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Understanding **Autism** FOR **DUMMIES**[®]

Stephen M. Shore, MA

Author of Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome

Linda G. Rastelli, MA

Veteran journalist and editor

A Reference for the Rest of Us!



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About the Authors

Stephen M. Shore received a regressive autism diagnosis at age 18 months, became nonverbal, and was deemed “too sick” to be treated on an outpatient basis. Today, he’s earned a doctoral degree in Education, and helps people with autism lead fulfilling and productive lives. When not teaching college-level courses in special education and teaching children with autism how to play musical instruments, he consults and presents on autism-related issues internationally. Some topics of particular interest to him include comparative approaches for helping people with autism, education, and disaster preparedness for people with disabilities. He also focuses on challenges faced by adults in terms of self-advocacy, disclosure, post-secondary education, employment, interdependent living, and relationships.

Stephen holds bachelor degrees in music and accounting and information systems from the University of Massachusetts at Amherst. He also holds a masters degree in Music Education and a doctorate in Education from Boston University. Although he seems to spend most of his time traveling in airplanes (Boeing 747-400 preferred), across the U.S. and internationally to lecture and consult on various autism topics, or the rare occasions that he’s home, he resides with his wife in Newton, Massachusetts.

Linda G. Rastelli is an award-winning journalist, instructional designer, and author with 20 years of

experience in writing and designing instruction for health, education, and business topics. In her career, she has focused on making complex and technical information understandable to the layperson. Although she has covered subjects ranging from financial ratio analysis to educational reform, her most challenging inquiry to date — an undertaking that has made her other projects look like finger painting in comparison — has been autism.

Linda holds a bachelor of arts degree from the University of Delaware and a masters degree from Columbia University. She lives on the New Jersey coast with her husband and her cat, who have reached a blissful state of detente. She hopes to keep her day job.

Dedication

From co-author Stephen M. Shore: This book is dedicated to my wife, Yi Liu, my parents and siblings, and to all people on the autism spectrum.

From co-author Linda G. Rastelli: This book is dedicated to my husband, Bob Galante, and to Robert Rastelli, in memoriam.

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Foreword

There are many different educational programs and treatments for autism, and their originators all claim that their methods are the best. The purpose of this book is to provide parents, teachers, therapists, and others who care for individuals with autism with a guidebook that offers objective, balanced information, thereby enabling you to make intelligent decisions. Like the original *DOS For Dummies* (Wiley), *Understanding Autism For Dummies* is meant to be a user-friendly manual that cuts through the load of information you find out there and helps you make the decision that's best for your situation.

Autism is a neurological disorder caused by abnormalities in the brain. Researchers have discovered that the parts of the brain that process emotions don't develop normally in autistic people. Further research has shown that some of the long-distance circuits that connect different regions in the brain may fail to connect. For example, one person may be sensitive to fluorescent lights, and another person may be sickened by strong smells. One individual may be more socially and emotionally related than another. It all depends upon which circuits connect.

The autism spectrum is very broad and ranges from severe autism, where the child never learns to speak, to mild Asperger Syndrome, where the child has no obvious speech delay. Doctors and caregivers don't often diagnose children with Asperger's until they have problems socializing with other children. An Asperger's child may play alone and have few friends. Some individuals with Asperger's are very intelligent; many eccentric, famous scientists, musicians, and artists probably had Asperger's. The spectrum is continuous, ranging from a person who needs lifetime help with basic living skills to a college professor. The great variability on the autism spectrum may be due to the extent of the abnormalities in the brain.

Co-author Stephen Shore is a college professor who has autism. As one who's been there, he will walk you step-by-step through the complicated world of autism spectrum disorders. An author who's on the autism spectrum can provide an insightful perspective that many academic authors may lack. Co-author Linda Rastelli is an experienced writer who brings unusual clarity to some of the most confusing issues surrounding autism and its treatment. Throughout the book, the authors use quotes and statements from other autistic individuals so you can appreciate the varied nature of the effects of this condition on the people who have it. I support this book and both these authors because in addition to writing a badly needed resource on autism, I, too, am an individual with autism.

To help you better understand how far we've come, and how far we still need to go, I would like to discuss some of my own early childhood experiences as a child with autism.

I had no speech until I was age 3 1/2. For hours, I dribbled sand through my hand. Loud noises, such as the school bell, hurt my ears the way a dentist's drill hits a nerve. Fortunately, I had a great early educational program that started at age 2 1/2. All autism specialists agree that an intensive educational program is most effective if started shortly after symptoms of autism occur. Specialists disagree on which program to use, but everybody agrees that waiting is the worst thing you can do.

Having good teachers is also vital with young children. I've observed that effective teachers know how to be gently insistent so as to draw a child with autism out of his/her world and improve both language and social interaction.

More than 50 years ago, the teacher who worked with me used methods that were similar to some of the best autism programs today. I had structured-speech therapy that resembled the behavioral programs used now. My mother hired a nanny who spent hours each day playing games with me and my sister. She had us take turns coasting down the hill on a single sled or playing board games. Every day I had to sit through three family meals where I had to behave and use good table manners. All these activities added up to over 40 hours a week where I was kept tuned in to the world and wasn't allowed to tune out and retreat into my autistic world of humming, twirling things, and rocking.

Today, I, too, am a college professor who has made contributions to animal science and who has been able to offer hope and perspective to others with autism and to those who care for individuals with autism.

Another important function of this book is to lead you through the maze of the different medical and biomedical treatments. This is often an area of controversy. Stephen Shore and Linda Rastelli explain all the methods in an evenhanded manner, which enables you to make rational decisions. Due to the great variability of autism, a medication or biomedical intervention that works for one individual may not work for another. It's usually best to carefully try different things. Keep using those things that seem to work, and stop using things that don't work. In very young children, it's often best to try the safest methods first, such as diets and supplements. Some older children and adults may need to take conventional medication to control anxiety, aggression, or obsessive-compulsive behaviors. In some individuals, a combination of conventional medication and biomedical treatment may be most beneficial. For other individuals, we have yet to discover what helps. But every day, scientists, researchers, therapists, parents, behavioral specialists, nutritionists, and individuals with autism are contributing to the growing body of knowledge about autism spectrum disorders with the goal that, some day, all individuals with autism can make their place in the world and help make it better for everyone. Don't give up hope. Trust your instincts, and use the network of parents, teachers, and others devoted to the care of people with autism to help you cope and provide the best environment you can for you and your family.

Temple Grandin

Author of *Thinking in Pictures*

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Introduction

The Centers for Disease Control in Atlanta estimates that as many as half a million children in the United States alone have some form of autism. Still, some doctors inform the parents of the diagnosis, hand them some pamphlets, and tell them, in effect, good luck! Many pediatricians have never seen an autistic patient, so they don't know what to look for, and uninformed doctors may tell parents who have concerns that they're overreacting and that they need to wait and see. Such an approach is risky if your child is displaying symptoms of an autism spectrum disorder, because time is so crucial; we explain why in this book.

If you're reading this book, you probably have a child or other loved one who's received a diagnosis of autism or developmental disability, or maybe you suspect that your child is showing symptoms that you've heard associated with the disorder before, and you want to find out more. Maybe you've received such a diagnosis yourself. The diagnosis of autism can be a devastating and confusing experience, and you want answers fast. You have so many questions, and you don't even know which ones to ask first. How do you put it all together? What do you do tomorrow? Next week? We designed this book to help you answer those questions. If you don't have an autistic relative or dependent, but you do have questions about

how to educate, advocate for, or communicate with the autistic people in your life, this book can help you, too.

But first, you need to understand what autism is and isn't. Autism is a neurobiological condition that may come with many challenges, but also imparts great gifts. Autism isn't a mental illness, a result of bad parenting, or a death sentence for fulfilling and productive lives. Many autistic people have made great strides personally and have given amazing contributions to the understanding of autism, including the author of our foreword, Dr. Temple Grandin, who teaches animal science at Colorado State University. Grandin is a sought-after professional speaker on autism and the inventor of numerous livestock-handling innovations. I (co-author Stephen Shore) was diagnosed with atypical development and strong autistic tendencies when I was 2 1/2, but with much help from my parents, friends, teachers, wife, and other professionals, I've gone on to the finishing stages of my doctoral dissertation, and I teach college courses and other activities. I'm honored to be able to contribute to the autism community.

Autism isn't new, but professionals no longer consider it rare. Autism touches the lives of more people than ever before, yet — and maybe because of this frequency — we have much reason for hope.

About This Book

You have in your hands an introductory reference to get you started in your quest to know what to do and where to turn in order to help people with autism. We provide plans and suggestions that we hope are useful to you, whether you're a parent, caregiver, family member, child-care worker, teacher, therapist, or other person supporting an individual with autism.

Understanding Autism For Dummies is designed to provide accessible, practical, user-friendly information in a format that's easy to navigate and follow. We designed each chapter to be self-contained so that you don't have to read the book sequentially or read the first parts to understand any later chapters. You should concentrate only on what you need. The table of contents and the index can help guide your search.

Because the topic of autism is so broad, we rely on many contributions from experienced professionals, experienced caregivers, and people with autism, such as Dr. Temple Grandin. We feel fortunate to have their input, and we believe you will, too. Along the way, we also share quotes and insights from parents of kids with autism and people who live with autism. These people may or may not have stories that are similar to your own, but you can be confident that they've all come through the fire and want to help others to understand what it's like and what they can do to help people with autism.

This book will help you sort out the bad ideas from the good and to understand that each child's plan for

intervention is as different as each child's symptoms. And above all, we hope not to insult our audience. We've taken care not to make light of what can be a challenging and heart-wrenching disability. "Dummies" are people approaching a new subject who want clear, concise explanations and guidance. We're confident this book will serve your wants and needs.

Conventions Used in This Book

To help you navigate the waters of this book, we've set up a few conventions:

- ✓ We use *italics* for emphasis and to highlight new words or terms that we define.
- ✓ We use **boldface** text to indicate the action part of numbered steps and to highlight key words or phrases in bulleted lists.
- ✓ We put all Web addresses in monofont for easy identification.

Also, we're aware that some people with autism prefer to be called just that, "people with autism," whereas others on the spectrum prefer "autistic people." Although we respect each individual's preference and understand that nobody wants the label "autistic" to define a person, for purposes of clarity and simplicity, we use various constructions throughout this book.

Likely, you'll read the terms *low functioning*, which describes people with severe autism who have great difficulty in successful communication and just making sense of their environment, and *high functioning*, which describes people with mild autism or Asperger Syndrome who have greater verbal ability and increased success with interactions and their environment.

And although the word "autism" itself may not be as precise as terms like "communication disorder," "Pervasive Developmental Disorder," or even "autism spectrum disorder," we think it's a useful term, so we use it to describe the set of symptoms we outline in Part I.

No matter what terms you use, it's important to remember that although some people use labels to limit others, you can use labels to encourage greater awareness, cooperation, and understanding. An autism label can be useful in terms of obtaining services, for example.

What You're Not to Read

You don't absolutely, positively have to read every word in this book, but that doesn't mean that you shouldn't. The bottom line is that if you're in a hurry, you can skip some topics and still not miss the important stuff you need. Sections you can skip include the following: