

Disability or Difference?

One Aspergian Author's Crusade to Change the Way We Think and Speak About Autism

by John Elder Robison

Nearly one million kids in school today have been diagnosed with Asperger's syndrome, or some other form of autism. What will happen to those kids when they grow up and emerge into the wider world? That's the big question facing parents, educators, and mental health workers all over the country. It's easy to panic and lose hope when we see our children struggling mightily with simple tasks.

I know all about struggling, because I was one of those kids. I grew up in the 1960s, before there was widespread understanding of autism in schools. When I struggled, I didn't get help; I got discipline. I was tagged as lazy or uncooperative. Kids called me a retard, and responded to my differences by teasing or shunning me. Adults tried to understand me until their patience ran out. When that happened, they resorted to a doomed cycle of threats, demands, and discipline. It was an ugly situation.

No one knew why I acted as I did. People could see that I was smart, yet I couldn't connect. I didn't have



any friends, and whenever it seemed I might make a friend, I said or did something totally bizarre.

Things are better today, but schools are still full of kids who don't fit in. Name calling, teasing, and bullying remain facts of life—especially for kids with differences, who often seem to become the focal point of such torment. Yet it's possible to rise above that behavior, as I've proven in my own life.

Conditions like autism and Asperger's have traditionally been called *disabilities*, but with my focus on success, I prefer to call them *neurological differences*. Words can be powerful, and by changing the way we talk about autism, we begin thinking about it differently. Eventually, I hope, we will see autistic children differently, and by doing so—by seeing their gifts as well as their handicaps—we will expand their vision of what is possible.

Thanks to our expanded knowledge of autism, adults tend to be more patient and understanding today. But even now, expectations are low for kids with autism. Too often, conventional wisdom dismisses them by saying, "There's no cure. You can't expect too much. You have to be happy with little victories." It troubles me to hear comments like these. The implication is that kids with autism aren't any good, and they won't get better. There's no hope.

Worst of all, those remarks are often uttered by parents and teachers with good intentions. Yet their effect on kids is corrosive.

The fact is, these well-meaning adults are just plain wrong. Over the course of my life, I have gotten tremendously "better." For me, "getting better" is a process that continues even today. And I know plenty of other Aspergians who feel the same way.

That is the reason I wrote, *Look Me in the Eye*. I



wanted others to see autism as I experience it, not as a dark and profound disability. Although some people *are* profoundly impaired by their autism, most of us are more mildly affected. The majority of people on the autism spectrum do indeed grow up to lead good lives.

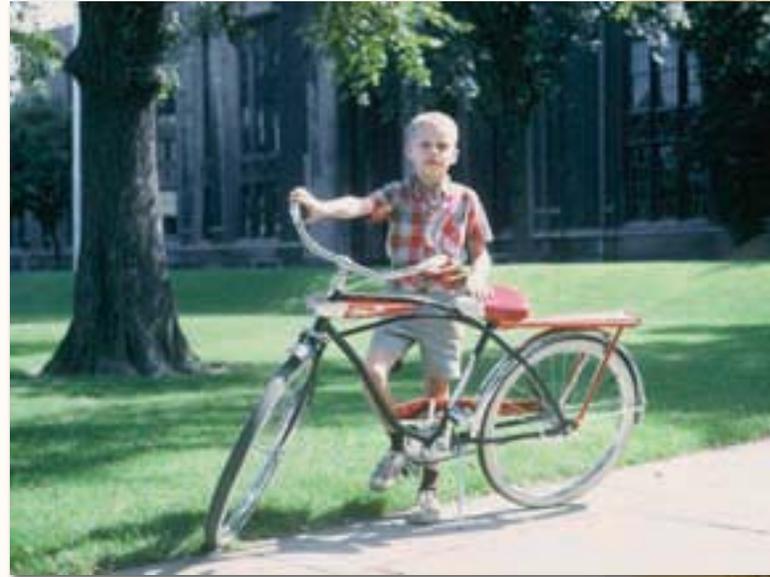
In my book, readers first meet me as a struggling child. At age four, my disability was obvious to everyone, and I originally expected readers to see me as a freak in those early chapters. But something interesting happened when people read my stories. Almost everyone, it seems, saw themselves in my words.

That realization provided a profound life lesson. I had always assumed that I was some kind of weirdo, that my very thought processes were alien to those of a normal person. The overwhelming response to *Look Me in the Eye* showed how wrong my thinking was.

As a person with mild autism, I sometimes act in ways that appear strange or unfathomable. But underneath, I now know that my thoughts and feelings are just like yours or anyone else's. We all share the same humanity, however different we may look. Things that make you happy make me happy, and things that make you sad make me sad. However, autism may cause me to express my sadness or happiness in peculiar ways. Sometimes I don't show any emotion at all, even though I feel it inside.

I developed unusual abilities as a teenager. I had an extraordinary aptitude for electronics and cars, and I found a love of music, though I was too clumsy to play an instrument. I now see how those abilities were enhanced by my Asperger's.

My gifts didn't help me much in school. In fact,



they may have hurt because I wanted to study my special interests and ignore everything else. Eventually, I dropped out, left home, and began the process of finding my way.

When I left home, I joined a band, and within a few years my unusual talents had taken me to the top—designing special effects for KISS and others. After that, I took a job designing electronic games, and then I started a business repairing and restoring Land Rovers, Rolls Royces, and other exotic European cars. I did all that without any diagnosis of my condition. As an adult, I was still eccentric, but people appreciated my unique skills, which allowed me to become a success.

Look Me in the Eye also tells the story of how I got married, started a family, and, at the age of forty, finally

LOOK ME IN THE EYE

by John Elder Robison

Look Me in the Eye is about growing up with Asperger's syndrome — a high functioning form of autism — overcoming limitations, and ultimately becoming a successful adult.

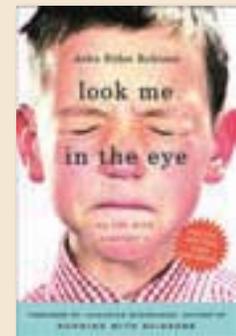
"Of course this book is brilliant; my big brother wrote it. But even if it hadn't been created by my big, lumbering, swearing, unshaven 'early man' sibling, this is as sweet and funny and sad and true and heartfelt a memoir as one could find, utterly unspoiled, uninfluenced, and original."

—from the foreword by Augusten Burroughs, author of *Running with Scissors*.

"John Robison's book is an immensely affecting account of a life lived according to his gifts rather than his limitations. His story provides ample evidence for my belief that individuals on the autistic spectrum are just as capable of rich and productive lives as anyone else."

—Daniel Tammet, author of *Born on a Blue Day: Inside the Extraordinary Mind of an Autistic Savant*

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Now In Paperback!

learned that I had Asperger's. The knowledge of why I am like I am really set me free, and I describe how my life took off following that insight.

I believe the book has some strong messages that resonate with educators, parents, and young people. Students who read the book see how traits that may cause a kid to be ridiculed as a “geek” or “nerd” can, once he's out of school, carry him to the top of the world. That was certainly the case for me. Thousands of young people share my dreams of being in a big band, designing games, and working with fine cars, and many have written to tell me that they were inspired by seeing how I triumphed over adversity.

Another important message of my book is that you should always set goals and never lose sight of them. Focus is one of the key traits that got me where I am today. (Among other things, my focus helped me avoid

drugs and liquor even when they were all around me.) I also learned to take responsibility for my own life, and build upon my strengths rather than dwell on my weaknesses. Finally, I think my book vividly drives home the importance of understanding and accepting differences in people.

I hope that *Look Me in the Eye* will show readers what it's actually like to live with a condition like Asperger's, and by extension, what it's like to live with other neurological differences (autism, ADD, ADHD, PDD, etc.) At the same time, the insights from my story may help people understand, live with, and work next to individuals with Asperger's. With an incidence of one in one hundred fifty people in America with autism, this condition is everywhere (CDC, 2007). Nearly every teacher in the United States either works with or teaches people on the autism spectrum, often without knowing it.

EXCITING NEWS ON THE PAPERBACK EDITION

Seeing the response to the hardcover, I've made a number of changes to the paperback edition for younger readers, their parents, and the academic market:

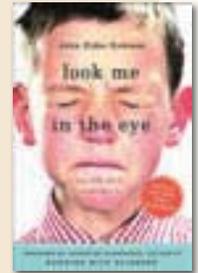
- At the suggestion of several educators, I've cleaned up the language in some thirty passages, leaving the stories themselves unchanged. The hardcover version will remain as I originally wrote it, but the paperback is now free of profanity.
- I've written a postscript that talks about some of the things I've learned in the year since *Look Me in the Eye* was published, including my discovery that there is a distinct, “voice of autism,” which is apparent on the audio version of my book.
- The Reading and Resources section at the end of the book has been enhanced and expanded.
- Finally, the paperback contains a reader's group guide and there are additional educational support materials on my website, including an extensive database of Asperger's and autism support organizations.

I am supporting the paperback release with extensive additions to my website, www.johnrobison.com. In addition, I have a busy lecture schedule, speaking to schools and educational and health groups all over the country. I'm available to run programs with students alone, or students and faculty. I also do faculty-only talks and seminars, including speaking to boards of education and special needs societies. Finally, I speak to mental health and medical professionals about the messages in my stories, and our need to recognize, help, and appreciate all people with neurological differences.

I encourage you to read testimonials from past speaking engagements on my website, or the site of my lecture agent, www.thelavinagency.com.

You'll find my current schedule, news, conversation, and the latest scoop on the sequel to *Look Me in the Eye* on my blog, jrobison.blogspot.com.

School administrators can contact Lauren Verge, my lecture agent, at
The Lavin Agency, 800-762-4234 or lverge@thelavinagency.com





After receiving his honorary high school diploma from the Monarch School in Houston, Robison proudly walks down the aisle with two Monarch students.

That being the case, you might ask, *Are there any other messages teachers should take away from this story?*

First, be aware that kids are not always what they seem. If you speak to a kid on the playground, and he does not seem to acknowledge you but just stares at the ground, don't assume he's just ignoring you or being defiant. He may have autism and be unable to connect with you like an average kid, even though he hears every word you say. Undiagnosed adults may also manifest this behavior. Such people often have reputations as rude or standoffish, when in fact they are just different.

I cannot overstress the importance of sensitivity in these situations. Kids' psyches are fragile and easily damaged by what they see as harsh criticism of a behavior they don't even understand. Be sensitive and gentle, and remember that children aren't the only people you meet with autism. Diagnostic knowledge of autism

spectrum conditions is fairly new, so the world is full of middle-aged people with mild autism who never got a diagnosis, or got a wrong diagnosis.

Second, be aware that, like any other neurological difference, there are both good and bad aspects to autism. It's easy to lose sight of this, especially as a primary school teacher. At that age, almost all we see are the disability aspects of conditions like autism. As kids get older, those annoying fixations turn into wonderful career talents, and emotional blindness may be offset by brilliant logical thinking and creativity.

For example, some of the neurologists I know have speculated that as many as one-quarter of the students in engineering programs at Harvard and MIT may well have Asperger's. And many of those kids were misfits and even seen as failures in grade school.

I urge you to keep this in mind, particularly around kids' families. Parents hear so much negativity about autism and Asperger's; try to give them a positive and encouraging message. I can assure you from my own life experience—it is not all bad. Far from it. My own neurological differences are what set me apart, made me unique, and took me on a remarkable life journey, leading me to where I am today. ■



About the Author

JOHN ELDER ROBISON grew up in an era when Asperger's was not diagnosed in children, and no one had answers about his often inexplicable behavior. Having dropped out of high school, he went on to design special effects guitars for the band KISS in the late 1970s, and then worked as an engineer with a major toy and game company for a decade. For the past fifteen years he has run an independent automobile repair business, J E Robison Service, specializing in Mercedes, BMW, Jaguar, Land Rover, Rolls Royce, and Bentley motorcar work. His company is known nationwide for its restoration and customization work, and he proudly identifies himself as a "machine aficionado." He and his wife live next door to his brother, Augusten Burroughs, in Amherst, Massachusetts.