Chapter 1

Stephen
The Eccentric Entomologist

I sit and watch Stephen play in the afternoon sun outside my window. He is nine years old. I have not seen him for some time, and I'm surprised at how much he's grown. It's a warm day in December, but it feels more like spring as an early snowfall melts on the lawn. I work at an old hospital that used to be a tuberculosis sanatorium, and the maintenance staff are putting up the Christmas lights on a very tall pine tree, as they have done every December for many years. Stephen runs around the path in circles, paying no attention to the lights going up. His mother keeps a slightly anxious eye on him, as do the gentlemen working on the tree. When it's time for me to greet him, he clumps up the stairs, too heavily for so slight a boy. He announces in a loud voice, "I catch wasps!"

"Do you?" I reply, feeling rather taken aback. "That must be dangerous."

But he does not answer. He has a messy crop of blonde hair as well as lots of freckles, and he darts around my office almost like a bird, checking out the toys, the books, and the papers on my crowded desk.

He casts an anxious eye back at me and says, "I don't want to grow up!"

I nod sympathetically and try to inquire why, but again he does not answer. He would rather talk about wasps, which are his passion. He tells me all about the different kinds of wasps that exist in the world, how he has them encased in epoxy at home and how mad they get when he captures them.

"Why do you like wasps so much?" I ask.

"I like the sound they make and how their legs hang when they fly."

How their legs hang? I have never noticed the legs of a wasp, when they fly or otherwise. What is there to like about the sound and their legs?

* * *

What indeed? This book is about people with autism, Asperger syndrome (AS), and pervasive developmental disorder not otherwise specified (PDDNOS), three common and important forms of autism spectrum disorder (ASD). It is about the sound wasps make and how their legs hang in the air when they fly. Children and adults with ASD have behaviors that professionals characterize as obsessions, preoccupations, rituals, resistance to change, and self-stimulation. But instead parents might see a young boy with an excessive fascination with wasps, a child who insists on keeping all the doors on the second floor of her house open (even the one to her parents' bedroom), or a boy who gets terribly upset if the blanket on his bed is changed or the wrong cup is placed by his plate at breakfast. People with these types of disorder also typically have trouble communicating with adults and children and experience difficulties with relationships in general. In conversation, they may go off on tangents, ask the same question over and over again, even if they know the answer, or talk only about wasps or their particular, often rather eccentric, passion. Parents and other family members know that these are the often debilitating symptoms of a terrible disorder that strikes at the heart of childhood. A thousand times every day, parents feel as if they will never understand what goes on in the mind of their child, that they will never find a common ground with other people who do not have a child with one of these disorders. The simple task of shopping for groceries can become a nightmare as perfect strangers stare at them and pass judgment on their parenting skills.

In this book, I hope to convey to parents and professionals another context: how the world is perceived by children with ASD. In turn, I hope this will change our perception of the children themselves. Behaviors like Stephen's can also be seen as passions that teach us about the world and how it looks and sounds. By unraveling one mystery, I hope to reveal another, more fundamental, one. And that is that children and adults with ASD live in a concrete world, palpable and immediate, a world without metaphors. Theirs is a world of detail and of infinite variety. It is a visual world built of images, not language. Feelings, emotions, and personal relationships do not have the same value for them as they do for us and for other, typical, children. It can be terrifying and confusing to live in such a world, and it is true that the opportunities for growth and development are often limiting. But the way these children perceive the world can change and transform the way we see the world and make it a more magical place, full of wonder and variety. Children with ASD can teach us about the infinite variety of sameness, and, in seeing their diversity, we realize that there is a sameness to us all. Once we appreciate this, our attempts to help children with ASD accommodate to our world can be more successful and perhaps accomplished without the loss of their special gifts.

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Stephen has been interested in wasps for several years. This is not just a passing fancy or a hobby that he finds amusing or that fills in the time between episodes of his favorite TV shows. He is obsessed with wasps, passionate about them. He talks about them all the time, with his teachers, his parents, and grandparents, even with complete strangers. If people show little interest, he chatters on, unaware of the boredom or frustration experienced by his listener. In the summer, he only wants to go to the park or the garden center to chase wasps around the plants and bushes and try to catch them. If, for some reason, his parents cannot take him there, he becomes very upset. Of course it's difficult for him to have a friend over to play since other children are afraid of wasps and do not want to be stung. Stephen has been bitten several times, but this in no way diminishes his enthusiasm. He catches wasps in a bottle and then releases them in his bedroom and enjoys watching them fly around the room, listening to the sound their legs make as they fly through the air, as I now learn. During winter, when the wasps go into hibernation, he spends hours in his room, poring over his collection of wasps encased in epoxy.

At first Stephen's parents were completely bewildered by his interest in wasps and not a little upset. After all, nine-year-old boys should be interested in sports, in toys that shoot and dart about. How could anybody find wasps enchanting? But now they find Stephen's interest charming. They too have acquired a detailed knowledge of the wasp's habits and lifespan. The four of us sit and talk about wasps as if we are all entomologists attending some esoteric conference about the mating habits of the yellow jacket. Stephen's disability has transformed us all; me for a moment, his parents for a lifetime.

In many respects, Stephen's story is quite typical for a child with autism. His parents first became concerned with his development when he reached age one and was not yet crawling. They also noticed that, compared to his older sister, Stephen was very clingy and could amuse himself for long periods of time by making humming noises. His parents took him to see a pediatrician, and this led to several assessments that finally, at age three, produced a diagnosis of autism. The time between that first visit to the pediatrician and the official diagnosis was very stressful for the family, and they became increasingly alarmed about Stephen's development. Living without a diagnosis was very difficult. In such circumstances parents tend to blame themselves for their child's delays in development, and these recriminations become ever more strident, as the time taken to arrive at an answer lengthens.

When I saw him at three years, Stephen spoke a few words but used them only occasionally to label objects. More often, he would yell, cry, or protest. He did not compensate for his lack of speech by pointing at things, gesturing, or nodding and shaking his head to indicate "yes" or "no." Although, for the most part, he seemed to be happy, he would not smile back at his parents when they smiled at him. When his father came home from work, Stephen would not run to the door to greet him but would jump up and down and flap his arms instead. He would not hug or kiss his parents and did not enjoy cuddling. He tolerated being held by them but generally did not reciprocate their affection. He would often run his hands through his mother's hair and then sniff them. In general, he would not ask his parents to join his play activities and did not direct their attention to toys with which he was playing. If he hurt himself, he would not come for comfort and would not offer comfort to his older sister if he saw that she was crying.

He loved to play with balls, though. He would spin them, throw them, bounce them off the ground, and line them up. He liked to carry a globe around with him all the time so that he could look through the hole from one end to the other. He also enjoyed watching water go down the toilet and playing with cars, but only if they went around in circles. He became particularly excited if the antennae wobbled. He also loved to watch ants travel across the pavement and to drop sand on his balloons or pour water over them. Even though he experienced considerable pleasure from these activities, he would not share his enjoyment with others; he would not have his parents come and watch him move the cars or have them look at how happy he was. He would play with other children, but only if the games involved balls or playing tag. Left to his own devices, he would usually play with a ball, wiggle the antennae on toy cars, or lie happily in bed making humming noises to himself.

Stephen had one ritual, and that was to insist that his parents give him a hug before he entered the kitchen for breakfast. If for some reason this was not possible, he would become very upset and could not be comforted or reassured. He would also become distraught if one of his balloons made a loud noise when the air escaped. He was particularly afraid of the balloon flying around the room.

At age three Stephen began to attend a community school four mornings a week. There, he had an opportunity to be with typical children in a structured situation and with a special teacher who worked with him very closely. She had experience in working with children with ASD and was aware of the many strategies that are effective in promoting social interaction and communication. (Sources of information on such strategies are listed at the back of this book and are referred to throughout the book.) A year later, he was talking in short sentences and even asking questions. He now enjoyed being with the other children and would even initiate some rough-and-tumble play with them, although very little of his play consisted of sharing or turn taking. There was also still no evidence of pretend play with his cars or action figures, and he started to flap his arms and walk on his toes when excited. He continued to be fascinated by water and by balloons, but now he added an interest in the moon and in vacuum cleaners to his list of fascinations.

Obviously, Stephen's interest in wasps was just one of a long line of special interests and preoccupations. The first consisted of very simple visual stimuli: water going down the toilet, looking through holes, dropping sand, wobbling antennae, and bouncing balls. As he matured, the interests become more complex (the moon, vacuum cleaners, and wasps), but all shared the quality of variation in shape, movement, color, and pattern. Sometimes the visual stimuli were accompanied by sounds—simple humming noises and the sounds wasps make when they fly. Shapes, movement, patterns, and sounds never lost their immediacy and their magnetic appeal for him. Stephen, it seemed, had a gift for not being easily bored by the simple things of life.

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Many people think of the child with autism as someone who is totally mute, completely self-absorbed, and who sits in a corner and rocks all day. Other common misperceptions are that people with autism are extremely violent and aggressive, capable of the most horrific forms of self-mutilation, such as gouging out their eyes or banging their heads. Stephen shows none of these behaviors or attributes; he is talkative and gentle, and he is engaged in the world, except he sees the world from his own perspective. He is completely endearing and charming in an eccentric way. The child with autism as popularized by the media and television shows is nowadays quite rare. Such individuals were much more common when disabled children were removed from their homes and placed in large institutions with little stimulation or opportunities for useful activities and social interaction.

There is, in fact, enormous variety in how autism presents in individual children. While it's true that many people with autism are not capable of functionally useful language, a substantial proportion, perhaps more than fifty percent, are able to use language, at least to have their essential needs met. It is also true that the vast majority of children with autism do interact socially with other children and with adults but do so in a limited, unusual, or fixed fashion. It is the *quality* of their social interaction that sets children with autism apart from other individuals, not whether they do or do not interact. There is also enormous variation in their cognitive abilities. Some children with autism are able to perform only rudimentary arithmetical operations, and some will never learn to read. Others, however, are able to perform the most astonishing mathematical calculations, or are able to identify the day of the week on which any individual is born in any year. And some have an amazing capacity to read at an early age or have an encyclopedic knowledge of specific topics.

In spite of this enormous diversity, there are three key features that characterize all children with autism, AS, and PDDNOS. These are impairments in reciprocal social interaction, impairments in verbal and nonverbal communication, and a preference for repetitive, solitary, and stereotyped interests or activities. In other words, children and adults with any form of ASD demonstrate a difficulty (1) in building social relationships and (2) in communicating through words, gestures, and facial expression, and they all (3) spend their spare time doing puzzles, watching things, collecting things, or being fascinated with shiny objects or specific topics and the like. These three general characteristics make up the autistic triad as articulated first by Lorna Wing, and the triad underlies the astonishing number of behaviors that a child with autism may show at one time or another. It is also important to appreciate, as illustrated by Stephen's story, that the symptoms and behaviors vary with the developmental level and age of the individual and can change dramatically over time. But these changes are usually a variation on the theme already contained in the notion of the autistic triad.

For parents, it's the impairments in social reciprocity that most clearly define the predicament of the child and family. The simplest social interactions between parent and child and between siblings, which other families may take for granted, can be extremely difficult for a child with ASD. The rapid building of satisfying relationships, often the most natural thing in the world for most families, becomes instead an arduous task for families where a child has autism. Many of the children limit their social overtures to those required to get their personal needs met, such as asking for help with a toy or getting food from the fridge. The children who do approach their parents for more intricate social interaction often do so for physical games such as tickling, wrestling, and tag, which are enjoyed not so much for the social enjoyment as for the physical sensations these activities evoke. Other children with autism show *too much* social initiative, acting overly friendly with strangers or hugging other children or adults when it's inappropriate. When they do make friends, play activities are often limited to those that fascinate the child with autism, whether it's playing with computer games, watching TV, or setting up scenarios with action figures. Parents may point to these relationships as a sign that their child's social impairment is not all that bad. But it's important to understand that even if the child likes to wrestle with his big brother and will play with miniature cars for hours on end with the little boy next door, the social world does not have the same value and meaning for the child with autism as it does for other, typically developing children, and this difference will affect other areas of the child's life as he grows up. For typical children, social praise, subtle threats such as raising an eyebrow or using a firm tone of voice, and social approbation are powerful learning tools precisely because social interaction holds such high value for them. For the child with ASD, the value of social interaction does not carry the same weight or meaning. As the children mature, these impairments in understanding social interaction evolve into difficulties with empathy and understanding the motivations, beliefs, and feelings of others and themselves. They lack a theory, or an intuitive understanding, of other people's minds and of their own minds. For example, it might be all right for a child with AS to run his fingers through his mother's hair, but it would be quite inappropriate to do that to a complete stranger in the grocery store. No doubt the stranger would be mortified, but the child with AS might not have a clue how that person would feel. Teenagers with AS have a terrible time in high school as they try desperately to understand the ins and outs of dating. The idea that first you have to be "friends" with a girl before she can be a "girlfriend" is often too much for them. It is the subtlety of language and social nuance that proves elusive and confounds their attempts at making deep and meaningful friendships based on mutual understanding.

Difficulties in communication also place a demand on their ability to navigate the social world. Even if they were to develop vocabulary and a mastery of grammar at the same pace as typical children, children with autism and AS do not use language on a day-to-day basis to negotiate the social world, to build bridges between themselves and other people. Their speech is often limited to everyday tasks and to simple requests to meet their own needs: asking for help, going to the park, finding certain favorite toys and objects such as stones, hubcaps, and maps. If they lack speech, they do not substitute nonverbal means of communication as do children who only have simple delays in speech, who can point and gesture in ways that their parents find easy to interpret. The parents of children with autism often have to guess what the meaning of a behavior might be. A familiar story is that a child will pull his parents by the hand to the fridge, indicating a desire for food. A mother will stand in front of the open fridge, getting out different food items, because she has no clue what treat the child is actually requesting. The only way of knowing that the right item has been selected is that the child suddenly stops crying and trots off to the family room with his Popsicle or chocolate milk firmly in hand, without a glance back at the exasperated parent who never learned the knack of reading minds.

Those children with autism who do develop fluent language will often talk incessantly about their favorite subjects—TV shows, sports statistics, the characteristics of subway trains, the sound of thunder, flags of the world, wasps, and so on. Their conversation is rarely reciprocal in the sense that it builds on a listener's contribution to the conversation or refers to events or experiences taking place in the wider social context. Their references are mostly to the physical world and tied to their immediate surroundings.

In some cases, it may not be so much that children with autism are unable to speak as it is that they do not have the motivation to use their communication skills for social interaction. A story in the life of one particular boy illustrates this point quite well. Gavin was nineteen years old and was severely affected with autism. While he spoke a few words as a toddler, by the time he was five he was totally mute and did not communicate with words. Instead he used a variety of nonverbal ways of communicating, such as pulling his parents by the hand, pointing, or simply protesting. As he matured, he ignored others altogether and looked after himself quite independently. One of his favorite activities as a teenager was to go on family outings to an amusement park filled with wild and exotic animals from Africa. Gavin particularly enjoyed watching the monkeys dance around the car as the family drove through the park. On this Sunday afternoon, Gavin was sitting in the back seat of the car while his parents were in the front. His parents noticed a very large giraffe approaching the car, but they were distracted by a large troupe of monkeys cavorting playfully on the hood. All of a sudden, they heard a loud voice from the back seat shout, "Get that thing out of here!" The giraffe had put its head through the back window of the car, and Gavin was so frightened that he spoke for the first time in years. He had not said a word for fourteen years, and to his parents' knowledge, never said another word after that one, perfectly formed, articulate emphatic sentence. Once the motivation to communicate was there, Gavin was able to speak; however, in the normal circumstances of everyday life, there was not enough motivation to communicate. Whether other children with autism who are mute are capable of such perfect speech under the right circumstances is not known, but we have learned that motivation plays a major role in speech therapy.

The third characteristic feature of children with autism and AS is the preference for repetitive, solitary, stereotyped behaviors, activities, or interests. What does have value and meaning for children with ASD is the world of concrete sensation. Their play activities repeatedly recreate situations that evoke sensory stimulation in one form or another. There is an almost endless variety of objects that can catch the interest of the child. These may involve spinning wheels, flashing lights, water dripping into the sink, bubbles, kites flying in the wind, letters, numbers—the list is endless. As the children mature, concrete facts or esoteric bits of knowledge can replace more immediate sensory stimulation, so that flags of the world, bus timetables, plumbing, computer programming, or drafting can replace these more immediate sensory experiences. Nevertheless, the essential feature is that these activities are highly concrete, are not psychological in nature but are more like systematizing, are pursued independently of other people, and can provide amusement and fun for the child for hours on end.

Rituals and resistance to change are other manifestations of this third construct that can often cause considerable difficulty for the family. Many children with autism find it very difficult to tolerate trivial changes in their personal environment or routine. Major changes such as moving house or going to a different school may be accepted with equanimity, but changing the furniture in the living room or the blankets on the bed can cause an uproar. Rituals are fixed patterns of behavior that serve no obvious function and that have to be performed in a specific sequence. They are difficult to distinguish from resistance to change, but some examples include keeping all the doors open in the house, touching the bush at the end of the veranda before entering the house, placing one's kitchen utensils in a certain pattern, getting dressed in a particular order. Children with autism have to perform rituals such as these or else their anxiety escalates and aggressive, noncompliant behavior may occur in response to the interruption of that fixed sequence of activities.

Stephen exhibited many aspects of the autistic triad, and these changed with his development and maturity. His social overture to me at our appointment was unusual and reflected his one-sided interests. His communication was characterized by comments that seemingly came out of nowhere but in fact were motivated by his own eccentric interests. Early on, he did not use gestures or facial expression to add emphasis to his words, and to this day he often carries a fixed smile as he stares intently at another person, questioning whether any wasp's nests could be seen in their garden. No? Perhaps there was one hidden by the branches of a bush? Did any wasps visit the compost heap? Or the apples that fell from the tree in the orchard of the conservation park? And so on, and on, as the eyes of the listener glaze over in the face of this relentless onslaught of intense and passionate observation and inquiry.

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The classification of autism and the other ASDs has had a long and mostly confusing history. While the term "autism" is well known, the term "pervasive developmental disorder (PDD)" is of more recent origin, and its meaning is not immediately obvious. PDD is the term that is used in the official diagnostic manuals published by the American Psychiatric Association and the World Health Organization. It is true that the disorder is pervasive, insofar as the autistic triad pervades all aspects of a child's life. It is also developmental in the sense that it first appears within the first two or three years of life and the manifestations change over time. In addition to autism, other types of PDD have been identified as well. These include Asperger syndrome, atypical autism or PDDNOS, disintegrative disorder of childhood, and Rett's disorder. As these terms are relatively new, the clinical features that distinguish these types of PDD from autism have not yet been established firmly. Moreover, whether these different subtypes are caused by different processes is a subject of considerable current controversy. Nevertheless, it's useful to think of a spectrum of disorders with autism at one end and Asperger syndrome at the other. Indeed, some people prefer the term "autism spectrum disorders (ASD)" rather than PDD. The term PDD implies different disorders that vary in several ways, whereas the term ASD implies a spectrum of related conditions that vary only by severity of symptoms. There are not yet enough research data to choose which of these two terms might be the most appropriate, and enormous confusion about their use exists among both professionals and parents. Many people use the term PDD for a disorder that is different from autism: "My child was given a diagnosis of PDD, not autism," many parents will say. Since PDD is a general category and autism a more specific example of a PDD, this usage is not strictly correct but is certainly understandable. The problem is that the diagnostic criteria for autism have changed dramatically over the last twenty years, and the results of this research have often been confusing, contradictory, and controversial.

Autism was originally described by Leo Kanner. He was the first academic child psychiatrist in the United States and wrote the first textbook on the subject. In a classic paper published in 1943, he described eleven children who tended to be aloof, had unusual patterns of communication, and were very insistent that things in their environment stay the same. He used the term "infantile autism" to describe these children, and the preceding list of characteristics guided the diagnosis.

Over the years, these criteria were refined and basically codified in the third edition of the official classification scheme used in North America, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-III) of the American Psychiatric Association, which appeared in 1980.

But clinicians had also been aware from the beginning that there were many children who were similar to those described by Kanner, though they did not fully meet the description contained in the original paper. Kanner himself was careful to apply the term "infantile autism" to a relatively small group of children. What to call these other children became a problem. At one point, such children were said to be "psychotic" or to have "childhood schizophrenia," a truly unfortunate choice of words. However, work in the United Kingdom by Israel Kolvin, Michael Rutter, and Christopher (Kit) Ounsted correctly pointed out important differences between children with true schizophrenia and those with autism. At roughly the same time, Lorna Wing described in careful detail the larger group of children with autistic-like symptoms and showed how similar they were to those with autism in terms of their social and communication difficulties. This observation led to the concept of a group of disorders called the PDDs, a term that included autism but was not limited to that category.

The problem at that point in the early 1980s was that the criteria for autism derived from the work of Kanner and contained in DSM-III were too narrow and excluded a large number of children who experts believed had autism but for one reason or another did not meet the official criteria. This was an important limitation since diagnostic and treatment resources in many countries depended on a diagnosis of autism (and still do!). In addition, at that point in 1980 there was no evidence that the different PDD subtypes differed from autism in any clinically important way. A decision was made to broaden the criteria for autism to include more children and to collapse all children with PPD but without autism into a category called PDDNOS, or PDD not otherwise specified. This PDDNOS category was intended to include only a small number of children; most children with PDD would have autism. It turned out otherwise. Not only were there many more children who received a diagnosis of autism, but an even larger number received a diagnosis of PDDNOS. This was most unsatisfactory for parents:

"What disorder does my child have, Doctor?"

"He has PDDNOS," the doctor might reply.

"I beg your pardon—what does that mean?"

"It means PDD not otherwise specified."

“I’m sorry, but I still don’t understand. Could you be a bit more specific?”

“Well, I can’t actually; it’s NOS.”

Such discussions, which were not uncommon, did not inspire much confidence in the ability of the diagnostician. Soon clinicians dropped the NOS part and started referring to children with PDD as a shorthand and to distinguish them from those with autism. Hence, parents and professionals started to talk about autism and PDD as separate disorders, whereas autism is really a type of PDD. However, very little was known about children with PDD but not autism (a more precise but still clumsy term), and parents searching the library or the Internet found very little. This too led to a lot of confusion, and often parents would ask for a second opinion, or else authorities would not accept PDD as a diagnosis that would allow children to access services.

Another change to the official classification of autism and the other ASDs occurred in 1994, the third change in fifteen years, with the publication of DSM-IV. This time the other PDDs (the PDDNOS group) were more carefully defined in specific categories known as Asperger’s disorder, atypical autism, disintegrative disorder, and Rett’s disorder. Of these, most is known about Asperger’s disorder, and this subtype of PDD is distinguished from autism by an “absence” of clinically significant language and cognitive delay. In other words, such children have many autistic features but do not have global developmental delay and have roughly age-appropriate use of grammar and vocabulary in their speech (this type of ASD is discussed in detail in the other chapters). Children with atypical autism differ from autism in either having fewer symptoms than autism or having a later age at onset. In our research, we have found this category to be a very difficult diagnosis to apply to children consistently. It usually refers to a heterogeneous group of children who either have severe developmental delay and some autistic features, or else to children with very mild early developmental delays who show some symptoms in the repetitive activities domain at an early age but then grow out of them. The trouble is that clinicians all too often cannot agree on whether the child has autism or atypical autism. The current criteria for this subtype are just too vague, and the differences between PDDNOS or atypical autism and typical autism are just too subtle. Children with disintegrative disorder show completely normal development until four years of age, then regress and develop autistic behaviors just like those with autism. It is a very rare subtype of ASD.

Rett's disorder is a very specific condition that occurs only in girls and is characterized by normal development, then a period of slow head growth, loss of speech, hand wringing, and loss of functional hand use. It is so different from autism in its very specific presentation that it should probably not be included as a PDD subtype, particularly since a genetic mutation has now been discovered for Rett's disorder, a mutation that is not seen in the other PDDs.

If this terminology was not meant to be confusing to begin with, it has certainly become so over the years. Part of the problem is that the research has moved very quickly in this field and there is a time lag between the research findings, their publication in the diagnostic manual, and their dissemination and uptake by clinicians and community services. For parents, it is important to separate the wheat from the chaff, as it were, to take away what is well established and what is still a matter of academic debate. What is well established is that there exists a substantial group of children who display the autistic triad as articulated here. As a group, these children have a common clinical presentation and, as far as we can tell, common needs for treatment that focuses on improving skills in socialization, communication, and play, and on eliminating behaviors (like aggression and severe noncompliance) that prevent their inclusion in schools, day care, Cub Scouts, Brownies, and other community activities. The details of treatment will change with the individual characteristics of the child and his or her developmental level, but not the general orientation and approach. Whether or not a child has autism, atypical autism, or Asperger syndrome does not determine the type of treatment required (except that perhaps speech therapy is not as essential in Asperger syndrome since the children have speech). What does matter is whether or not the child has PDD or ASD; that is the crucial diagnosis to make. Perhaps, when more evidence accumulates on subtype-specific treatment, the differentiation between autism and Asperger syndrome will take on more meaning. But that time is not yet upon us. As the chapters that follow show, it's important to get the diagnosis of PDD or ASD early, so that treatment can begin as quickly as possible. In that way, overall outcome is much improved. Too much time spent on deciding what type of ASD a child has or what caused it can lead to unnecessary delay. Heather's story in Chapter 2 recounts a single mother's attempts to come to terms with the diagnosis and what the experience of getting an early diagnosis meant to her.

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Susan Sontag has written about how certain diseases that are mysterious and cannot be treated easily have unwittingly and often inappropriately become metaphors for the human condition: the plague, tuberculosis, syphilis, cancer, and, more recently, AIDS. That is because each disease is also an illness, a presentation in the world, and is associated with a predicament that is unique to every affected person. Autism is not so general a metaphor, but what is so tragic is that the impairments in social interaction, in communication, and in play strike at the very heart of what it means to be a child. After all, childhood is about playing with other children, being looked after by adults, learning to talk, and experiencing the pleasures of communicating and exploring the environment in all its diversity. Childhood is about play, fantasy, and creativity within a world of other people. Autism limits the capacity to develop these to the fullest, and the process derails development onto a somewhat different pathway. What I hope to show in this book is that while this derailment is tragic and produces considerable suffering for the family, it also carries with it the capacity to see the world in a way that has its own value. Within the disability, there is a focus on the intimate architecture of the world. There is an innate capacity to see that architecture without the use of metaphors that may obscure what is seen, so that it may be truly appreciated.

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