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# *Foreword*

Stephen presents an optimistic view of Asperger Syndrome and high-functioning autism. It is refreshing to have his positive and constructive outlook. As a person with high-functioning autism myself, I can relate to many of Stephen's experiences, both as a young child and as an adult. One of the most valuable insights this book offers is helping individuals on the autism spectrum to understand the subtle intricacies of social interaction. It is like a roadmap for navigating the social world.

When I was in high school, I was constantly teased and bullied. I had absolutely no idea why the other kids chose me to tease. I was unable to figure out what I was doing wrong. Stephen's book provides practical advice on combating teasing. As I read through the book, I thought back to my own experiences. I went through almost 30 years of not knowing that people had subtle social cues that they sent to each other with eye movement and body posture. I did not know that people communicated with eye movements until I read about them in a book when I was almost 50 years old. Stephen's experiences will help many people have a more fulfilling life.

Friendships are often gained through shared interests. My best friends have similar interests in subjects I am interested in such as animal behavior or designing livestock equipment. Both Stephen and I strongly recommend the cultivation of interests.

Stephen also provides lots of practical information about employment. For example, he describes how he lost a good music teaching job because he failed to recognize faculty politics. People on the spectrum are usually good at jobs where they can utilize their special skills such as architectural drawing or computer pro-

gramming. However, they often get into trouble with the social aspects of the job. I have heard several sad stories of talented persons losing their jobs when promoted into a management position that they could not handle. Stephen has an excellent section in the book to help employers understand the social limitations of a person on the spectrum. This will help employers to understand why their otherwise brilliant computer programmer, for example, has social difficulties. I really liked the suggestions for how to handle problems with misinterpreting the behavior of a person on the spectrum. One of Stephen's suggestions rang a bell with me. A boss should be asked to: "Let me know if I have offended someone so that misunderstandings do not develop and grow." In my own case, I did not realize that in some situations I appeared rude or abrupt. Stephen suggests that a boss should let the person on the spectrum know if he or she has unintentionally been hurtful or abrupt.

In my book *Thinking in Pictures*, I discussed how to get a job by selling my talents and showing a portfolio of my work. Stephen's book provides information that will help people keep their jobs by avoiding social mistakes. Stephen's book would have been very valuable to me when I was starting and developing my career.

– Temple Grandin  
Author, *Thinking in Pictures*



# *Preface*

**W**hat unique challenges face the person on the autism spectrum? What is meant by the “autism spectrum” anyway? How does one relate to persons with autism and Asperger Syndrome? Are they really that different from all the rest of the people in the world? What causes autism spectrum disorder?

In this book I hope to explore these and other questions. I use the word “explore” because there is so much more to learn about autism and related disorders. Researchers and people who work in the field of autism are increasingly coming up with data that will one day resolve some of these questions. Until that happens, however, we all will continue to explore the uncharted territory of the autism spectrum.

In addition to being an autobiography, this book represents my search for knowledge about Asperger Syndrome and autism, how it affects me, and how I might use this knowledge to help others on the autism spectrum. There are three narrating voices in the book. The first is the autobiographical voice that tells the story of my life. The second is what I call the time shifter. This voice describes events in my life that are relevant to the topic at hand but are out of sync with the strict chronological order of an autobiography. The third is the researcher voice. In my quest for more knowledge about myself as I relate to Asperger Syndrome and autism, I have examined some of the literature to see how it relates to me and the work I do with children on the autism spectrum. As a result of the three-voice method, some of the chapters are very conversational and autobiographical whereas others, particularly towards the end of the book, get rather theoretical. This is how I make sense of my life. Hopefully this presentation will make sense to the reader too.

Starting with Chapter One, I take a snapshot of what my life looks like today ... as an adult with the residuals of the autism spectrum disorder. Chapter Two goes back in time, starting from my birth where I seemed to develop at a slightly faster-than-normal rate until the autism bomb hit. Where did this bomb come from and what caused it? Some people point to genetic and environmental influences, vaccinations and other causes. Some have even attributed my situation to an emotional cause. While I am tempted to say that we do not have a clue, I think the prognosis for finding the etiology of autism is better than that. The problem is that there are too many scattered clues that need better organization and more direct correlation to autism. Perhaps in time we will find out that what we now consider the autism spectrum is a series of separate disorders causes that present themselves in a very similar manner.

Chapter Three depicts the period when I sink into autism. While I have some memories, I have relied heavily on my parents for descriptions of what they did with me and how I behaved and functioned in those years. At that time there was no concept of early intervention. Ignoring the professionals' call for separating me from my home and the environment I knew, my parents did what they thought was "right." Chapter Four, the Putnam Period, looks at my experience in a special school for children with "atypical development." For this material, I am indebted to my nursery school teacher. In this edition, Chapter Five on my nursery school years contains an expanded portion devoted to how sensory issues may affect people with Asperger Syndrome and autism. Chapters Six, Seven, and Eight cover my years in public school. They started out as a social and educational disaster. But contrary to the experiences of many people with autism or other differences, things got better in middle and high school as I learned how to better relate to the environment and discovered the joys of producing music with others.

College and work experiences comprise Chapters Nine, Ten, and Eleven. While college was, and continues to be, a sort of paradise

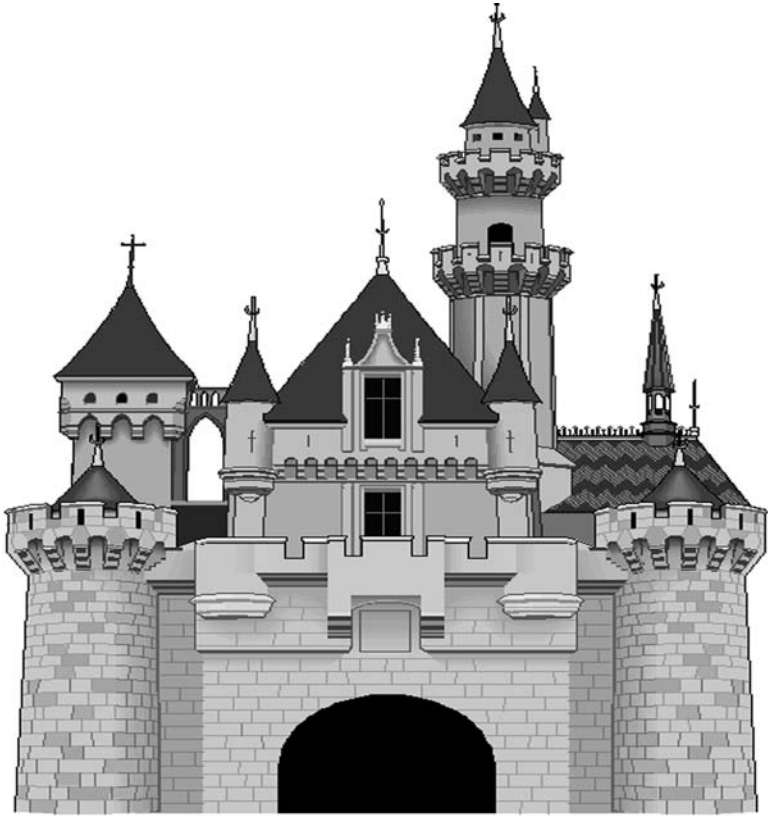
for me, the world of work and what some consider as reality was not. With an emphasis placed on learning and creativity, educational institutions seem to be much more forgiving of individual differences than the business universe of accounting and finance that I encountered. As a result, my work remains and I expect will continue to be concentrated in the world of academia. With more people on the autism spectrum now seeking higher education, I have included new material on choosing a college that best matches the student (see Appendix B). In addition, a section has been added on steps to prepare a person for the challenges of self-advocacy as he or she transitions to postsecondary education as well as the workplace and community.

In the remaining chapters, the writing of this autobiography and my life begin to intersect. This is where the sleeping dragon of autism reawakened and drove me on a quest to find out more about this way of being and its relation to me. I use this term “way of being” rather than “disorder” because I wonder whether the autism spectrum should be considered as “another order” of being as opposed to a disordered, deviant way of existing. Societal constructs relating to how others compare those with autism and Asperger Syndrome to the rest of society play a heavy role in this respect. Revisiting autism by relating to and working with others who have autism and examining how to best disclose one’s placement on the autism spectrum to others has helped me hone in on and analyze what autism means to me.

This book represents my search for answers to the many questions I have about autism and Asperger Syndrome and how I can use my personal experiences and research to help make lives easier for others on the autism spectrum.

Stephen M. Shore  
Brookline, Massachusetts

# The Castle



**I**magine that you are trying to reach a young prince locked inside a huge castle. First, you must cross the wide moat, which is filled with hungry alligators. Once across, you must find a way into the castle. Arriving inside you see armed guards everywhere.

You must find your way past the guards as you look for the secret stairway up to the highest tower in the castle. Should you find the way up, you must search for the correct key to open the



lock. With key in hand, you may open the heavy door. Inside you see the child looking out the window. He does not turn to greet you. You may walk over, and being ever so careful not to speak to the child or even touch him, you may stand beside him and look out the window. After a while, you may speak, in quiet tones, about what you see when you look out the window.

If you have been careful and respectful enough and have noticed the “right” things as you looked out the window, the child may turn to acknowledge that he is no longer totally alone.

You will spend a long time in the tower, often longer than you imagined. Then a day may come when the child notices the door and leads you to it. You open the door. The child lets you hold his hand as you creep down the castle stairways, past the guards, out the door, across the moat and into the outside world. You will spend a long time exploring together. Maybe the day will come when the child, who has now grown older, says, “Farewell, I’m ready to explore with others and by myself.”<sup>1</sup>

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<sup>1</sup> A metaphor given by Pierre Johannet, M.D., to the nursery teachers at the James Jackson Putnam Children’s Center, Roxbury, Massachusetts, between 1962 and 1967, as retold by Nancy Reiser to therapists she supervises and parents she sees. Nancy Reiser was the author’s nursery school teacher at this center.

In the 1960s, given the child on the autism spectrum’s insistence upon sameness along with an unawareness of the environment, autism was considered a psychological disorder. Consequently, these children were treated with utmost delicacy lest they erupt into a tantrum. While the causes of autism and Asperger Syndrome remain unknown, we now know that working *with* the child’s resistance to change and lack of awareness is the crux of how to lead children on the autism spectrum towards more meaningful and successful lives.



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