

Introduction

This is a book for parents who already know a thing or two about autism. You probably already realize that as the parent of a child who has or may have an autism spectrum disorder (autism, Asperger syndrome, or pervasive developmental disorder not otherwise specified [PDDNOS]), you'll need to learn some extra-ordinary skills to deal with this situation you now find yourself in. You're going to need new expertise on how your child sees the world and how he can learn. You're going to have to analyze all kinds of therapy and special education services available out there and figure out which ones might be what your child needs most. You're going to need a new kind of understanding about parenting—not just to deal with any problem behaviors, but importantly, to proactively “wrap around” all your child's treatments to make what's happening in them meaningful and motivating in your child's everyday life so every moment becomes a chance for your son or daughter to get better.

In this book, I'll help you understand your child's relative strengths and weaknesses so you'll understand how stronger abilities can be used to bring up the weaker areas (Chapter 6). We'll talk about many kinds of treatments and treatment strategies for autism (Chapters 7 and 8). Then, equipped with this knowledge of your child's strengths and weaknesses, you can hook up with the treatments and treating professionals who can help *your* child best. To make sure you can get treatment going smoothly, we'll talk about how you can recognize the “best fit” therapists, teachers, programs, and schools for your child

(Chapter 10). We'll talk about your legal rights as a parent of a child with autism—so you know what your child is entitled to and how to ensure that your child's rights are protected and honored (Chapter 9).

When you finish this book, I want you to feel you are absolutely equipped to be the best parent you can be for your child with autism. What do I mean by that? Well, this: If, instead of autism, your child had been diagnosed with diabetes, cystic fibrosis, or even severe asthma, you'd have to read, take classes, and talk to different kinds of doctors and therapists to learn what to do to get the best possible care for your child. You'd have to find the right kinds of doctors and therapists, learn to administer tests and medicines, be trained to watch for signs of a downturn, and create an environment at home where a specific diet or an allergen-free environment gave your child the best chance of living symptom-free. Parents of children with a physical condition have many more resources out there to give them the training they need. With that in mind, this book was written to prepare you to be the same sort of specialist in caring for your child with autism. Instead of becoming an expert at testing insulin levels and measuring carbohydrates, you're going to become an expert at sussing out the right therapists and teachers and at parenting your child so that you boost the work they do by motivating him to use his developing abilities.

I'll teach you the special principles that govern how children with autism learn. I'll show you how to make sure *your* child's *specific* needs are identified through the right kinds of assessment, and then how to navigate through many different systems of care, support, and resources to get what your individual child will require to grow and develop to the best of his or her potential. All children with autism spectrum disorders have slightly to very different difficulties, and therefore will have different treatment needs. You as the parent are in the strongest position to ensure that your child's program is individualized appropriately. There is all sorts of information out there about autism, and this book will provide you with some ideas for sorting the wheat from the chaff (Chapter 5).

Who Exactly Is This Book For?

This book is for you if you've either learned your child has autism or strongly suspect your child has some form of autism. It's for you if you feel you're going to need a bit more help to get things started—or really change what is already happening to help your child. Sure, there is al-

ways more you can learn. So, how do you appraise whether what you know now is enough to get started?

Read Part I of this book if you're still thinking about the diagnosis—whether it's right, and what sense you're supposed to make of having simply been told, "Yes, your child is autistic." Chapter 2 will tell you what a good diagnostic assessment should give you. In fact, if you aren't that far along yet, Chapter 1 is about screening for autism and will help you know whether you really have something to be concerned about—and whether you need someone with more expertise to help you decide that. If you've had a diagnosis, did it seem right? Do you feel you need or want a second opinion? Did you get all your questions answered? Do you need help gathering your thoughts and organizing those questions so you can approach an(other) assessment well informed?

Maybe you're farther along. If you're done with diagnosis and assessment, you might start with Part II of this book: Do you already know enough to get started with treatment? What kinds of services is your child entitled to anyway? How do you get those services? How do you know if services you have are the right ones or if they are working the way they are supposed to? How do you take the knowledge you've gathered so far and apply it to making your child's life better?

In my earlier books on autism I've tried to help parents and teachers understand who their child with autism is and how their child learns. In *The World of the Autistic Child: Understanding and Treating Autistic Spectrum Disorders*, I've written about understanding what makes for the diagnosis of autism, what getting a diagnosis involves, and how to understand treatment. In *What about Me?: Siblings of Developmentally Disabled Children*, my colleague Stu Silverstein and I talked about how autism and other disabilities affect siblings, marriages, and the whole family. In *Helping Children with Autism Learn: Treatment Approaches for Parents and Professionals*, my latest book, I wrote about how each symptom of autism can really be seen as its own type of autistic learning disability, how different treatments may address some but not other autistic learning disabilities, and how parents and teachers need programs that cover all these autistic-type learning difficulties when designing an individualized treatment plan for a child with autism.

Now, in this book, I've put it all together to help you get the best for your child with autism. I draw on all my past writings, which themselves are based on more than twenty-five years of working with children on the autism spectrum as a researcher, diagnostician, educator, and treatment program consultant. In my years in this field I've

worked with autistic children, their families, and their treatment providers in many capacities. I have a rather polyglot professional identity—with an undergraduate degree in clinical psychology, a master's in early childhood education, a doctorate in child development (applied studies of children), with a doctoral minor in developmental psychology (more theoretical and empirical studies of children). On top of that, I did postdoctoral research training to hone in on methods especially applicable to bettering our understanding of autism. For almost twenty years I've been a professor in a department of psychiatry and a faculty member in a child psychiatry program. So, I speak the languages of many different professions. I feel like a bit of a cultural anthropologist in the role of a "participant observer," pretty much passing myself off as a clinical psychologist when among clinical psychologists, as an educator when I am with educators, and as a "native speaker" among child psychiatrists. This has enabled me to draw readily on all these areas of endeavor to understand children with autism and their families, and particularly to understand the special learning processes we see in children on the autism spectrum. For almost twenty years, I've been doing research and running a large diagnostic and treatment planning clinic I founded in 1989 at the University of California, San Francisco: I have seen close to 4,000 children with autism spectrum disorders.

There are many questions that I have found parents ask when they worry or find out that their child has an autism spectrum disorder. Some questions will have to do with the child himself, but others are about what this will mean to them as this child's parents—and as the individuals who existed before they became parents of a child with autism. What will autism mean for our marriage? For other children we have or may have? How will my child be seen by grandparents and our other relatives? How do I explain this to them? These topics will be addressed in Chapter 4.

Very likely, you will also have questions about the health care system, including the doctors who make diagnoses and develop treatment plans, and then the therapists who provide individualized services like speech and language therapy or occupational therapy; these questions will be addressed in Chapter 3. Following close behind your time learning from health care providers will be your time to start understanding therapies and education and the laws and entitlements you need to know about when you have a child with special needs. In this book, as you learn to travel through these different new areas of your life, I'll try to be your navigator.

Doing Everything You Can

As your child grows, develops, changes, and improves, how do you know what to expect? It's natural for parents to wish for their child to be "cured." Parents of young children with autism wish for this a lot. No one wants to take away hope. Everyone wants to encourage dreams. Your child is *your* child. You love her because she is yours. She is a part of you.

Evolution has endowed parents of any species with the most tenacious of drives for seeing to the perpetuation of that species. However, it is only the human that is endowed with a massive frontal cortex—the thinking, reasoning part of the brain. We human parents therefore seek to use this unique endowment to do all we can for our children. However, more often than not, there will be things we can't accomplish, try as we might. I'm going to help you try your best so you can do as much as possible to enable your child to fulfill his potential.

No one asks to be the parent of a child with autism. No one says to his or her husband or wife, "Well, we've got a boy and a girl; let's have one more and try for an autistic child this time. It could be *so* rewarding! There is *so* much we could learn!" Autism, and all the extra burdens of care, are thrust upon each and every person whose life it enters. Several years ago, I was on a traveling lecture panel for California Early Start (a delivery system for federally mandated services for children from birth through age three). Another panelist was the mom of a ten-year-old boy with autism. She would always begin her lecture with a story she had read in an issue of *The Advocate*, the newsletter of the Autism Society of America. The story was about a woman who had long planned a trip to France because she loved good wine and French food and had learned to speak French. One day, she finally had an opportunity to go on her long-awaited trip. When the airplane landed, though, she found she was in Holland, not France. The woman was disappointed, and although she had not planned for Holland and knew nothing about it, she realized she could learn. They didn't have vineyards, but they had charming windmills. They didn't speak French, which she had studied for such a long time, but Dutch. The mother who told this story was really a wonderful person: She said that she loved it because she found it a fitting metaphor for finding oneself the parent of a child with autism. She felt that she had learned that Holland was a place where she could be quite comfortable living. This book is about learning to live in a new place, at home with autism.