's strengths? What can you do to make sure that your child doesn't slip through the cracks because her needs are not as extreme as those of children with more severe autism? What are your child's chances of going to college, getting a good job, and marrying? When a child displays such a mixture of challenges and strengths, it is often difficult to predict what the future holds. Of course, what may lie ahead is one of the first questions parents ask.

We see tremendous variability in individuals with ASD as they get older. Some go to college, develop successful careers, and form lasting friendships, while others continue to live with family members and are underemployed in jobs that do not take advantage of their intelligence and special abilities. Adults with ASD, such as Temple Grandin and Liane Willey, have written books that eloquently describe overcoming early challenges and successfully adapting to society (see the Resources at the back of the book). Many adults continue to have a variety of residual social and communication difficulties, however, and the rates of independent living and full-time, unsupported employment are lower than we would like to see.

Our ability to predict the future for children with ASD is still limited. While we are beginning to understand the wide range of possibilities, we don't yet know how to match specific early characteristics with later outcomes. Previous research is not as helpful as we might hope because the study participants were either diagnosed with more classic autism in childhood or diagnosed late in life (since the field did not generally appreciate the existence of higher-functioning forms of ASD until recently), and therefore did not receive the treatments that we now believe are very helpful. Dr. Kanner predicted that the outcome for people with autism

might improve in the future as the disorder became better recognized and new treatments were developed—just as we’ve seen with bipolar disorder and other conditions that once came with a poor prognosis. Recent studies have in fact found that very poor outcomes, such as institutionalization, are rare nowadays. As individuals with ASD are diagnosed earlier and provided with state-of-the-art treatments, we expect that the rate of the best outcomes, including satisfying careers and independent living, will continue to increase. In this section, we briefly describe what is currently known about how ASD unfolds and what might happen in adulthood. Much more on this topic appears in Chapter 9.

As with many conditions that begin in childhood, both the challenges and the triumphs of ASD change over the person’s lifespan. Symptoms begin in infancy, increase for a few years, usually peak in the preschool period, and then begin to level off in the school-age years. Virtually everyone with ASD improves with time and age. Children learn to express themselves through language and understand language better as time goes on. They become more and more interested in social contact, and they gain skills such as making conversation and using eye contact appropriately. Still, most children will continue to qualify for a diagnosis of ASD as teenagers and adults. A recent review investigated how often individuals “recovered” from ASD (that is, met criteria for an ASD diagnosis at one point in their lives but lost the diagnosis as they got older). Looking across many different studies, they reported that between 3 and 25% of children lost their diagnosis and entered the normal range of cognitive, adaptive, and social skills as they got older. While most individuals continued to meet criteria for ASD, many made significant improvements in social behavior and communication skills over time. However, many adults with high-functioning ASD admit they still feel somewhat awkward or unsure of themselves when talking to and interacting with others; their speech is still often very formal; and they still have trouble knowing how much to say or when to stop talking. Dr. Patricia Howlin, a psychologist in the United Kingdom who

has written a great deal about outcome in adult life for individuals with ASD, concludes that while some individuals may succeed as adults, such achievements depend on the available support systems (parents, intervention programs, educational accommodations) as well as on the individual's personal characteristics and abilities. She describes how the pressure to fit into a culture with very different values can come at a high cost, including stress, anxiety, and depression. Even when adults with ASD achieve important milestones, like graduating from college and establishing careers, they sometimes struggle with independent living. Seth's mother summarized both her hopes and her fears by saying "I bet he'll become an astrophysicist, but I might have to dress him and drive him to work."

Finding Social Support for Yourself

As you search for answers about how and why your child is so different, you may feel alone. You may have spent years feeling that no one else has a child just like yours. In fact you might never have heard of ASD before your doctor or someone else raised the issue. Actually, you're not nearly as alone as you may now feel. The most recent prevalence estimates released by the Centers for Disease Control and Prevention (CDC) in 2014 found that one in 68 children in the United States (or 1.5% of the population) are diagnosed with ASD. These numbers have been rising over the last several decades. Thirty years ago, we estimated only two to four of every 10,000 individuals had an autism-related condition, and even 10 years ago the published rate was one in 250.

Only about a third of the individuals with ASD in the CDC's 2014 study had the kinds of intellectual and learning impairments of classic autism. Fully two-thirds of the children were on the high-functioning end of the autism spectrum, without intellectual disabilities. This suggests that children like yours are actually more common than children with classic autism.

If we now think that ASD is much more common than we did a decade or two ago, a question naturally arises: Is autism increasing in frequency? Is it truly more common than it used to be, or do the rising prevalence figures simply reflect better diagnostic practices and increased awareness of the milder end of the continuum? The jury is still out. There is no doubt that diagnostic criteria have changed over the years to include milder forms of ASD and that professionals are more aware of and better trained to make accurate diagnoses, all of which would contribute to increased prevalence rates. Another influential factor in the rise of prevalence rates is the improvement in services for ASD that has occurred in the United States and other parts of the world over the last three decades. This is important because prevalence rates are calculated using records from service agencies. Very few prevalence studies go directly into communities and assess all the children to figure out how many of them have ASD. Usually, prevalence studies (like those done by the CDC) review the records of schools and community agencies that serve individuals with ASD. Therefore, if we are doing a better job of providing treatments to children with ASD, then more of them will have records in these service agencies to be counted—and prevalence rates will rise. In addition to these explanations, some scientists also suspect that environmental factors increase the risk for ASD and contribute to increased prevalence rates. This is an active area of investigation at research centers around the world. We talk more about these studies and their findings in Chapter 3.

All autism spectrum disorders are much more common in males than in females; this was recognized by both Leo Kanner and Hans Asperger and has been validated by numerous studies since their time. The CDC's 2014 report stated that 1 in 42 boys were diagnosed with ASD (over 2%), whereas only 1 in 189 girls (or about 0.5%) were affected. Another study has shown that the recurrence rate (the likelihood that a family with one affected child will have a second one) is substantially lower for girls than for boys, with only 1 in 10 younger female siblings developing

ASD, while 1 in 4 younger male siblings is at risk. In fact, boys are at greater risk than girls for virtually all developmental, behavioral, and learning disorders.

The reason that girls are affected less often than boys is not yet clear. As you will read in Chapter 3, ASD seems to have multiple causes, and more than one factor may have to be present for the disorder to develop. It has been speculated that there is something about being a girl (perhaps a different prenatal hormonal environment or sex-related patterns of brain organization) that “protects” females from ASD and other developmental problems. With such protective factors present, the risk for developing disorders is lower in girls than boys and may require the presence of more of these causative factors.

In this first chapter, we described high-functioning ASD and how it influences the lives of affected children and their families. Our goal, at this point, is to help you decide whether the diagnosis of ASD is relevant to the person in your life you are worried about and whether this book will help you in your search for answers. The next chapter will explain how professionals currently arrive at a diagnosis, which conditions can be confused with ASD, and how recent changes in diagnostic practices may affect your child and you. The more you know about the diagnostic process, the greater power you have to ensure that your child receives the most accurate diagnosis possible.