

foreword by SUSAN SENATOR, author of MAKING PEACE WITH AUTISM

ROBERT PARISH & FRIENDS

Embracing

Autism

*Connecting and
Communicating*

with Children in

the Autism Spectrum



CONTENTS

[Acknowledgments](#)

[About the Editor](#)

[About the Contributors](#)

[Foreword: The “Secret” Key to Connection,
by Susan Senator](#)

[Introduction](#)

[Chapter 1: My Journey with Jacob, by
Diane Bayer](#)

[Minnie](#)

[Speaking the Language of the Natives](#)

[All in a Song](#)

[Autism and Artism](#)

[Penguin Kisses](#)

[Chapter 2: Relating to ASD Children, by
Arnold Miller](#)

[The Child’s “Difference” Is Not the Fault of
Parents](#)

[There Is Often a Bond, Even When It Is Not
Immediately Apparent](#)

[Can a Bond Be Built When There Is None Initially?](#)

[Four Common “Support and Demand” Stances
Toward Special Children](#)

[Chapter 3: Three Special Kids—No
Apologies Necessary, by Kim Stagliano](#)

[Chapter 4: Patience—The Least Important
“Super Power,” by Kristin Kaifas-Tennyson](#)

[Rational Detachment](#)

[Detachment Strategies](#)

[The Three S’s](#)

[Implementing Strategies That Lead to Connection](#)

[Chapter 5: North of the Border, by Gay
and Dennis Debbaudt](#)

[Welcome to Canada](#)

[First Steps](#)

[Reaching Out](#)

[The Learning Curve](#)

[Walking the Line](#)

[Developing Empathy](#)

[Academic Life](#)

[Sharing the Wealth](#)

[Into the Future](#)

[Chapter 6: Getting to Know You, by
Stephen Shore](#)

[Making the Initial Connection](#)

[Making Deposits into a Child’s “Word Bank”](#)

[You Say “TomAto,” I Say “TomAHto”](#)
[Special Interests and Passions for a Successful and Productive Life](#)
[Music for Children with Autism](#)
[Structuring the Stage for Successful Communication](#)
[Self-Advocacy and Disclosure as a Means to Better Communication and Success](#)
[Growing Up](#)

[Chapter 7: Life with Shawn, by Jeanne Lyons](#)

[Active, But Odd](#)
[Fixations](#)
[Meltdowns](#)
[The Power of Music](#)
[School](#)

[Chapter 8: The Freedom to Be Odd, by Cammie McGovern](#)

[Chapter 9: Just a Little Autism, by Teresa Becerra](#)

[Fasten Your Seat Belts, We’re in for a Bumpy Ride](#)
[Life-Changing Experiences](#)
[Follow the Yellow Brick Road](#)
[Here and Now](#)

Chapter 10: Acceptance in Waves, by Robert Becerra

Chapter 11: Everyone Has a Chance to Grow, by Jackie Marquette

Trent

The Importance of Supports

Everyone's Gift Counts

Walking with Others

See the Whole Person

Chapter 12: Grass in the Wind, by Kristina Chew

Chapter 13: Now for Our Feature Presentation, by Robert Parish

Jackie, Can You Hear Me?

Just a Label?

Fill That Prescription!

Hanging Around

Checking Out

Blessed Are the "Angels"

I'll Have Fries with That (Part One)

I'll Have Fries with That (Part Two)

Slow Down and Breathe

What Next? What If ?

Chapter 14: The Big Question

[Resources](#)

[Index](#)

More Praise for *Embracing Autism*

“The voices here confirm what I’ve always suspected: everyone is part of one large continuum, and the approaches and insights recounted here can help any parent, any educator, any person deal with any child—or, for that matter, any other person—more effectively and with more compassion. I only wish I’d encountered earlier this cadre of experienced and caring individuals whose humor and resourcefulness represent clearly how best to love and nurture a child.”

—Cynthia Nitz Ris, J.D., Ph.D., University of Cincinnati

“A rare, engaging look at individuals with autism and those who love and care for them. Each of these warm, lively accounts educates and entertains. Thoroughly engrossing.”

—Marti Leimbach, author of *Daniel Isn’t Talking*

“An inspiring, riveting must-read for parents of children with autism and for anyone who aspires to more meaningful communication with the autistic among us, the brilliant late-talkers and non-talkers who may one day save the world.”

—Annabel Stehli, author of *Sound of a Miracle, a Mother’s Fight to Free Her Child from Autism*

“Written by and for parents, educators, and people with autism spectrum disorders (ASD), this book is a compilation of wise, loving, sensitive, and hopeful stories. This thoughtful advice from those who know will be useful for people who care about someone of any age with ASD.”

—Robert L. Hendren, executive director, M.I.N.D. Institute,
UC Davis

“What a joy to read! There is, perhaps, no better way to learn about autism than to pay attention to the experiences of those living with it. This collection of stories from people with autism and their families, friends, and colleagues shows a side of autism we don’t hear enough about. The authors share that living with autism can be hard, frustrating, and chaotic but also, at times, brilliant, inspired, and pleasantly unpredictable.”

—Dr. Paula Kluth, author of *“You’re Going to Love This Kid”:
Teaching Students with Autism in the Inclusive Classroom*

“To connect with a child with autism is a very special gift . . . not only for the child, but for the few people lucky enough to develop that connection. Robert Parish is sharing this gift with the world.”

—Jennifer Strauss, M.Ed, executive program director,
Autism Consulting & Training, Inc., Miami

“Robert Parish and his contributors provide a perfect blend of first person insights about autism spectrum disorders. Their accounts are informative, uplifting and hopeful, whether you’re working with ASD kids in the classroom, or your living room.”

—Sarah E. Caruso, Cardinal Hill University

“An extraordinary collection of stories that allows us to better understand, appreciate, and connect with children on the autism spectrum. These personal accounts provide insight, encouragement, and optimism to families and professionals working with this remarkable and inspiring group of children.”

—Lindsey Sterling, M.S., University of Washington Autism
Center

EMBRACING AUTISM

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COMMUNICATING
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IN THE AUTISM SPECTRUM

[ROBERT PARISH AND FRIENDS]

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*To Jack Michael Parish,
for always being exactly who you are.*

ACKNOWLEDGMENTS

Hundreds of loving, supportive people have been involved in creating this volume about embracing children and adults diagnosed with autism spectrum disorders (ASDs). I will resist the temptation to name them all.

It seems appropriate to first acknowledge my “co-creator” of Jack Michael Parish: his mother, Diane Maier Knight. Despite the fact that Diane and I endured a difficult divorce nearly a decade ago, her vitally important role in Jack’s life is recognized and appreciated.

Jack’s three older siblings have also made a huge difference in our family’s journey with autism. Graham and Ryan Parish (technically, Jack’s half-brothers), although not present in his day-to-day life, have—inspired by Jack—embarked on careers working with special children and adults, and they’ve helped me embrace my youngest son’s “difference” more than they’ll ever know.

Courtney Parish, at this writing nearly sixteen years old, has been an amazing presence in our family. For a number of reasons, Jack’s diagnosis has had a significant impact on nearly every aspect of her life. More often than not, she’s handled all the curve balls thrown at her head with humor, understanding, and grace.

Jack’s grandparents, Blanche and Jack Maier, have lent important financial support to Jack’s therapy and educational life. Sadly, many of the interventions we (and most every other ASD parent) pursue are not covered by insurance.

Arnold Miller and Stephen Shore, who you’ll meet on these pages, have been with our family from the beginning of our autism trek. Both have taught me about acceptance and embracing our son for who he actually is.

The editorial and marketing team at Jossey-Bass have been a pleasure to work with. Editor Margie McAneny, who approached me about writing a book during a special education conference in Salt Lake City, has guided this project with passion, professionalism, and humor. Leslie Tilley's content and editorial suggestions shaped the entire manuscript—not an easy task with nearly a dozen writers involved. Other important Jossey-Bass contacts who I've relied on through my maiden "big time" publishing voyage include production editor Matt Hoover, copyeditor Tom Finnegan, senior editorial assistant Julia Parmer, executive editor Lesley Iura, senior marketing manager Dimi Berkner, and publicist Maria Meneses. Thank you all for your creativity and energy.

All the very talented and insightful contributors to this work deserve special mention. For several, it was a first attempt at writing their thoughts and feelings about this mysterious and perplexing difficulty. Everyone, including the already published writers, handled my editorial direction without the slightest bit of hesitation or pride of authorship. Thanks so much for trusting me.

It is important for me to acknowledge a trio of mentors. Sadly, all have passed away. Vivian Kwiatek, my English teacher at Millburn High School in Millburn, New Jersey, was the first one to recognize my "gift" for writing. Courtney Whitney Jr., during my teenage "what should I do for a living?" crisis, gently encouraged me to pursue a career in media and communications. Last but not least is legendary Cincinnati broadcast journalist Al Schottelkotte—absolutely, positively the best writer I've ever worked with.

Finally, a special acknowledgment to my mother, Beverly Jane Acomb Parish, who through example showed me the true meaning of unconditional love. My ability to connect with Jack and write and edit a book about this not-so-

comfortable subject is a direct result of her presence in my life.

ABOUT THE EDITOR

Robert Parish is an award-winning journalist with four internationally broadcast television documentaries about autism spectrum disorders (ASD) to his credit. Parish has also produced more than one hundred digital video segments about ASD for educational distribution. His projects are used in coursework at universities; by professional associations; and to inspire and educate special education teachers, the medical community, and parents. Parish maintains a Website (www.comebackjack.org) that receives thousands of visitors each month. He is frequently interviewed in the media as an expert on autism. He also hosts a bimonthly program on Autism One Radio. His son Jack has been an inspiration to him, his family, and thousands (perhaps millions) of others.

ABOUT THE CONTRIBUTORS

Mother of ten-year-old Jacob, *Diane Bayer* has written extensively for dozens of ASD-oriented Websites, blogs, and electronic publications about her son, his diagnosis, and her perspective about it. She has a master's degree in special education. Her Website is www.theautismexpress.com.

Robert Becerra is an executive in the insurance industry, a budding novelist, and, thanks to his son, Robert Jr. ("Little"), a dedicated student of ASD. He and his wife, Teresa, spend a great deal of time advocating for their own son and countless children and adults with an ASD diagnosis.

Teresa Becerra lives in Miami with her husband, Robert. Her son, Robert Jr., was diagnosed with autism at twenty-three months. She is the founder of I Know Someone with Autism—Now You Do Too, a Dade County School program. She is also the president of Parents for Exceptional Progress, South Florida Chapter. In addition, she lectures at local universities and serves on a number of special education boards. She was recently elected president of the Autism Society of Miami.

Kristina Chew is an assistant professor of classics in the Department of Modern and Classical Languages at Saint Peters College in northern New Jersey. She is also the mom of a young boy with ASD (Charlie) and the publisher of "AutismLand" (www.kristinachew.com), a popular blog.

Gay and Dennis Debbaudt are the proud parents of Brad, a twenty-three-year-old who has autism. They have written reviews of autism-related books for the *Detroit Free Press*. Dennis has written about autism and law enforcement issues for the *FBI Law Enforcement Bulletin*, *Sheriff* magazine, *The Autism Advocate*, and the Eunice Kennedy Shriver Center at the University of Massachusetts School of

Medicine. He has also written a book on this topic for Jessica Kingsley Publishers and created training curriculum and video for law enforcement in North America and Europe. (www.autismriskmanagement.com)

Kristin Kaifas-Tennyson is a graduate of Illinois State University with a degree in education and a concentration in learning disabilities and severe behavior disorders. She has a diverse background in teaching special education, writing behavioral and skill programs for children and adults with mental retardation and other developmental disabilities, and operating group homes and supported living programs for private agencies in the Indianapolis, Cleveland, and Cincinnati areas. She is the principal of an alternative school for children with special needs in Cincinnati.

Jeanne Lyons is the mother of seventeen-year-old Shawn, who has Asperger's Syndrome. Shawn collects and studies exotic plants and has twice been a guest on the *Tonight Show with Jay Leno*. Jeanne writes and performs songs for and about people along the autism spectrum. Her CD, *Gather Stars for Your Children: Songs to Enhance Social Skills and Foster a Welcoming Attitude*, received the Autism Society of America's 1998 Musical Contribution of the Year Award. She has presented autism awareness programs in schools throughout the country. (www.lyonstunes.com)

Jackie Marquette has more than twenty years of experience as a special educator and school consultant. She wrote *Independence Bound*, a book about finding and establishing independent living for her son, Trent. Jackie developed the ACT Project in Kentucky through the Kentucky Autism Training Center, which established employment supports for young adults with ASD. Jackie received her Ph.D. from the University of Louisville, where she studied how youths with ASD reached independent living. Trent has autism, is employed, and has lived independently with "creative supports" for six years. (www.independencebound.com)

Cammie McGovern was awarded a creative writing fellowship at Stanford University and has received numerous prizes for her short fiction. Her stories have appeared in such magazines as *Glamour*, *Ladies Home Journal*, *Redbook*, and *Seventeen*, and she is the author of the novel *The Art of Seeing*. She lives in Amherst, Massachusetts, with her husband and three children, the eldest of whom has a diagnosis of autism. She is one of the founders of Whole Children, a resource center that runs after-school classes and programs for children with special needs. Her recent novel *Eye Contact*, a mystery focusing on a young boy with ASD, has been a critical and commercial success. (www.cammiemcgovern.com)

Arnold Miller, director of the Language and Cognitive Development Center of Boston and affiliate professor of psychology, Clark University, received his doctorate in clinical psychology from Clark University. He has held research appointments at Boston University and Harvard Medical School, served on the faculty of the University of Montana, and directed the Language Development Laboratory at Wrentham State School in Massachusetts. He and his late wife, Eileen, founded the internationally respected Language and Cognitive Development Center (LCDC) in Boston in 1965. From then to the present—with the help of research and demonstration grants from the U.S. Department of Education—the Millers have introduced a range of innovative strategies for helping developmentally challenged children achieve their fullest potential. (www.millermethod.org)

Susan Senator is a widely read writer, speaker, political activist, wife, mother of three boys, popular blogger, and belly dancer. The author of *Making Peace with Autism: One Family's Story of Struggle, Discovery, and Unexpected Gifts*, Senator has written dozens of articles and essays on disability, education, parenting, and living happily in

publications such as the *Washington Post*, the *New York Times*, the *Boston Globe*, *Exceptional Parent Magazine*, *Family Fun*, and *Education Week*. Senator's oldest son, Nat, was diagnosed with autism at the age of three. Her publications, event listings, and blog can be found at www.susansenator.com.

Diagnosed as a youth with "atypical development with strong autistic tendencies," *Stephen Shore* was viewed as "too sick" to be treated on an outpatient basis and recommended for institutionalization. Nonverbal until four, and with much help from his parents, teachers, and others, Stephen recently completed his doctoral degree in special education. He is also an accomplished author and presenter. He has authored or coauthored three books, including the 2006 Wiley release *Autism for Dummies*. (www.autismasperger.net)

Kim Stagliano has been an autism activist since the oldest of her three autistic daughters was diagnosed in 1996. Never accepting the blunt, dire diagnosis given by the doctors, Kim embarked on a mission to find internal and external treatments that would work best for her children. She contributes to the *Huffington Post's* Fearless Voices column as "the Autism Mom," and she has written a humorous novel with an autism twist. She runs an autism biomedical support group on Yahoo and serves as a committee member for the National Autism Association. Married to Mark since 1991, she lives in Connecticut with their three girls. Her blog is at www.kimstagliano.blogspot.com.

FOREWORD

THE “SECRET” KEY TO CONNECTION



The big secret to connecting successfully with a child or adult in the autism spectrum is that there is no secret. But that doesn't mean it's easy. Much has already been said, done, and written about autism spectrum disorders (ASDs), especially since 1989 (when my son Nat was born) and 1994 (when he was diagnosed).

Yet the magnitude of literature and accrued wisdom does not make this particular mission any more straightforward. The wealth of conferences, autism experts, therapists, and myriad approaches and therapies all deepen our collective knowledge and understanding of people with ASD, and maybe they give us a flash of inspiration here and there. But what about the actual interacting, educating, connecting, and carrying it out with the right mixture of discipline, compassion, creativity, and, of course, humor? This is something you cannot learn from an expert. However, just as parents learn that their children with the diagnosis are not a mystery, puzzle, or creature, but rather simply a

person, so can others learn their own special way of reaching ASD children.

What, then, is the key to dealing with autism? To paraphrase from the location mantra of real estate agents: “acceptance, acceptance, acceptance!” Acceptance, however, is hard for many to come by.

Like so many parents I know, I went through years of wondering and worrying, of not understanding why I could not get little Nat to play with toys other than to line them up or mouth them. Or why he showed no interest in other children but seemed to be content for hours looking at the dust in a sunbeam. And then, after we knew for sure, there were the years of the learning curve, the confusion about what to do for him, how to do it for him, along with my grief over this change in the direction my life was supposed to take.

Once I realized it was really OK that Nat was the way he was, that there was no shame, there was no failure of anything going on, there was nothing that had to change, nothing I had to do except help him learn, I was happier. I was better at parenting him too. I could work with the boy I had, not with some fantasy child created by made-for-TV movies and Hallmark cards. But to do this, I had to trust my gut.

The first breakthrough I had with Nat was with a technique I figured out intuitively. Having no knowledge of social stories or autism approaches, I created my first social storybook for him, the “Nat Book.” My instinct told me, and my husband encouraged me, to make a Thanksgiving guidebook for three-year-old Nat so he would have a way of understanding the upcoming holiday. Using cut-up family pictures, Nat could see in the book who was going to be there, what was going to happen, and how the day would end. I even told him that he might be a little scared, but if he stayed calm and remembered that everyone loved him

he would have a good time. After reading it over and over, Nat was convinced that he would! He walked right into my aunt's kitchen reciting snippets of the book. Thanksgiving went completely smoothly—the first successful family outing we'd ever experienced.

Not every day is a breakthrough day; most days are not. The point is to use what you know, and then take the leap. If you work with ASD children, the same principle applies. Be prepared and well versed in autism approaches and educational training, but just as important, suspend what you know and just get to know the kid. A certain degree of letting go of your expectations, prejudices, and baggage has to happen.

In letting go of so much, I feel at times as though I am in some ways on my own, which is a scary feeling but also empowering. I am navigating uncharted territory, where I follow my feelings and intuition as well as my autism education, but most important, I follow Nat's cues to gain my insights. When I created the "Nat Book," it was out of sheer desperation, but it was also from the knowledge that books appeared to be the only things outside of himself that interested Nat.

Because ASD children can be unpredictable, intense in what they do, and difficult to read, connection is difficult to come by. Yet I have seen that connection can be difficult with "typical" children too. Or for that matter with husbands, mothers, or friends. These days I apply the perspective I've gleaned from ASD everywhere. To me, everyone is a little in the spectrum. Everyone has their quirks! My son is just more overt in his, more at one with his desires and pleasures. But I want to connect with my son, so I have to do what it takes to get there. I have to tolerate his testing or evasive behaviors, and stay on his side, because my priority is connection, no matter how his neurology looks.

The secret to happy relationships, autism or not, is acceptance—of what you are, and of what he is, warts, synaptic gaps, and all. Then, forging a relationship anyway. It is a bit of an act of faith, at first, an existential journey. But if you literally follow a page from “Nat’s Book” (“stay calm”) and remain confident that it will happen between you, and that everything really is OK though just different, you will get there. It may not look like anything you’ve ever known, but this is actually the best part.

The book in your hands is a treasure of epiphanies from those who have been there and who are there. You will find a variety of experiences with the autism spectrum, from people who have lived with ASD in one way or another. Some of the voices—they come from an accomplished professional in the spectrum, nationally recognized educators, a passionate group of autism parents—are wryly witty, while some are raw with emotion; others are in between.

All of the stories offer insights that will both move and educate those working with ASD children, imbuing you the reader with a perspective on ASD that is at once helpful, genuine, and hopeful.



Susan Senator
Brookline, Massachusetts
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