



Foreword

by John Elder Robison

HAVE YOU EVER WONDERED what it would be like to raise a kid with special needs? I have. You'd think I'd know, since I was a kid with special needs myself. I have Asperger's syndrome, a form of autism. The autism spectrum encompasses a wide range of conditions from total disability to mild eccentricity. I'm fortunate to be at the less-impaired end of the spectrum.

The one thing all of us on the spectrum have in common is some degree of social impairment. We may also have speech, coordination, learning, and health issues. Most of the kids who populate this book have some kind of autism. It may be called Asperger's, PDD-NOS, Rett's syndrome, or childhood disintegrative disorder. Whatever the flavor, it's all in the same family, and it stems from the same cause—configuration differences inside the brain.

I recognize myself in many of these stories. The kids bumble and struggle and fail, and I remember experiencing those very same things long ago. Then I read of their triumphs, and I remember my own small victories. Exceptional clarity of memory is fairly common among people on the spectrum.

After all the names I was called growing up, it's no surprise I saw myself as a misfit child. With that self image, I naturally thought anyone like me must be a misfit, too. However, I know different now. Today I realize that the autistic condition is really the human condition. Our hopes, dreams, and feelings are exactly the same as anyone

else's. We just don't show our feelings in the conventional way, and we don't respond to other people's signals as expected. Yet inside, we are all the same.

It's very frustrating how much of the world is oblivious to that simple truth. In fact, my own distress over that bit of ignorance is one of the things that drives me to be a writer, speaker, and advocate today.

I thought I could contribute a story from the special needs child's perspective, but as I read what others had written I saw my own experience was fundamentally different. It's true I am a person with Asperger's, and I have been this way all my life, but there is a very important distinction. When I was a child, I didn't know I was autistic, and neither did anyone else. I was just a regular kid with a lot of problems and very few friends. I was also a kid who did strange things. And I was a kid who got into a lot of trouble.

You might also think I'd understand the special-needs perspective because I raised a kid with special needs thirty-some years later. My son Cubby, who is now full-grown, also has Asperger's. However, I didn't know he was Aspergian until he was seventeen, and by then, the kid-raising was mostly done.

My special-needs parent experience was limited to watching Cubby get tested, listening to inconclusive results, and arguing with an uncooperative school system. Eventually, I gave up. "He's just not applying himself," they said. That was the same line they fed me, thirty-some years earlier, and I gave up then too. At one level I knew they were wrong, but I did not know exactly how to counter them. Naively, I believed they had my son's best interests at heart. I don't know why I should have thought that, because I knew they were not on my side as a kid, but there you have it. Maybe it's the eternal optimist in me. Anyway, I now know better. If I get a third chance, with an Aspergian grandson, I will not send him to that school system. I will make better choices.

Faced with failure and an endless hassle, I dropped out of high school, and so did Cubby. He's in college now, but he's had a harder time than he might have, had the school been a little smarter or a little more cooperative, or if I'd pushed them a lot harder. But it's not

my nature to whine about such things. Cubby is in school and working two jobs, and he's making his way. That's all any of us can hope for, short of rigging a lottery machine and getting away with it.

I guess my experiences show that it was possible to raise a special-needs kid in ignorance in the sixties, and it's still possible to do it today. But can parents do a better job with the benefit of additional knowledge? My sense is, they can. That's why books like this exist. I wish I'd read one myself, long ago.

I also wish someone had told me about Asperger's when I was a teenager. I knew I had problems, and in the absence of an explanation like autism, I assumed I was just defective. The corrosive aftereffects of that childhood assumption followed me right into middle age, when I finally received a proper diagnosis. Much suffering could have been avoided if I'd known at fifteen.

That's one good side to early diagnosis. Another is the benefit of early intervention. Countless medical studies have shown that kids who receive early diagnosis followed by aggressive therapy do better than kids like me, who grew up in a free-range state.

So those are two great reasons to raise kids in a state of awareness and focus. Every parent in this book does that. If I could go back in time and raise myself again, or start over with my son, I'd do the same. What parent wouldn't?

So what's the downside? I can sum it up in two words: Reduced expectations. There is a real risk that a diagnosis will place limits on a kid's development because people will forevermore say or think, *He has autism, so he can't do that...* When I grew up, no one had any knowledge of Asperger's syndrome. That meant I was held to the same standards as every other child on the street. I had to learn to get along, attend classes, and get passing grades just like everyone else. At least, that was the idea. I followed that path till tenth grade, and then I dropped out and went my own way.

There was absolutely nothing to hold me back except myself. In fact, I often had more incentive to make my own way because I was always on the edge of starvation and ruin. In my early adult years, I lived as an outlaw, working with traveling music groups, riding with bikers, and even living in the woods. I did those things because I

failed in my efforts to follow the conventional path. I dropped out of school because I could not learn in the manner the teachers taught. I could not attend college because I lacked a high school diploma. And I couldn't get a good job because I wasn't a college graduate.

But I didn't let that stop me. I made my own way and found some measure of success. However, the fact that I was an outlaw and an outsider always weighed heavily on me. I was always peeking over the sills to look at legitimate life, wondering what it might be like inside. As successful as I became, that remained the hard truth.

That's where things stood when I finally got The Diagnosis.

By the time Asperger's officially entered my life, I was forty years old. I had married and fathered a child. I had designed video games at Milton Bradley, directed research at Simplex, and then left the corporate life to found J E Robison Service Co., a specialty automobile business. Chicopee Savings Bank had named me to their board, and I was involved in my community. By most standards, I had a full life. If you asked me who I was, I'd have defined myself by those achievements.

If you asked for more, I might have fallen back on the basics. I was a white male, six foot three, two hundred twenty five pounds. Born in Athens, Georgia. If you pressed me some more, I'd volunteer that I was middle class, and generally conservative. That was how I'd describe myself.

Suddenly, with the receipt of The Diagnosis, none of that mattered. The whole concept of "people like me," took on a whole new meaning. All those former adjectives were out the window; rendered meaningless. From D-Day forward, I was a guy with Asperger's. Everything else was rendered secondary to that new facet of me.

The doctors are quick to tell you autism isn't lethal. Yet it's still one of the big scary words in medicine, like AIDS or cancer or Alzheimer's. As such, it's no surprise it came to dominate my thinking. I thought of what I'd previously known—or thought I'd known about autism. I thought of Tommy, the kid on the *St. Elsewhere* television show. I thought of *Rain Man*. I thought of all the silent lost people on the grounds of the Belchertown State School. Were they autistic, too?

Alzheimer's doesn't kill you, but it gradually takes away your mind. Would autism do that to me? Luckily, my reading abilities were still good. Nothing had started failing. Yet. I set out to learn as much as I could, while I could still read and speak.

I was in a state of extreme anxiety at first. My new diagnosis left me feeling as if I had just caught a new and deadly disease. I soon learned that wasn't the case. My midlife diagnosis was attributable to new medical knowledge, not my own deterioration. I was relieved to learn that I am actually getting slowly and steadily "better" through a lifelong process of learned adaptation and acquired wisdom.

So many things suddenly made sense. For the first time, I understood how I could be smart and yet get straight Fs in school. I saw how Asperger's had made school hard for me, and I'd done some pretty unusual stuff after dropping out. New insight brought those memories into focus, and I saw how the differences in my brain had shaped the course of my life in countless subtle ways. Yet I also realized the success I enjoyed as an adult was real, and it wasn't going away. In fact, as I moved forward with new knowledge and confidence, I saw my life was getting better every day.

Asperger's is not a disease. It's a way of being that comes from nonstandard wiring in the brain. The latest science suggests we're born different, or else we become Aspergian early in infancy. That means Aspergian life is the only life we've ever known; we don't get sick and get Asperger's as teenagers. We will always be aliens when we gaze at people who don't have Asperger's, and they will always struggle to understand our thinking.

How does that affect the parents? I never really considered that question until quite recently. This book contains many stories that describe the joy, pain, confusion, frustration, and triumph of raising a kid like me. I had no idea. It also contains stories of resolve and determination that surprise even me. Some of these people are what you might call High Performance Parents.

One thing strikes me in almost every story. Autism has taken over the lives of these people, perhaps to a greater degree than it took over my own life. I talk about life as an autistic outsider, gazing in at the world of normal people. Autism has made these parents outsid-

ers, gazing into the unreadable minds of their own children. What a strange reversal.

When you're a kid on the spectrum, autism is all you know; all you ever knew. There was frustration at things I couldn't do, and even rage. But there was no sense of loss, because I never possessed what autism is said to have "taken away" from me. I started with a certain set of abilities and I built on them. Sure, I may have had less ability in some areas than other kids, and it sometimes hurt to realize that, but I believe we all make the most of what we have. What else could I do?

The situation for aware parents is very different. They see and imagine all manner of things their disabled kids (us) are lacking, and they suffer terribly for us. At least, that's the impression I get from talking to parents today. Was my own mother that way? I really don't know. Oblivion to others is, after all, an Asperger trait. I know I wasn't that way raising Cubby. In that sense, ignorance is indeed bliss.

But does this awareness, focus, and worry produce a better kid? Or does it just produce a more stressed parent? I really don't know. That is one of the great mysteries of kid-raising. Any of us—if aware—would do all the things parents in this book do. And the evidence in favor of early and aggressive intervention is strong. But it's a hard road, no matter how you do it.

Anyway, let's get on with the stories. I hope you enjoy them.
Woof.

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