

PREFACE

Stevie was 2½ years old. His mother told me not to interact with him, just to sit on the other side of the room so he could get used to me being there. I had done a lot of volunteer work with kids (things like the Big Brother/Big Sister Program, coaching, etc.), so I had experience with children, but not with autism. I sat there and watched. It was as if I were invisible! There was no interaction and no acknowledgement whatsoever from Stevie. That was 1995. I was a graduate student, and I had never even heard the term autism before.

In my very first graduate class, I was given a flier advertising a job for someone to work as an in-home therapist with Stevie. A young and willing student, I was excited to work in my field of study and I jumped on the chance to go for the interview. After that first meeting, I was hired by Stevie's family and trained in applied behavior analysis (ABA).

Nothing could have prepared me for the first day we implemented ABA with Stevie; I had never heard such a scream before. My immediate thought was, "I cannot do this!" But within five minutes, he was responding to my commands, although minimally, and while he was still screaming. Eventually, he responded so well to treatment that he had a successful run in public school and is now gearing up to start college. I ended up working with Stevie for two years as an in-home therapist, and that changed the course of my career and my life forever.

I learned so much while working with him that I ultimately began working for other families with children on the autism spectrum and I started seeing clients in the Community Clinic at Saint Xavier University in Chicago. After my experience with Stevie, I was so intrigued to learn more about autism that I could not stop thinking about it, reading about it, and studying it; it became my passion and I have not stopped studying it ever since.

One day, my graduate school advisor, Dr. Rotatori, asked me what I thought was going on inside Stevie's head. "What is he thinking?" he asked me. I thought to myself, "I do not know, but I want to try and figure this out." That was the beginning of 15 years of work with autism that has brought me to the point of writing this book. I have spent my professional life devoted to studying autism, Asperger's disorder and autism spectrum disorder (ASD).

I do not have a child on the autism spectrum; I did not have any children when I began this journey. Today, I have three beautiful daughters, Elli (11), Gia (10) and Cece (8), whom I adore, and who also give me a baseline to understand how children on the autistic spectrum are different. I have treated hundreds of children on the spectrum, and I see approximately 50 to 60 each week in my office. I feel very fortunate to do what I do. My job is never boring and is filled with challenges. In the past two years, I have founded the Prairie Clinic, in Geneva, Illinois, where we specialize in treating children on the spectrum and the families of the children on the spectrum.

A clinical psychologist and a school psychologist, I speak both regionally and nationally, educating parents on autism and Asperger's Disorder. I have given hundreds of presentations on autism, and written and published academic articles and books on autism, but I have never written anything specifically for the parents and educators who work with these unique individuals. This book is intended for all of you parents who have children on the spectrum, and also for teachers, professionals, and caregivers who work with children on the spectrum, but who do not know where, or how, to start to help them.

When families first receive a diagnosis of autism it can be devastating. I have given the diagnosis for more than a decade and have worked with hundreds of parents who were referred to me because they had just received the painful and frightening diagnosis of autism. I have experienced their suffering and desperation first hand as they become aware of the possible implications. Often, all they are told is, "Your

child is on the autism spectrum...good luck,” and they are sent on their way without further help. Many are left to ask the question, “Well, now what?” This book is the now what—a guide map to begin the process of understanding and adapting to this new reality.

When parents google autism and get 30 million hits, they come to my office and ask, “What do I read? Where do I start?” Start here, with this book, to begin to step inside the world of autism, to begin to understand the unique perspective on the world these people have, and to begin to understand their unique way of processing the world. Diagnosis, although painful, opens the doors to better understanding and new treatment possibilities. There is a lot of hope.

Years of research and clinical observation have led me to develop a theory of what autism is and how people who are on the autistic spectrum see the world. However, the purpose of this book is not to focus on the research; the purpose is to help readers—parents, educators, therapists—identify and respond positively to people on the spectrum.

This book provides both a starting place to increase your understanding of autism and a resource for realistic ideas on how to teach children who are on the spectrum to be more functional and more successful. Many parents have gone around in circles, working diligently with doctors and therapists, achieving seemingly little gain because the autism was missed. Being aware and understanding autism changes that. Hopefully, this book will provide that moment of, “Aha! I get it now...their world is starting to make sense.”

In order to respond in a positive way, it is important to know how individuals on the spectrum think and process the world around them. You will come to see that the way they see things is not wrong; it’s just different. When you understand that difference, and how it impacts the child, you can begin to understand his experience and his world. Once you can enter into that world, change begins to take place and your child will become more functional and better able to manage the

world around him. As you grow in your understanding, you will learn that your child on the spectrum has a personality first and autism second. Children with autism are people just like us, facing problems just like we do.

Children on the spectrum have, first and foremost, a social disability. This book presents a clear picture of the why behind this, along with techniques to teach them to overcome this challenge and ultimately persevere in a very social society and social world. My objective is that this book will help you to see that picture fully, gain a solid understanding of autism, and, ultimately, experience more success in shaping your child into a happy and functional adult. Happy and functional. That is my goal for these exceptional people.

For the most part, these are very smart individuals. Teaching them how their brains work and how to be functional in the very flexible, dynamic world in which they live is pivotal to their ability to be successful. I accomplish this by focusing on their relative strengths and using those strengths to supplement areas in which they struggle. Their world is not easy; they are forced to deal with significant challenges every day. They need to learn how to master those obstacles in order to prosper in the world. If we can teach them how to be more social, how to overcome their tendency to think in black and white extremes, and how to live life in the middle ground, they can achieve as much as anyone without autism.

There are many stories in this book that are based on composites of the children and families that I have worked with over the years. Most of them describe higher functioning individuals on the spectrum, although I feel this book and its content applies to all individuals on the spectrum, including those more severely impacted by autism spectrum disorder. My intent was to capture an accurate characterization of an individual on the spectrum that could be applied to someone of any age. I have attempted to describe the guiding concepts that 15 years of providing therapy have proven to be useful in understanding someone on the spectrum. As a result, I have needed to revisit certain

topics in order to describe them from different perspectives and as they relate to different exceptionalities.

There is incredible hope for these individuals who are so talented, bright, and autistic. Working with them is extremely gratifying. Seeing therapeutic change, watching individuals and families learn to persevere and to take the gifts these children possess and use them to their children's advantage, and improving their ability to function in our social world, is very rewarding.

Those who succeed in life do “find the gray” area when they learn to compromise and be flexible. They then can go out into the world functionally embracing all of life—including the middle ground between the extremes. As a result of that increasing functionality, they can play the game of life and win!