



Inside autism:New insights shattering myths surrounding spectrum of disorders

By **Julie Kirkwood**
Gloucester Daily Times

—
Step into the brain of Stephen Shore, a man who was diagnosed with autism at age 21/2.

He is at an autism convention and the lights at the hotel are so bright it's like staring into a 100-watt bulb.

"You can sort of do it," he said, "but it's really, really uncomfortable and it will probably distract you from doing other things."

Strangers pop up on all sides and talk as if they know you. You don't recognize faces well, so you don't know who you've met and who just knows you through your books or workshops.

You have trouble understanding body language and tone of voice, so you need to concentrate to speak this foreign language.

You try to focus, but the lights and noise and zig-zag carpet are overwhelming. You grow tense and jumpy, and feel like you're trapped in a video game.

"It can be draining," Shore said.

For years, it was anybody's guess what was going on inside an autistic person's head. Autism causes people to disengage from the world and not communicate, so from the outside people with autism seem to have no emotions, no sense of humor, and no rational reason for their outbursts.

But those myths have been shattered, now that people who have autism are finding their collective voice.

First there were the voices of just a few people, like book author Temple Grandin and activist Jim Sinclair. In the 1980s and 1990s, they began to make people realize that not everybody who has autism is nonverbal.

Then the American Psychological Association recognized Asperger syndrome in 1994. Asperger's is an autism spectrum disorder, characterized by impaired social skills, without impaired verbal skills. Suddenly there was a group of people who experienced the internal world of the autistic brain who could be ambassadors to the rest of the world.

Hard to relate

"When I talk to people, I have a tendency to not look them in the eye," said Alex Gershaw, 28, of Middleton. "I have to remind myself to look people in the eye when I'm talking."

Gershaw is one of the growing number of adults who didn't have a name for their autistic tendencies until adulthood.

In school he was diagnosed with "social disability, not otherwise specified," and there were no services like there are today to help children on the autism spectrum. It wasn't until he went for private therapy as an adult that somebody suggested he might have Asperger syndrome.

Gershaw has a data entry job, a good fit because it doesn't require much social interaction. Still, in an office of 100 people it's impossible to avoid all human contact. That's where he has trouble.

"It's a strain for me to even listen a conversation and follow what's going on," Gershaw said. "I remember in first grade, one of the things the teacher said about me was, 'Alex doesn't listen.' It's not that I don't listen, it's that I have a hard time following conversations."

He would like to become friends with his coworkers and maybe join them for drinks after work sometimes, but he finds it terribly difficult to initiate conversations and even harder to take an interest in their banter.

"When I have a hard time relating I just can't listen," he said "I just don't care."

It's not because he's mean. It's the way his brain is wired.

Sometimes it's hard not to blurt out the first thing that comes to mind, said Michael John Carley, who has Asperger syndrome and runs GRASP, the Global and Regional Asperger Syndrome Partnership.

"All those times that person hurt your feelings, they didn't intend to," Carley said.

A growing force

GRASP is testament to the growing voice of people with autism spectrum disorders. In 2003, the group had about 400 members. Today there are about 2,300.

"I'm just sitting there watching this absolutely beautiful thing happening and it seems to have a life of its own," he said.

As people with autism spectrum disorders find their voice, they have a mission, though not everyone agrees what it is.

Some autistic activists argue against Applied Behavior Analysis, a common autism therapy, and against the search for a cure. They say they like the way they are and don't want to be forced to conform to somebody's idea of normal. The view is highly controversial among parents of profoundly disabled autistic children.

Others within the movement are just promoting tolerance, self-advocacy and an appreciation for the autistic mind.

"They're their own thinkers," said Dania Jekel, executive director of the Asperger's Association of New England. "They tend to think things through very carefully. ... Very often we have people who are almost obsessive about things, but in a very positive way."

She said they often join political campaigns.

"They join Greenpeace, animal rights, ecological movements and are very, very persistent in ways other people aren't," she continued, "in some ways because they care a little less about what other people are thinking about them."

Shore said he loves the way his brain can very quickly scan a page of text and pick up errors, or as he calls them, "violations." He loves the way he hears music, with rich texture and detail in the overtones and harmonies.

"Autism and Asperger's syndrome are a different way of being, not necessarily a disordered way of being," Shore said. "If we think of it as a difference, a collection of characteristics as opposed to a collection of deficits, that will set the stage for much more effective advocacy for all people on the autism spectrum and, I'd say, for all people with all differences."

Shore, who will be speaking at a University of New Hampshire autism conference next month, said people

on the autism spectrum should be encouraged to find strategies for getting by in a non-autistic world, rather than taught to be typical.

His childhood diagnosis of autism has been downgraded over the years to Asperger syndrome, then to "learning disorder-not otherwise specified, with characteristics consistent with childhood autism." But he still constantly relies on the strategies he developed to survive in a neurotypical (a term coined by the Asperger's community for those who do not have autism).

Shore, 44, types notes on a computer whenever he meets with professors on his work toward a doctorate degree from Boston University. That way he doesn't get tripped up trying to process all the information at once.

At conferences, he wears a baseball cap to block the blinding lights. He has studied body language the way one might study Chinese and trained himself to translate crossed arms, foot position and other subtle signals other people take for granted.

He also decides when it's worth coping and when to avoid overstimulation. As a general rule, he doesn't hang out in bars because he would have to wear ear plugs and a baseball cap, and focus intently on nonverbal communication skills.

"It's knowing enough about yourself so that you can anticipate situations, and make your needs known to another person," he said.

FOR GRAPHIC:

The characteristics of people with autism spectrum disorders vary tremendously. Some people may have several of these characteristics, while others may have just a few or only one. In some people they may be debilitating, while in others, barely noticeable.

- * Ability to shut out the world and focus inwardly or concentrate very intently on a task.
- * Trouble making eye contact.
- * Sensitivity to visual cues. Lights may seem terribly bright. Colors, flickering fluorescent lights, and patterns, such as zig-zag carpets, may be overwhelming and distracting.
- * Sensitivity to touch. Clothing may feel as scratchy as sandpaper digging at the skin. An affectionate touch on the shoulder may cause searing pain.
- * Sensitivity to sound. Temple Grandin, who has written about growing up autistic, said the school bell sounded like a dentist's drill going through her ears.
- * Sensitivity to odors. Lotions and deodorant may smell unusually strong. Perfume can be overpowering.
- * Sensitivity to taste. Eating may be a dreaded chore because nothing tastes good.
- * Inability to talk. There may be something the person wants to say but can't. Some people can communicate through writing but not speech.
- * Doesn't naturally learn to interpret body language and other unspoken forms of communication, which neurotypical people learn by watching others. Some people may study and learn body language as a foreign language, but it does not come naturally.

Tips for the 'neurotypical'

The Asperger's community has coined a term for people whose brains are wired differently from theirs: neurotypical.

The Autreat, an annual conference by and for people on the autism spectrum, assembles a panel of neurotypicals to explain why they do the things they do - a twist on the traditional autism conference with a panel of people with autism.

Here are some hints provided by **neurotypical Dania Jekel**, executive director of the Asperger's Association of New England, on how a neurotypical can improve his or her communication skills when talking to a person with Asperger's.

- * **Be concrete with your language.** A person with Asperger's may miss the context, the emotion in your voice or the significance of pauses, and instead focus just on the literal words. For the neurotypical, words are only about 25 percent of communication. Try to put more into words.
- * **Be clear about your emotions.** Facial expressions alone may not convey the context of what you're saying.
- * **Write things down** and allow the person who has Asperger's to communicate in writing, if he or she is more comfortable. Use e-mail. If you are a supervisor, write out lists of tasks when you assign them.
- * **Communication is often easier** one-on-one than in a group of three or more people.
- * **You may need to give** the person some advice on what behavior is expected in a particular situation. Don't assume, for example, that a person with Asperger's will figure out the office dress code by noticing what co-workers are wearing. Tell the person directly, without being condescending, that a dress shirt and tie are expected.
- * **If you are dating somebody** with Asperger's, don't play subtle games. Don't say, "I'll call you later," in a dismissive tone and expect them to know you're breaking up. They may wait for that call. Just say, kindly, something like, "I don't think I'd like to go on another date."
- * **The more you prepare** a person with Asperger's in advance for how an activity will play out, the less stressful it will be for that person. Tell them when the meeting will start, what to bring and that there will be a 10-minute break.
- * **Avoid interrupting** a person with Asperger's in the middle of a task. It's better to give the person a clear plan at the beginning of the day and let them follow their work through to the end.

Tips from people with autism

Here are some tips from **Michael John Carley and Stephen Shore, two adults who are on the autism spectrum**:

- * **Understand that a person** who has autism may blurt out thoughts as they occur, without any intention of being rude or hurtful. Try not to take offense.
- * **Take their passion** and excitement as something positive, not as an obsession that needs to be stopped. Encourage a person with autism to indulge their passion, especially if it's productive and healthy. If it's a passion for something nonproductive, like video games, encourage them to direct that passion elsewhere.
- * **Be aware that a person** with autism may take longer to process a question and respond with an answer. In a classroom, tell the autistic student to think about question five and then start the rest of the class on question one. By the time you reach question five, she will have had time to process and show her true intelligence with an answer.
- * **Don't be frightened** or threatened by "stimming," a term that's short for self-stimulatory behavior. These are repetitive body movements, such as rocking, finger snapping or vocal sounds, that some people with autism do habitually.
- * **Know that people** who have autism do have emotions and senses of humor. They just may not laugh at

the same jokes or show their emotions in the same way you do.

Get connected

The Watertown-based Asperger's Association of New England is a network of about 2,000 people who have Asperger's syndrome. The organization **runs support groups, discussion groups and activities** throughout the region, including groups for parents **in Andover, Newburyport, and Concord, N.H.**, and an adult group in **Danvers**. Information is available at (617) 393-3824 or **www.aane.org**.

Stephen Shore, author and public speaker, has organized information about his experience with autism spectrum disorders at **www.autismasperger.net**.

Information about GRASP, the Global and Regional Asperger Syndrome Partnership, is available at **www.grasp.org**.

Autism Summer Institute

What: A three-day workshop featuring personal accounts from people living with autism spectrum disorders, offered by the University of New Hampshire Institute on Disability.

When: Aug. 14 to 16

Where: The university's Holloway Commons, Durham, N.H.

Keynotes: Stephen Shore, author and Boston University doctoral student; Ros Blackburn, a lecturer from Essex, England; Larry Bissonnette, an artist. All three have an autism spectrum disorder.

Cost: \$390 per person. Discounts for full-time students, family members of individuals with autism spectrum disorders, and for keynote sessions only.

Registration: (603) 228-2084 or www.iod.unh.edu.

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