

HOWARD C. SHANE, PhD

Director, Center for Communication Enhancement, and Director, Autism Language Program, Boston Children's Hospital; Associate Professor of Otology and Laryngology, Harvard Medical School, Boston, MA; and Monarch Center for Autism, a division of Bellefaire JCB, Shaker Heights, OH

Appreciating Asperger syndrome: Implications for better care and outcomes

The behavior of an Einstein, Ford, Edison, or Beethoven might lead to a diagnosis of Asperger syndrome today

IN THIS ISSUE of the *Cleveland Clinic Journal of Medicine*, Prayson and Franco paint a comprehensive picture of the key medical and therapeutic issues faced by patients with Asperger syndrome.¹ They offer a refreshing optimism about contemporary treatments aimed at enhancing independence and quality of life, while being realistic about the challenges for these patients, such as making the transition from pediatric care to adult care. Importantly, their overview offers practical suggestions for improving medical care through a greater understanding of the syndrome, along with strategies for how to relate to patients who have a difficult interpersonal style.

See related article, page 875

In this editorial, I focus on lessons learned in our practice that help identify the problems that people with Asperger syndrome have, and I build on the advice of Prayson and Franco on how to improve patient experiences in the adult medical setting, particularly by diminishing confusion and uncertainty in doctor-patient interactions and by supporting ongoing functioning.

PEOPLE WITH ASPERGER SYNDROME HAVE ALWAYS LIVED AMONG US

Asperger syndrome is being diagnosed more frequently, using criteria recognized by a greater number of professionals. This diagnostic distinction offers a clearer understanding of a group of people who have always lived

doi:10.3949/cjcm.79a.12153

among us—often standing out because of their appearance, behavior, and communication style, even before a common label existed for their condition.

In less-informed communities, they might be described by neighbors or peers as eccentric or odd, even when they present no obvious dysmorphic or other distinguishing physical features. In fact, some may stand out more because of their accomplishments. The behaviors reported for some innovative scientists (Einstein), inventors (Ford, Edison), musicians (Beethoven), and others might lead to a diagnosis of Asperger syndrome today, while an obsessive nature also characteristic of Asperger syndrome might well have enabled them to think and create in astonishing ways.

As we have come to understand this syndrome better, we have recognized that it is a spectrum. Some patients are highly functioning, for example, and different patients have different needs.

Steve Silberman,² writing for *Wired* magazine, coined the term “geek syndrome” and suggested that geeks marrying geeks may help account for the comparatively high prevalence of autism and Asperger syndrome in “tech-heavy” communities such as Silicon Valley in California and Route 128 in Massachusetts. “At clinics and schools in the Valley, the observation that most parents of autistic kids are engineers and programmers who themselves display autistic behavior is not news.”² Temple Grandin, arguably the best-known person with an autism spectrum condition, has characterized the NASA Space Center in Houston, TX, as a similar community.

Given this correlation, it follows that colleges and universities offering engineering, computer science, and other technical programs or degrees should have a relatively high prevalence of students with Asperger syndrome. The Massachusetts Institute of Technology, where such a pattern is often observed, offers a course entitled “Charm School,” and its online course description is suggestive of the unique needs of this population³:

“How do I ask for a date? Which bread plate is mine? At what point in a job interview can I ask about salary? Should I use a cell phone while on the T or the elevator? How can a student network to find the perfect position? Join us for MIT’s 19th Annual Charm School to find out these answers and more.”

■ COMMUNICATION DISTURBANCES

The challenges a person with Asperger syndrome may be experiencing are often very difficult to understand. While these people may look normal and demonstrate average to above-average intellectual functioning, their sometimes-peculiar behaviors and deficits in social skills are often difficult for peers to interpret—and to forgive. People with Asperger syndrome want to get along with peers, develop relationships, and succeed in the workplace, and they feel perplexed that others sometimes seem put off by their behavior.

At the core of this discomfort are a range of communication disorders that negatively affect interactions with others. One practical indication of a communication disorder is whether more attention is paid to how something is said than what is being said. This may present to the physician in different ways.

Language

Difficulty with introspection and description may render a patient incapable of describing symptoms and related historical information. In addition, the idiomatic and figurative nature of English may lead Asperger syndrome patients to misunderstand what the physician is saying—even common nonliteral expressions such as “Hop up on the table,” “You’re as fit as a fiddle,” “Are you feeling under the weather?” and “I’m all ears.”

Speech and voice

For the person with Asperger syndrome, speech is often marked by prosodic disturbances, including problems with varying and atypical intonation and stress and, less commonly, unusual fluency patterns and residual articulation issues (*l*, *r*, and *s* sounds). These characteristics can be addressed in therapy.

Conversational style

When people with Asperger syndrome engage in conversation, it is usually brief, or they tend to monopolize it with topics of high interest to themselves or topics of a perseverative or obsessive nature. The patient also tends to have limited perspective and experiences difficulty with higher-order language (including inference and reasoning).

Nonverbal language

A host of nonverbal communication problems include the use of unacceptable social distance and the unintentional messages conveyed nonverbally by unusual clothing choices and poor grooming and hygiene.

■ WHAT CAN BE DONE IN THE OFFICE VISIT

The key to a successful visit with such patients is to help them anticipate and make sense of their experience. In the visit, predictability should be emphasized and “chaos” avoided. Try to schedule the patient with Asperger syndrome during less-busy days and times, and avoid surprises during medical examinations or procedures, as the unexpected often triggers an extreme reaction. Examinations and procedures should be conducted in a deliberate and slow manner, as rushing through the examination raises the risk of complicating the outcome. Care should also be taken to simplify communications to accommodate the language constraints of the patient.

■ ONGOING TREATMENT: THE PROMISE OF TECHNOLOGY

Access to support services is critical—especially as people with Asperger syndrome move into adulthood—while the apparent rise in

People with Asperger syndrome feel perplexed that others sometimes seem put off by their behavior

the prevalence of Asperger syndrome and other forms of autism spectrum disorder call for an expansion of current service models. Typically eager to address areas of social deficit, people with Asperger syndrome could benefit from ongoing social-skills support.

Mobile devices such as tablets and smart phones are a transformative technology that shows great promise in supporting treatment innovation. I believe they will have the greatest impact on quality of life for patients with Asperger syndrome by enhancing the potential to live completely independently or semi-independently. These devices can function as personal assistants for those who experience difficulty with time management, human connectivity, way-finding, and other tasks. We have observed, for example, that visual connectivity with caregivers (and others) through a cell phone, messaging, or video chatting, or the provision of electronic reminders for medications or appointments, can reduce the anxiety of a child with Asperger syndrome living outside the parental home. It can also help the physician better ensure that treatment regimens are being followed. Finally, an endless supply of entertainment “apps” along with robust search engines to suit every interest is afforded by feature-rich mobile devices.

Armed with these gadgets, therapists now tailor support to meet the patient’s individual needs, which can range from basic social-skills development and social-cue reminders to higher-level conversational and organizational supports. New tools and techniques, along with better understanding of the condition, portend far more innovative and improved treatments for the future. ■

REFERENCES

1. **Prayson B, Franco K.** Is an adult with Asperger syndrome sitting in your waiting room? *Cleve Clin J Med* 2012; 79:875–882.
2. **Silberman S.** The Geek syndrome. Autism—and its milder cousin Asperger’s syndrome—is surging among the children of Silicon Valley. Are math-and-tech genes to blame? *Wired*. http://www.wired.com/wired/archive/9.12/aspergers_pr.html. Accessed October 11, 2012.
3. **MIT Student Activities Office.** The MIT Student Activities Office presents Charm School. <http://studentlife.mit.edu/sao/charm>. Accessed October 11, 2012.

ADDRESS: Howard C. Shane, PhD, Boston Children’s Hospital, 9 Hope Avenue, 2nd Floor West, Waltham, MA 02143; e-mail Howard.Shane@childrens.harvard.edu.