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## A NEW UNDERSTANDING OF AUTISM SPECTRUM DISORDER

Autism was initially described in the 1940s as a single disorder of childhood. The hallmark symptoms described at that time are likely familiar to you: the children seen then, like children today with autism, had substantial difficulty with social interactions and communication and a restricted range of interests and behaviors. These still-classic features are seen in behaviors such as reduced eye contact, limited facial expressions, and unusual ways of interacting with other people. You may have noticed that along with unusually narrow and often intense interests, many children with autism are also highly sensitive to certain touches, textures, sounds, or sights—and prefer the same routine every day.

While these features are essentially how we still describe autism today, we have a more nuanced understanding of the life path for those with autism. Symptoms are rarely noticeable during the first 6 months of life and typically emerge at around 8–12 months. However, for about a third of children who will develop autism, development is apparently normal until toddlerhood, followed by a loss of skills at that time. Regardless of the developmental timing, autism severity varies widely—some individuals live and work independently; others cannot. Some develop adequate language skills; some never develop language. For most, the challenges are lifelong, but every child makes progress and acquires skills, although at widely varying rates. In other words, it is certain that not every single thing we say about autism will apply to your child.

In fact, while scientists treated autism as a single condition for decades, it no longer makes sense to do so. Kids with autism differ so much from each other that it's vital to take the general principles we'll cover and then tailor them to your individual child. You have no doubt already begun that process; we'll make more suggestions as we go. For now, it's important to realize that science agrees with many parents' intuition that there are many different kinds of autism.

These differences can be vast. Parents whose child cannot talk or do any math will wonder how their child can have the same condition as a child who can do algebra or explain the periodic table of elements.

Likewise, while the causes are only partially understood, we are confident now that there is more than one cause of autism. In fact, the latest scientific view is that ASD is a collection of several related conditions, with identifiable and partially shared characteristics. This new understanding has paved the way for major gains in understanding the causes—and new hope for effective treatments for children with ASD.

Although this book explains many recent advances in our understanding of ASD, some of the most significant to the outcomes we can expect for children with the disorder—and the most important for parents to be aware of—are the following.

## AUTISM FALLS ALONG A SPECTRUM

Let's start with the idea that autism occurs along a spectrum, a concept that is now generally accepted by researchers and clinicians. Before we delve into what we mean when we use the word "spectrum," how did we get from autism as a single disorder to a spectrum?

### The Evolution of the Diagnosis

Clinicians use a common system to diagnose mental health and developmental disorders. The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) is the guidebook for diagnosing a wide range of conditions affecting mental health and development. Developed shortly after World War II to standardize psychiatric terminology, and now published by the American Psychiatric Association, the manual has been revised

significantly over the years and now includes conditions affecting brain development and behavior in children. It is now in its fifth edition (DSM-5), which came out in 2013. Intended to guide clinicians, the DSM lists the criteria that must be met to make a valid diagnosis; other factors that should be taken into account, such as what other diagnoses should be considered; and current information about the disorder, such as its prevalence, known causes, and the physiological aspects of the disorder. The listed criteria generally include parameters for what symptoms or behaviors must be present, how long they must be present, and when they first began. But the pattern of behaviors also must cause significant impairments in social, vocational, or educational functioning. In other words, by definition, the behaviors must be causing impairments in the child's life. If they don't result in any challenges in these domains, they will not be defined as a disorder in the DSM.

Autism as an independent entity was first included as an entry in 1980 in the third edition of the DSM (DSM-III) under the label "infantile autism." In 1987 the American Psychiatric Association published a revised edition (DSM-III-R) in which the term "autistic disorder" was presented with some more formalized criteria based on new statistical analyses. In 1994, DSM-IV was published. Autistic disorder remained but was joined by associated conditions under the umbrella term "pervasive developmental disorders" (PDD). The umbrella included autistic disorder, Asperger syndrome, and PDD-not otherwise specified (these three subgroups became the future "spectrum") as well as Rett syndrome and childhood disintegrative disorder. Other associated terms, like nonverbal learning disorder, were excluded because they were not considered scientifically rigorous. Thus, for nearly two decades, from 1994 to 2013, we attempted to study and treat autism within three official subcategories: autistic disorder, Asperger syndrome, and PDD.

However, as we detail in a moment, that effort to create subtypes failed. In 2013, the new DSM-5 eliminated the subcategories, such as Asperger syndrome versus autistic disorder, and created a single autism spectrum disorder—thus broadening the autism criteria and simplifying the diagnosing clinician's task. The current criteria essentially cover what we've already mentioned—social communication and interaction challenges and narrow and/or repetitive behaviors that appear early in life and cause significant impairments.

Why was this done? While the initial years following psychiatrist Leo Kanner's identification of ASD in the 1940s were focused on describing the commonalities in ASD, over the years the broad range of challenges, strengths, and variability became apparent—culminating in the ill-fated attempt in DSM-IV to create formal subcategories. Several findings convinced the field to drop the separate diagnoses for Asperger syndrome and PDD. An important factor was that there were no treatments specific to the different subgroups. That is, there were no standardized differences in how a child diagnosed with Asperger syndrome and another child diagnosed with autistic disorder would be treated.

More crucially, it turned out that expert clinicians were not very reliable at determining which children should be assigned to which diagnostic subclassification. One decisive finding in 2012 that helped solidify the importance of conceptualizing autism as a spectrum disorder and not three distinct subgroups illustrates this. It involved the evaluation of diagnostic practices for 2,000 children across 12 university-based centers in North America where the research clinics were all conducting diagnostic evaluations for autism in the same exact way. At each site, expert clinicians at these top institutions used gold-standard diagnostic tools to assess autism and administered a standardized battery of tests to assess other features such as cognition and language. To ensure that everyone was conducting assessments in exactly the same way and following the proper DSM-IV guidelines, all the evaluations were videotaped. The final analysis showed that there were no differences in the types of children in the study—no one site saw more children with intellectual disability or more children with language impairment or irritability or motor problems or any of the other hundreds of variables—yet the clinicians arrived at radically different rates of the subclassifications. One site only diagnosed children with autistic disorder. Another site diagnosed over half of the children with Asperger syndrome. Another site didn't diagnose any children with PDD. In other words, the clinicians agreed that these children all met diagnostic criteria for the umbrella term "autism" but could not agree on the subclassification. The take-home message was that even the top diagnosticians in North America failed to consistently or effectively use the behaviorally based subclassifications. Finally, no convincing biological differences among the subtypes had been found either.

## WHY IS THERE A SPECTRUM?

The autism spectrum includes these former subcategories, as well as variation in severity and profile of symptoms. Scientists believe autism occurs along a spectrum because the core features take so many different shapes, and we now have evidence that the core deficits in the disorder develop along many different causal pathways involving different biological systems as well as different genetic and environmental inputs. To increase our understanding of the science behind autism, therefore, we now study the entire spectrum, and as we'll discuss, this approach has already paid off with clearer biological findings.

By recognizing there is a broad spectrum, scientists can use brain imaging, genetics, and other cutting-edge scientific approaches to understand the variability in the spectrum. In turn, the information we gain helps us develop treatment plans that will benefit a diverse population on the spectrum and design novel interventions and ultimately be better individualized for a given child.

One way to understand the different faces of autism, or subtypes, involves genetics. Genetic information has been helpful in doing the same thing for other conditions, such as intellectual and learning disabilities. A little over a century ago, all children with intellectual disability were considered to have the same condition. We now know, however, that intellectual disability, like ASD, is a behaviorally defined disorder with many causes. It gradually became clear, for example, that some intellectual disability ran in families and some did not, suggesting there were different causes. Over time many single-gene causes of intellectual disability have been discovered, to the point where today more than 1,000 such rare conditions are known. Yet other kinds of intellectual disability do not have single-gene causes.

One well-known example of a single-gene cause is the genetic disorder called phenylketonuria, or PKU. Prior to the identification of that gene mutation, children with PKU were simply diagnosed with intellectual disability based on their symptoms. But the discovery that the gene associated with PKU is responsible for processing phenylalanine in the body ultimately led to a simple route to preventing PKU. Babies can be given a heel-stick test at birth, and when it's positive, prevention of this subtype of intellectual disability is a simple matter of omitting from the

baby's diet the many foods containing phenylalanine. While the story is unlikely to end that way for ASD, the logic is similar—the biological and causal groupings will not be obvious on the surface, but much can be learned that will ultimately help kids at various points along the spectrum.

To elaborate on genetics for a moment, we've known that genetics plays a role in autism since the first twin studies in the 1970s. Since then many different genetic inputs have been identified for autism. As we'll discuss in Chapter 2, about 1,000 different genes and genomic regions are implicated in autism. Although these do not determine who will have ASD in the same way they do for some of the 1,000 kinds of intellectual disability, the findings do suggest that autism is probably best seen as a set of many related conditions and there are different pathways to developing the symptoms that we call autism. Finding out what, if anything, these gene effects have in common will be an important future goal for research. In subsequent chapters we will elaborate on what is known about both genetic and environmental influences on ASD.

### **Severity and Level of Impairment**

Until scientists can pin down certain subtypes based on biology, genes, or environmental causes, parents and clinicians can get information about how to help each particular child by understanding where the child falls along the spectrum. Where any individual child is on the spectrum depends to a great extent on the severity of the condition as well as the child's developmental level and chronological age. Very generally speaking, if the defining features of autism are fairly severe and impairing in a child, and the child has a developmental level much lower than is typical at that chronological age (say, a developmental level of age 3 in a 12-year-old), the child is on the end of the spectrum that will necessitate lots of support and intervention. But as recent research has shown, that very support and intervention can eventually improve the child's condition and reduce how much help the child needs in daily life going forward.

We like the spectrum idea because it can help us focus on the individual profile, the specific strengths and challenges a child has. This individualized attention allows for plans that incorporate strengths a

child may have, such as visual processing or rote memorization, to offset challenges in social processing or difficulties with transitions.

Aside from these autism-specific symptoms, research done in the last 20 years tells us that there is an array of other conditions often associated with autism, and these will also affect what kind of treatment and support an individual child needs. This is why it's so important for parents and clinicians to identify such factors in each child being diagnosed. It's not just the core symptoms that need to be addressed to produce a good outcome for the child but these other conditions too.

## MANY OTHER CONDITIONS AFFECT CHILDREN WITH ASD

One of the most obvious ways that children with autism differ from one another is the other conditions that frequently occur alongside of autism. These include physical as well as behavioral conditions. The reason for these frequent overlaps, while they are an important potential clue to causes, is generally not well known. However, the strong overlap of these conditions has been part of the motivation for the increasing contemporary scientific view that ASD and several of the conditions listed here constitute a family of related conditions associated with specific, yet-to-be-identified alterations in early brain development and growth.

### Intellectual Disability

The first of these to understand is *intellectual disability*—a term that replaces older and now stigmatizing terms like “mental retardation.” It basically means that the individual's intellectual abilities are not as developed as they are for most people who are the same age, and that, furthermore, the individual's practical life skills (what your child's clinician might call “adaptive” skills) are also less developed. These include practical skills like bathing and using money without help. About a third of people who have autism spectrum disorder also have intellectual disability. Intellectual disability can range from mild (perhaps not obvious to the layperson) to severe. If your child falls into the latter group, then additional special supports will be involved in helping him. We'll come to this again in Chapter 5.

## Language and Communication Disorders

Another condition that is commonly associated with autism is delayed or reduced language development. Language impairments vary and can range from a child having minimal or no spoken language, which occurs in about 15% of children with ASD, to a child who has unusual speech, such as repeating scripted words or phrases or echoing back what someone has just said (called “echolalia”), to those whose speech is not significantly impaired. Other types of atypical language use include the use of invented words (called “neologisms”), like using the word “coo-is-a-car” to refer to trees, or the use of pronoun reversals such as referring to oneself in third person or mixing up “you” for “I” when asking a question. For example, a child who asks “You want a glass of milk?” may actually mean “I want a glass of milk.” Other children may have difficulties only in expressing themselves in words (called “expressive language”) but be able to understand language much better (called “receptive language”). Children who have little spoken language can benefit from using technology, such as a tablet or other devices, to communicate and learn. Fortunately, with therapy, all children can learn to communicate, whether through words or other means.

## ADHD

Attention-deficit/hyperactivity disorder (ADHD) is a common syndrome, also with a spectrum of severity, that describes individuals who are extremely inattentive, unable to stay focused or organized, or else are extremely overactive (as if always driven by a motor) or extremely impulsive. As many as half of children with ASD have substantial problems with inattention or hyperactivity and would also meet criteria for a diagnosis of ADHD. Just since DSM-5 in 2013, clinicians are now allowed to codiagnose and treat both disorders. For some children problems with hyperactivity and difficulties regulating behavior can exacerbate existing social challenges because over time peers can become frustrated and withdraw from a child who is impulsive and hyperactive. That further restricts the opportunities for the child with ASD to practice and learn social skills. If your child is in this group, your treating clinicians may recommend medications for ADHD (in addition to the commonly known



Ritalin [methylphenidate], a dozen other formulations are available that can be helpful). We now know, from recent studies, that children with ASD who also meet criteria for ADHD can in fact benefit from such medicines. If the primary problem here is not hyperactivity but attention, the clinician may also recommend special skills training related to attention, to help, for example, with schoolwork. The potential lifestyle and alternative treatment proposals for ADHD and ASD overlap heavily, although the data gathered on what works reveal some differentiation between these conditions too. Interested parents may find more information about ADHD in Joel Nigg's book *Getting Ahead of ADHD*.

### **Emotional Problems**

Kids with ASD can experience emotional complications too. We live in a social world, and if you struggle to make your way through social situations, it's not hard to imagine that you would be susceptible to feeling anxious and sad. As you might predict, we often see higher rates of anxiety and mood disorders, like depression, in those with ASD—particularly in teens and adults who have more insight into their differences. Individuals with ASD who have limited language or difficulties with understanding their own emotional experiences will have trouble telling people about their feelings of anxiety or sadness. But you may be able to see it in your child's behavior, such as being overly fearful or losing interest in activities the child used to enjoy. If your child is in this group, a behavioral plan that takes into account the anxiety or mood concern can be helpful, as can methods to reduce stress and improve stress-related coping, all skills your clinician may recommend as part of your child's treatment.

### **Medical Issues**

Medical concerns that occur more often than we would expect with ASD, again for poorly understood reasons, include seizures, difficulties with sleep, and gastrointestinal (GI) disturbances. Although much remains to be learned, as we'll discuss later in this book, these medical conditions have recently provided new clues to causes of ASD. For example, epilepsy is diagnosed in a striking 20% of children with ASD—many

times its incidence in the general population. This led to the interesting finding that many of the same genes implicated in ASD are implicated in epilepsy. For example, the gene *SCN2A* is the instruction manual for the production of a protein embedded in the walls of our brain cells that controls the passage of ions across the cell wall. That passage of ions across the cell wall is what dictates how a cell functions and communicates. Disruption of the gene *SCN2A* can either facilitate too much of the passage of ions or too little. It turns out that *too much* passage of the ions leads to epilepsy early in development, while *too little* leads to seizures later in development—and ASD.

Sleep problems are common in ASD. Over half of parents of children with ASD report their child has had some sort of sleep problem, and one-fourth of parents report their child does not get enough sleep. That sleep problems commonly occur in ASD is nothing new to parents, who have been talking to their doctors for years about these challenges. However, recent scientific advances have shown that behavioral interventions to improve sleep hygiene have significant effects on learning and reduction of problematic behaviors. We'll discuss those practical sleep improvement techniques in Chapter 6. And further, improvements in your child's sleep have a positive impact on your ability to sleep as well.

Silvia's school-age daughter struggled with sleep, and their family was receiving support from a sleep specialist. Silvia's daughter had autism and intellectual disability and had experienced significant sleep problems all of her life. She would sleep for only a couple of hours each night and would sometimes go for a day or two without any sleep, which interfered with the sleep of everyone else in the family as well. In the weeks following the sleep intervention, which included a combination of behavioral training and a prescription of melatonin, Silvia became less pale, the vibrancy of her hazel eyes emerged from under baggy eyelids, and even her posture was far straighter. She said that she had forgotten after 9 years what it was like to sleep a full night through. She felt revived and engaged in the world as she hadn't in nearly two decades. Sleep interventions that have been adapted for individuals with autism can be very effective, and the positive effects extend beyond simply a good night's sleep for your child.

Similar to sleep, gastrointestinal problems are common in ASD. It turns out this is not a coincidence but a powerful clue into the causes of

autism. We talk about GI problems in depth in Chapter 7. Just to give a preview, we are now making rapid progress in understanding the relationship between GI problems and autism. This has led to a rapid change in clinical practice. Until recently, clinicians typically dismissed GI complaints as only of secondary or incidental concern. You may be among the parents who were told “We need to focus on the autism” or “I’m not sure what we can do about that.” However, it has become clear that GI complaints significantly impact behavior—children with GI complaints have more problematic and challenging behavior than those who don’t. And that makes sense. If you’re uncomfortable or in pain, surmountable stresses or frustrations can quickly become insurmountable. Over time the medical community has taken parents’ comments to heart, and now GI interventions for children with GI problems are incorporated into treatment plans.

In summary, intellectual and language impairments, ADHD, sleep, GI problems, and other associated conditions both complicate the planning for your child and provide usable scientific clues that we will turn into practical tips as we go through this book. The goal is enabling you to more readily create the “just right” individual plan for your child.

## **AUTISM CAN BE DIAGNOSED EARLIER THAN WE THOUGHT**

One of the first questions you likely heard from your doctor was “When did you first become concerned?” The answer to this question will vary for different parents and children. As surprising as it may seem, as recently as the late 1980s, ASD wasn’t diagnosed with confidence until late preschool age or even middle childhood. Clinicians simply did not know much about the early manifestations of autism. That changed with groundbreaking studies conducted in the 1990s, again emerging from parent–scientist collaborations, revealing that autism symptoms actually could be detected before the first birthday. However, it takes time to translate these scientific advances to the community, which is why there is a lag from scientific understanding to clinical practices that are available to families. As a result, it has only been in the past decade that we’ve seen clinicians apply this information to practice.

These first studies, conducted by one of us (Dawson) 25 years ago, broke new ground. The scientists obtained first-birthday videotapes from parents of school-age children definitively diagnosed with autism; they compared these to past videotapes of school-age children who developed in a typical manner without autism. The first birthday party just happened to provide something scientists prize greatly: a fairly standardized context in which to observe behavior. Most first birthday parties at some point have the child seated at a table, with friends and family gathered around. Typically, singing begins, a cake topped with flames or candles appears, and then there is lots of clapping. The tapes were coded by college students who had no idea which children had later developed autism. They were trained to simply rate the frequency of basic social behaviors, such as making eye contact or looking at faces. Although the first studies were very small, just a few key behaviors provided excellent (though not perfect) accuracy in separating which children would subsequently be diagnosed with ASD and which children would not: looking toward a person who said their name, the use of gestures, such as pointing and showing, and how much attention they paid to the people at the party (i.e., how much they looked at them). This study, and others like it, demonstrated that autism begins to emerge very early in life and pointed to behaviors clinicians might use for early screening and diagnosis. This opened the potential for imagining early intervention as an approach to prevent full development of ASD when the brain is most “plastic” (or responsive to input) in its formation. That, in turn, has provided new hope for the effectiveness of early intervention. More on this in Chapter 4.

But other recent discoveries complicate the picture. It’s not just that social skills are absent in early development. In fact, quite the contrary. Most often, babies who will later develop autism usually start out by making normal eye contact, responding normally to having their name called, and paying typical attention to other people. Then, between about 6 and 8 months, they diverge: they begin to subtly and gradually pay less and less attention to people. For some infants, however, symptoms are not pronounced until 12 months or even older. These new findings indicate that development starts typically but changes in early infancy.

This early “regression” or departure from the expected social development route seems to be the norm in autism, rather than the exception.

Usually, it occurs during the first year. However, providing another important clue to our puzzle, in a minority of children who will develop autism, that regression happens around 18–24 months of age. This can occur either gradually or fairly rapidly. This pattern can include loss of previously acquired language and social skills or simply a failure to progress or a plateau in development.

By studying the very early development of infants later diagnosed with ASD, we have learned that the early course and pattern of symptom onset are quite variable across children. We have also discovered that infants later diagnosed with ASD show other early symptoms, such as difficulties with feeding, sleep, and motor development. And some children end up with only very mild ASD symptoms, while others require lifelong supports. By the time a child is 18–24 months old, however, the *diagnosis* of autism tends to be stable for the majority of children.

## SOME CHILDREN LOSE THE DIAGNOSIS

Some features may emerge in the first year (although many diagnostic errors will still occur at that age), and the ASD diagnosis may be confidently made by about age 2, yet even then it's important to note that all children show at least some improvement once they begin to receive therapy. In addition, perhaps as many as 10% lose their autism symptoms altogether by school age—although those children typically show some other neurodevelopmental difficulty, such as ADHD, or emotional challenge, such as anxiety, that presumably led to the “false positive” in early life. When a child is very young—in the first 2 years of life—it is impossible to know whether the child's autism will end up being mild or severe. The important point is that you'll want to do what you can to help your individual child reach her full potential.

One driver for improving your child's outcome is early intervention—an exciting discovery. As we'll discuss later in this book, behaviorally based interventions for autism now bring great excitement because they really do work. However, they can be costly and difficult to obtain—in later chapters we'll explore some new ideas to build on this progress depending on your situation.

## THE SEX-RATIO GAP IS NARROWER THAN ONCE BELIEVED

Autism is diagnosed in boys four times more often than it is diagnosed in girls. One speculation was that this was due to genetic mutations linked to sex chromosomes, but it's become increasingly clear that it's not this simple. Rather, on the genetic side recent discoveries indicate that females with ASD tend to have higher rates of rare genetic mutations, or variants (discussed more in Chapter 3), than males with autism, but these variants are scattered throughout the entire set of genes (the genome) and not linked to the sex chromosomes. In fact, when looking at children with ASD who have these rare mutations, the sex ratio drops from 4:1 to closer to 1:1. Moreover, some rare gene variants that mothers pass on to their sons and daughters seem to cause ASD only in the boys and not the girls. These findings are interesting for two reasons. One is that the findings are consistent with the theory of female protection (that it is harder for girls to get ASD); in other words, for a girl to develop autism she needs more genetic disruption than a boy does. This "female protective factor" related to ASD is also seen in some other brain development disorders and may be related to how sex hormones differentially influence brain development in boys and girls prenatally. The other reason is that it adds to the idea there are multiple routes to ASD—rare genetic mutations are one route, and boys seem more sensitive to a given number of these mutations. The other, possibly more common routes likely involve complex mixtures of genes and environments, as we'll discuss throughout the book.

New advances in our understanding also suggest that autism looks different in the brain of each sex and may also produce different behavior in girls. That is, given the same underlying cause of ASD, the behaviors may look different or be milder in girls than in boys.

New research also suggests that autism is more often missed or misdiagnosed in girls—perhaps because clinicians expect it more in boys or due to other differences in how girls and boys with ASD behave—and that this accounts, at least in part, for the 4:1 sex ratio in ASD. The specific symptoms that girls exhibit might differ in how they are expressed or their severity. Some studies suggest that girls are better at "camouflaging" their symptoms compared to boys. The implications here are that we need to pay closer attention to subtle behavioral challenges to make sure we're not missing diagnoses in girls with ASD.

## WHAT KIND OF “SCIENCE” DO WE USE TO INCREASE OUR UNDERSTANDING OF ASD?

Throughout this book we'll be discussing findings from recent scientific advances in autism. We'll be extracting the key concepts and findings from different types of scientific studies. Each of these kinds of studies has strengths and weaknesses and offers pieces of the puzzle that we aim to integrate for you throughout this book. We highlight several of those study designs in the box on pages 24–25, so that as you review new findings that emerge in the scientific literature you have a little background as to the basis for our suggestions. We've pulled together the findings from all types of approaches, from meta-analyses to randomized controlled trials and prospective studies, to provide you with what the new science tells us about autism and, most important, what steps you can take toward making the changes that work best for your family.

## WHERE DOES OUR NEW UNDERSTANDING OF ASD LEAVE CHILDREN—AND PARENTS?

Increased awareness and the new science of autism have raised questions about how to think about ASD. One question is philosophical—what is autism? Is it a disorder to be treated or a natural variation in development to be appreciated, or both? Many family members and the providers involved in care for individuals with ASD aim to intervene to reduce or minimize the core symptoms that define ASD to enhance the opportunity for that child to shape his own destiny and achieve his own potential. For example, if a child exhibits repetitive behaviors, such as making unusual motor movements, a goal of treatment might be to reduce the frequency of such movements and provide the child with greater flexibility in behavior choices.

However, as in all of psychiatry, it's crucial to distinguish “helping someone achieve her true potential” from “moving someone toward conformity to social norms.” Sensitive to this risk, many advocate viewing ASD as representing differences that are part of the natural variation in ways of being human, a position that favors a focus on celebrating

### Different Types of Scientific Research Studies

- *Meta-analysis.* A meta-analysis is an approach in which all studies that address a common question are combined into one analysis to draw strong conclusions about that question. This approach, when done well, overcomes the problem that single studies are prone to chance findings, particularly if they have small samples. The meta-analysis greatly increases confidence in the estimation of an effect because it can better adjust for chance findings in individual studies. One common use of meta-analyses is to determine the degree of effectiveness of a treatment. Now, just as individual study results are less reliable if they are small or used weak methods, the reliability of a meta-analysis also depends on the size, quality, and number of individual studies being reviewed. That said, generally the findings will provide more definitive understanding of a topic than the insights from a single study.

- *Systematic review.* Systematic reviews are similar to meta-analytic studies in that they pull together the entire literature on a question using rigorous rules, but they provide less insight into the quantitative effect of a given intervention or variable under study. However, like meta-analyses, they pull together key findings from across studies, illuminating patterns that any single study cannot.

- *Randomized controlled trials.* Randomized controlled trials are a powerful way to isolate and examine the effect of a treatment. Their power comes from randomly assigning people to either a treatment group or a placebo group. When done well, the placebo is disguised so expectations from the participants or the experimenters cannot bias the results. The power of randomization is statistical—it means that when the study succeeds, we know for sure that the treatment caused the improvement and that the improvement is not due to some unmeasured factor in the situation. The treatment being studied can be anything from a 2-year behavioral intervention to a 6-week dietary approach to a single dose of medication. In this type of “double-blind” study (meaning neither the scientist nor the study subjects know which group each person is in) any conscious or unconscious biases that anyone involved in the study may have can be ruled out. The randomization also allows for ruling out any other systematic differences that



could influence the results. The key strength of this type of experimental design is that it can show that one thing caused another, not merely that the two just happened to appear together, which is what correlational studies demonstrate.

- *Prospective studies.* To improve our understanding of what autism looked like during early development scientists relied on retrospective studies, reviews of events and information that happened in the past. More recently, prospective studies have been used to shed light on autism. In prospective studies individuals with autism are followed over a period of time. These studies are important because an earlier event or “risk factor” is a clue to a cause and because they help us predict what might happen for different children even when we aren’t sure of the cause. For example, in a prospective study younger siblings of a child with autism (who we know are more likely to develop autism than the population at large) may be followed from birth and their patterns of behavior or exposure to experiences measured. Then some years later they can be assessed for ASD, and those earlier measurements can perhaps inform or predict diagnostic outcomes. While this type of study design would not prove causation, it is still more powerful than simply looking at the presence of behaviors and ASD symptoms at a single point in time. In that case we wouldn’t be able to determine which came first.

- *Whole-population studies.* Large population-based studies have proven invaluable in examining links between exposures and autism or the presence of genetic factors and autism because they can detect subtle effects that a smaller study would miss. In most studies of autism, participants are recruited from the local community or a clinic. This local approach has the advantage that kids can be evaluated in depth. But it has the disadvantage that results may not generalize to the whole population of children with ASD. Computing power and large databases have allowed scientists to examine data from much larger groups of individuals with autism, thereby increasing the likelihood that findings could be generalized to all individuals with autism. Their disadvantage is that the individuals cannot be assessed in depth, so there may be diagnostic errors and other limitations.

neurodiversity. Thus, they encourage efforts to focus on acceptance of ASD and reduce any disability associated with ASD by adapting the environment. People with this perspective might ask, “What is wrong with making unusual motor movements, especially if such movements help the child or adult feel less stressed? We should help other people accept these differences unless they are causing harm.”

The idea that autism is a difference that should be accepted has been championed by many, including adults with autism, or autistic people, which is the term that some self-advocates would prefer to use. This perspective is particularly important when individuals are already functioning quite well—for example, many of these adults are able to engage with the community and succeed in a variety of settings as part of everyday life, although not without challenges associated with ASD, such as sensory sensitivities or difficulty understanding social cues. These individuals don’t want their challenges to be misunderstood by others, and thus they advocate for increased acceptance of the differences that are part of ASD, as well as whatever supports are needed to succeed. What we call ASD is experienced as part of their personality and identity—not something they want “healed.”

At the same time, many people with ASD are suffering considerably. They are not able to engage in the broader community without significant treatment and support, such as having a constant caregiver and augmentative communication devices, which makes them vulnerable to serious suffering should those supports not be obtainable. Increasing their capacity to care for themselves and make their own informed decisions by increasing their skills is thus seen as a vital goal by many individuals, families, and caregivers as well as the mental health treatment community.

How you end up thinking about your child’s autism (and how your child will ultimately think about it) will be a personal decision, which will likely be influenced by the nature of your child’s autism, as well as personal and cultural perspectives. Science cannot provide a definitive answer to the value questions here. There is no “right” or “wrong” answer. Your view of autism will be shaped by your and your child’s individual experience. Regardless, your caring, accepting, and encouraging attitude toward your child will help your child and others feel valued and more confident.

So, as a parent, what can you do with this new understanding of autism? The first thing you can do is recognize that because autism falls on a spectrum, each child has unique challenges and strengths and thus interventions and supports will be individualized. Autism is not a “one-intervention-fits-all” type of diagnosis. One child may benefit from an intensive one-on-one treatment plan, whereas another may be better served in a group setting. One child may benefit from speech therapy, whereas another child may want to speak incessantly. The notion of a unique treatment and intervention plan can seem overwhelming at first, but recent scientific advances have provided a road map for developing a unique plan for moving forward with your child. That road map will include components from the latest scientific evidence outlining what is helpful, will include supports that build on your child’s strengths while addressing your child’s challenges, and will incorporate measures to manage co-occurring medical concerns. The second step you can take, given our new understanding of autism, is to educate yourself on what the science tells us about what autism is, how children develop, and what we can do to help each child with autism live the life that he or she wants to live. That step will provide you with the knowledge you need to sift through all the information and misinformation that is out there. It will also help you understand how your child thinks. By understanding how your child learns and thrives you will be in the best position to support him. Your third step will be to put together your own road map based on this information that you’ve pulled together about what autism is and what kinds of help can be included in a treatment package. This is a time to be hopeful. So let’s get started.