

# Life on and Slightly to the Right of the Autism Spectrum

## A PERSONAL ACCOUNT

By Stephen Shore

### THE AUTISM BOMB

Most of us are inducted into the Autism Community by what I call the “Autism Bomb.” Autism often strikes a typically developing child at approximately 18 to 24 months with a sudden, dramatic loss of speech and contact with the environment. Self-stimulatory behaviors (“stims”) such as hand flapping and repeatedly spinning objects can occur. All of this happened to me when I was hit with the autism bomb at 18 months.

### My placement on the autism spectrum

Autism is a “spectrum disorder”—the breadth of the condition ranges from severe to light. At the severe end, autism is what most of society considers people with autism to be like: nonverbal, rocking, perhaps in the corner, maybe being self-abusive. Towards the middle is moderate autism, PDD-NOS (pervasive developmental delay—not otherwise specified). Here, there is more environmental awareness, more receptive language and maybe some limited expressive language. At the lighter end of the spectrum, we see high-functioning autism (HFA) and Asperger syndrome.

I landed about in the middle of the autism spectrum. Even though I had lost verbal ability, I still had some awareness of the environment, some receptive language and favorite people I wanted to be with. Often, children on the more severe end of the spectrum have such a lack of body-to-environmental awareness that they’re not quite sure who their mother, father or anybody else is. Whether considering classic autism or Asperger syndrome, difficulty in socialization, communication, restricted interests and sensory issues exists throughout the autism spectrum.

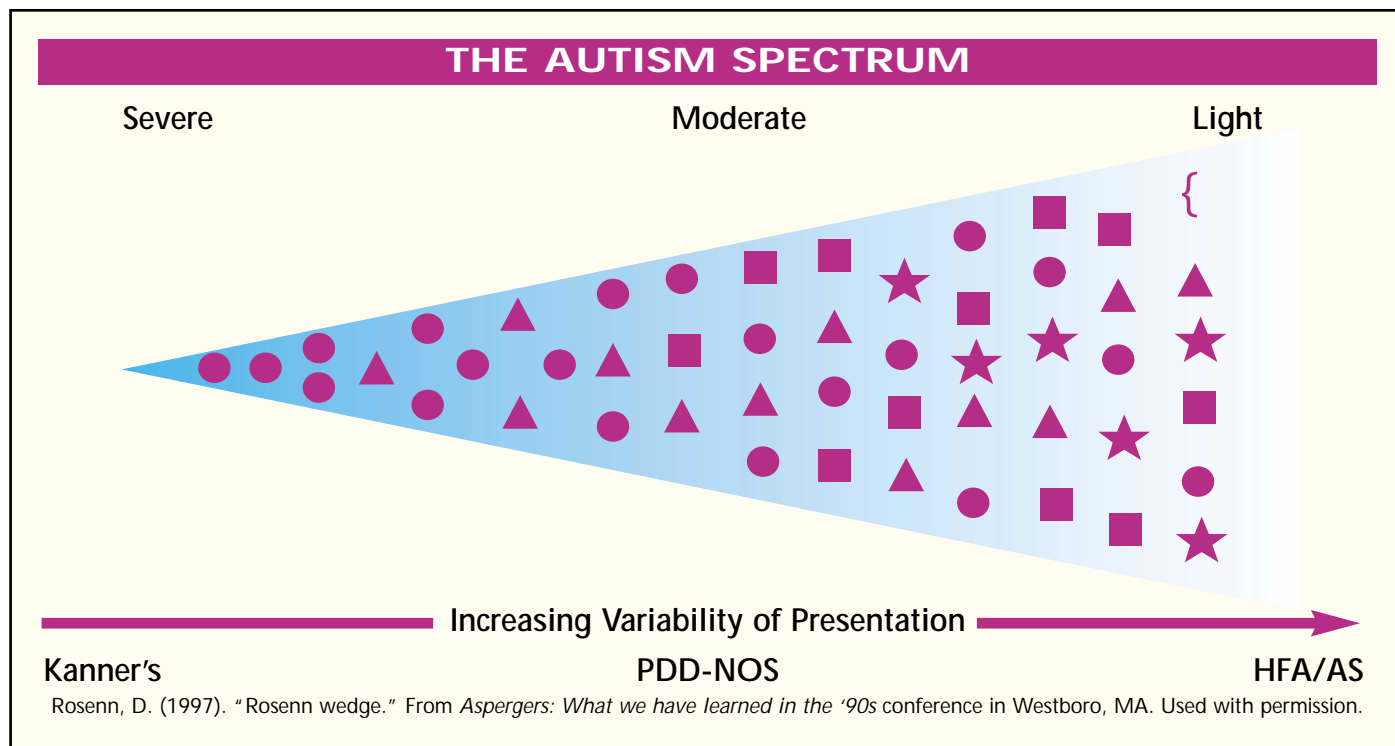
Just about everyone with autism I meet has some of their senses turned up too high or turned down too low. I term this “sensory violations.” Combined with distorted and unreliable sensory infor-



Stephen Shore with his wife Yi Liu, enjoying the beach.

mation, these sensory differences can make dealing with the environment in an interactive manner, especially when transitions are involved, very difficult. This distortion encourages those of us on the autism spectrum to stick to the same old routines because it is easier to do what you already know.

*continued on page 86*



continued from page 85

But an autism spectrum diagnosis is a dynamic rather than a static diagnosis and prognosis is difficult at best. You may have a child who, at age two-and-a-half, is flapping his hands so hard it looks like he is going to take off or, like me, walking in circles with his finger in his ear. However, by four perhaps he has learned how to speak, and by age six is in public school—part time in regular education, part time in a resource room—and goes on to improve from there.

#### Infant to toddler

*“Stephen had developed normally until he was a little more than a year old. He had started to talk and was relatively responsive. Without having any traumatic event to point to, somewhere in the first half of his second year, Steve stopped talking.”*

—Mother’s words, in *Beyond the Wall*.

It took my parents a full year to find a place to get me evaluated. In the mid 1960s, there were no autism conferences, support groups, books or other resources save for those declaring this condition a rare childhood disorder caused by bad parenting. At two-and-a-half, I was diagnosed with atypical development and strong autistic tendencies, and as psychotic. Never having seen a child who was so “sick,” the doctors recommended separation from my family to an institution where experienced professionals could better take care of their “disturbed” child. My parents said “NO” to separation from my family and finally convinced the team of professionals to take me in a year.

#### Early intervention

*“To try to bring Steve out, I decided to verbalize everything. I talked to him in the car, at the table, in his room. He didn’t appear to be hearing me, but I knew he was. On occasion I would speak nonsense or make a silly remark such as, ‘Look at that dog climb the tree’ to which he would respond with a small, amused look at me from the corner of his eyes. He was musically aware too. I usually had music on and Steve would move to the tempo.”* —Mother’s words, in *Beyond the Wall*.

My mother tried first to get me to imitate her, but failed. There was no connection. Changing tack, she tried imitating me. In doing so, I became aware of her existence—“Gee, you’re there,” I thought. My mother got inside my zone of attention.

*“When he made peculiar sounds or spoke in garbled words, I copied him. Slowly he began to acknowledge this and added the sounds of machinery, appliances, and animals to his vocabulary.”* —Mother’s words, in *Beyond the Wall*.

This imitation, even on a very early and basic level, had very important educational implications. Whether the learner is on the autism spectrum or not, the educator can strive to meet the student on his or her level, even if that means stimming with the student. It doesn’t have to be done all day, every day, but long enough to let the student know that the educator is part of his environment. Then the educator can start to pull the student’s attention in the desired direction.

## Self-Stimulatory Behavior as Self-Regulatory Behavior

Many parents and educators try to stop stims before they understand the purpose they serve. It is important to understand why a child is stimming, and then consider a substitute motion if there is a significant impact on daily functioning. Everyone stims at some time. Who has not tapped a pencil, doodled or engaged in other repetitive motion while sitting in a meeting? This is stimming. It's just that most adults know how to stim in a more socially acceptable manner. You can't "squash" a stim. Borrowing from martial art philosophy, if somebody throws you a punch, you deflect the punch. You don't stop it cold. It is the same with a stim.

Perhaps a child who hand flaps could be taught to squeeze a squishy ball. For a child who bounces up and down during class, perhaps seating her on a therapy ball, which has all sorts of sensory integration ramifications, may be a good solution. She will have to focus on keeping her balance instead of having to bounce on the chair because she loses contact with the environment.

### Environmental awareness and zone of attention

Arnold Miller, an autism researcher and author, indicates that one key issue for those on the autism spectrum is difficulty in body-to-environmental awareness. These children don't know intuitively know where they end and where the environment begins. Most people have an unlimited zone of attention which allows them to perceive objects and people far away from their bodies, across a room or a field. However, for children on the autism spectrum, the zone of attention can be a very limited "bubble." One of the goals in working with children on the autism spectrum is to expand this environmental awareness. My lack of body-to-environmental awareness probably explains why I seemed to ignore my mother's calling me into the house for lunch. I never heard her. She would have to actually touch me to make me aware of her presence.

At age four, I discovered the wonderful world of watch motors. I would pop the back off, pull out the gears and other workings, and then put them together again, and the watch still worked! How can one have the fine motor skills to take apart a tiny watch or other mechanical device, and yet find handwriting so difficult? The reason may have to do with structure and proprioceptive feedback from a mechanical device such as a watch as opposed to writing on a piece of paper.

Structure is vital for people with autism spectrum. The watch has a structure all unto itself and working within that structure is easy. Additionally, feeling the watch parts and putting them back into place provided proprioceptive stimulation. In contrast, hand-

*continued on page 88*

continued from page 87

writing has much less structure, presents a proprioceptive motor challenge and is more of a cognitive task for many people with autism. Having to actually *think* about the physical process of writing takes precious cognitive energy away from other tasks, such as processing and understanding other information that is coming in from the environment.

### Public school

At about four years old, verbal ability started to return to me and I entered the school that initially recommended separation from my family. My condition improved to neurotic from psychotic. Things were looking up.

Upon entering regular education public school kindergarten at age six, I was a social and academic disaster. As a “different” child, I received more than my share of teasing and bullying. Fortunately, school systems are now beginning to realize that bullying is not to be accepted as some developmental phase youngsters go through, but rather is something not to be tolerated.

Two things were very helpful during that time. First, even now, I like school because I enjoy learning new material and I find the regular schedule reassuring. Second, but even more important, was my parents’ unconditional acceptance of me combined with their understanding and desire to help me make sense of what could often be a confusing environment.

My parents used the word “autism” just as they used any other words around me ever since I can remember. For me, even as early as kindergarten, “autism” had no negative connotations; it merely explained why I was different from the other children. Autism is just a name for a collection of traits, not a label with limiting connotations.

### Special interests

I sensed that the teachers did not know what to do with me and so I spent many hours reading my favorite books and wondering, “Should I be doing something else in class?” However, since I was not a behavior problem, they just tended to leave me to my own devices. Around this time a teacher told me that I’d never be able to do math. Somehow, though, I learned enough of this subject to teach statistics at the college level. Another instructor informed my parents of my reading difficulties. My surprised parents responded with, “What are you talking about? He’s reading the newspaper at home.”

The teachers didn’t recognize and employ my special interests. Autism researcher and author Tony Attwood defines a special interest as “an interest of such great intensity that it interferes with daily function.” My mother instinctively supported my special interests with active involvement. For example, when I was interested in collecting seashells, she would help mount them categorically in boxes.

My many special interests would, and still do, come and go. Often I maintain more than one of them at a time. Had the teacher noticed the foot-high stack of astronomy books on my

## SOME SPECIAL INTERESTS

Children on the autism spectrum often have special interests. Special interests can be subjects or things that fascinate them and on which they can become “expert”—learning as much as they can about it, and often communicating this knowledge at any opportunity. The following are a few topics which might be attractive to children on the autism spectrum:

Airplanes	Hardware
Astronomy	Locks
Autism	Mechanics
Bicycles	Medicine
Cats	Music
Chemistry	Psychology
Computers	Rocks
Dinosaurs	Shiatsu
Earthquakes	Tools
Electricity	Watches
Electronics	Yoga
Geology	

From Shore, S. (2003) *Beyond the wall: Personal experiences with autism and Asperger Syndrome*, 2nd Ed. Shawnee Mission, Autism Asperger Publishing Company, p. 31.

desk, she would have discovered a way to reach me. I daresay there was more than enough math and reading involved in astronomy to enable me to learn these subjects at the elementary school level.

### Literal thought

At age ten, during a grammar lesson, I learned the rule of dropping the “e” at the end of a word before adding the suffix “ing.” This was terribly upsetting to me as I worried about how that poor “e”, formerly situated in an alphabet strung about 10 feet above the blackboard, was going to feel when dropped. That “e” was going to get hurt! I perseverated on that for weeks to anybody in my vicinity.

When a friend of mine said he “felt like a pizza,” I argued with him that he didn’t look, nor smell like one, so how could he feel like one? It wasn’t until college that I learned he meant he felt like EATING a pizza. Here, what may be interpreted as a challenging behavior is really just an issue of translation or literal interpretation of content.

Idioms like these still go zinging by me. However, now I can usually catch them and pull them back for analysis before I say something ridiculous. But it takes extra cognitive work on my part to construct meaning in words that don’t make immediate contextual sense.

### High School

Difficulties with high school are not solely constrained to people on the autism spectrum. Some of the challenges include complexity of social interactions, dating and conforming with peers. In high

school, however, I was able to specialize in my special interest. I discovered the band room, was good at music and could base much of my social interaction there. It is important to realize that building relationships for people on the autism spectrum (a precursor to community involvement) can develop through special interests. Bicycling, another special interest, led me to start a bicycle club. There I had a captive audience for my bicycle perseverations—at least for a couple of minutes. For people with autism, it is important that the main goal of a gathering of people is activity-oriented. In other words, the best chances for success exist when the reason for getting together is to talk about computers, bicycles or whatever their special interest is.

However, any event that is socially oriented or unstructured, such as a cocktail party or a senior prom, is hard for people on the spectrum. Giving someone on the autism spectrum something simple and concrete to do is very helpful. Some jobs might be to help the host with passing out the drinks, organizing the music, or serving as DJ.

### Building an intuitive sense of social interaction

It is possible to approximate an intuitive sense of social interaction. One good way to do this is to give us algorithms. In other words, somebody needs to tell us, “This is what you do; this is how social interaction with another person works.” These explanations are the basis of the series of books by Gray & White called “My Social Stories” and are used to help teach people with Asperger syndrome the rules of social interaction. For example, in working with “George,” a person with Asperger syndrome, I explained to him, “When people look at their watch, it means they’re bored with what you’re talking about. That way, you know that you need to talk about something else or, better yet, give them a chance to talk.” I said, “Now, George. I’m looking at my watch. What does this mean?” He thought a moment and said, “WELL, some watches have roman numerals, other watches have Arabic numerals and there’s a clock on the wall if you want to see what time it is.” He didn’t get it. Eventually, though, George did catch on. By showing him the other person’s viewpoint in a social interaction and explaining to him what social cues mean, I was able to make him understand how he should respond and enable him to flesh out and refine his social side.

Another important element of social interaction is eye contact. As for many people on the autism spectrum, eye contact was difficult for me and can still be. People with autism have great difficulty in processing the huge quantities of nonverbal data coming from the eyes and the face. Attempting to do so takes away cognitive energy from processing conversation. For situations that require perceived eye contact, I say “fake it, but don’t break it.” Others probably are unable to differentiate whether I am looking between their eyes, at the bridge of their nose or in their eyes.

*continued on page 90*

Circle #63 or visit [www.eparent.com/adinfo](http://www.eparent.com/adinfo)

stewart

Circle #62 or visit [www.eparent.com/adinfo](http://www.eparent.com/adinfo)

## A word about echolalia, echopraxia and echoemotica

I went through a period of “echolalia,” the unintended imitation of sounds from the environment, prior to the return of speech. I still experience residual effects of my non-verbal period, however, which can be the cause of some social embarrassment, so I try to be aware of them. Recently, while speaking with a student in my college office, I logged off America OnLine and unexpectedly echoed the “goodbye.” When the student thought I was speaking to him and turned to leave, I quickly explained that I was speaking to the computer. I also often pick up accents and expressions and begin speaking like the person who is talking to me.

Another residual of my youth is “echopraxia,” or imitation of another’s movements. Sometimes I feel like my interactions with the environment involve many little pieces of other personalities I come in contact with. These little bits get compressed and employed here and there.

A third residual is “echoemotica,” or taking on other people’s moods and emotions and not being able to separate them from your own. This happens with most people to some extent, and quite often in children who pick up on a parent’s or a teacher’s emotion and act out accordingly. At this point in my life though, I know that if I feel an emotion that’s out of context with the environment, I need to look around and say, for example, to my wife, “Are you feeling upset or agitated today?” Once I find out that she does feel upset, I can then separate from her feelings, still empathize with her, but also realize that it’s not my emotion. In doing so, I’ve cognitively built typical empathy.

*continued from page 89*

### College and beyond

At age 19, I entered college. College was a sort of utopia with more friends and interesting courses, free from the conformity and bullying of public school. I studied music education as well as accounting and information systems. Most of my coursework was successful and I was in both the university and departmental honors program. However, one course involved a semester-long research project. After approval from the instructor on my topic of research, I was left on my own. Unable to structure the research project meaningfully and after some misunderstandings with the professor, I dropped the course. Having an outline of the protocol for a research paper would have been a great accommodation. It never occurred to me to ask.

For many on the autism spectrum, college presents myriad challenges in structuring one’s day, socialization, independent living skills and obtaining needed accommodations. Exacerbating these difficulties is the big paradigm shift—from being provided accommodations through the Individualized Education Plan (IEP) to self-advocacy.

### Self-advocacy

Self-advocacy is realizing what one needs in order to maximize functioning in life and knowing how to arrange the environment or obtain accommodations to do so. The road to self-advocacy includes discussions of disclosure, special interests, learning styles, learning accommodations and even relationships. One way to teach these skills is through involving students to the fullest extent possible in the development of their own IEP the moment it is known they are on the autism spectrum. The sooner this is done, the more prepared they will be for a productive, self-guided future.

There is much hope for people on the autism spectrum since an autism spectrum diagnosis is not a static diagnosis. The challenge to all who work with this population is to bring them as far and as fast as possible to the lighter end of the spectrum. At this time, we don’t know all the answers to working successfully with children on the autism spectrum. However, the following variables seem to have a large effect: Appropriate early intervention; family support and love that accepts a person with autism as they are along with wanting to help them better interact with the environment; proper education; friends as well as teachers and other professionals that truly understand the child with autism.

*With much help from his parents, teachers and others, Stephen Shore is now completing his doctoral degree in special education at Boston University with a focus on helping people on the autism spectrum develop their capacities to the fullest extent possible. In addition to serving as Board President of the Asperger’s Association of New England, Board of Directors for Autism Society of America, Unlocking Autism, and the Asperger Syndrome Coalition of the US, Stephen presents and consults on autism-related issues internationally as described in his recently released book, *Beyond the Wall: Personal experiences with autism and Asperger Syndrome*, 2nd ed. EP*

### REFERENCES

- Autism Society of America, web site <http://www.autism-society.org>.
- Gray, C. & White, A. (2002). *My social stories book*. London: Jessica Kingsley Publishers.
- McGahee, M., Mason, C., Wallace, T., & Jones, B. (2001). *Student-led IEPs: A guide for student involvement*. Arlington, VA: Council for Exceptional Children. Available at <http://www.cec.sped.org/bk/catalog2/iep.html>
- Shore, S. (2003). *Beyond the wall: Personal experiences with autism and Asperger Syndrome*, 2nd ed. Shawnee Mission, KS, Autism Asperger Publishing Company.
- All images from Shore, S. (2003). *Beyond the wall: Personal experiences with autism and Asperger Syndrome*, 2nd ed. Shawnee Mission, KS, Autism Asperger Publishing Company.