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Asperger's Confounds Colleges

A surge of students diagnosed with an autism-related disorder poses new challenges

By **ELIZABETH F. FARRELL**

By the eighth grade, Stephen M. Shore had taught himself to play every instrument in his school's band. But seven years later, during his junior year at the University of Massachusetts at Amherst, a run-of-the-mill academic assignment stumped him.

Mr. Shore, a double major in music and accounting, was assigned a research project on a topic of his choosing for his "Physics of Music" course. But after finding some books in the library and doing some reading, he felt lost. The syllabus had given him no specific instructions or intermediate deadlines.

"I didn't know what to do with the materials I found," says Mr. Shore, who withdrew from the class to avoid failing it. "It didn't even occur to me to go to the professor and ask him for help."

For an honor student, the experience was baffling: Why couldn't he tackle an assignment that his fellow students handled with ease?

What Mr. Shore, now a doctoral candidate at Boston University, did not realize at the time was that his problem is related to a neurobiological disorder -- Asperger's syndrome, one of the milder forms of autism known as autistic spectrum disorders.

People who have Asperger's tend to struggle with social interactions because of their extreme literal-mindedness. They typically are unable to infer meanings from tone or context. And when they lack explicit instructions on how to complete an assignment, some of them, like Mr. Shore, hit roadblocks. Researchers have not determined the cause of Asperger's, but most attribute it to a combination of genetic and environmental factors.

As more students with Asperger's are getting the help they need in elementary and secondary schools and making it to college, campus health professionals are struggling to determine how to help them. Some colleges have developed services for such students, but many health-care providers have only a vague understanding of the syndrome, and of the needs of students who have it.

The absence of a common approach to students with Asperger's has led to widely differing interpretations of what constitutes "reasonable accommodations" for them on campuses, as required by federal law. "One of the dilemmas here is that we haven't decided where the lines ought to be drawn, where Asperger's starts and stops," says Fred R. Volkmar, a specialist on the syndrome who is a professor of psychiatry at the Yale University Child Study Center. "We realize there are things that legitimately cause these people to have trouble, but there are a lot of gray areas."

Special Accommodations

There are no definitive statistics tracking how many students at the college level have the syndrome and similar autistic spectrum disorders. Some experts even dispute that Asperger's is a form of autism, further clouding estimates.

Studies have confirmed that autistic spectrum disorders, including Asperger's, are on the rise: In California, for instance, the Department of Developmental Services reported a 273-percent increase in the past decade, and a study conducted by the U.S. Centers for Disease Control and Prevention estimated that one out of every 165 children has some form of the disorders.

The disorder, recognized and classified in 1944 by an Austrian doctor named Hans Asperger, did not receive widespread awareness until 1994, when Asperger's was first listed and explained in the Diagnostic and Statistical Manual of Mental Disorders, the standard reference for psychologists and psychiatrists. The number of Asperger's diagnoses has soared ever since.

Educating students with Asperger's can be particularly vexing because of the extreme inconsistency in their abilities. They often have an amazing aptitude for one specific subject, like Mr. Shore's for music. In fact, Asperger's is also known as the "little-professor syndrome." "I've had professors say to me that not only did this student read the textbook, but they could have written it," says Jane Thierfeld-Brown, director of student services at the University of Connecticut's law school.

But some of those same students cannot write a coherent essay on their favorite subject. In such cases, says Ms. Thierfeld-Brown, "creative

accommodations become very important." She regularly works with students to figure out exactly what an assignment requires and break it down into literally defined steps, helping them understand how to complete the task.

"You always want to maintain the integrity of the curriculum," she says. "I often tell them that college is not a trade school, and you can't just make it through by mastering one subject." Mr. Shore's struggle with Asperger's as a graduate student at Boston University presented the disability office there with a quandary. Although he overcame his academic difficulties at U. Mass to graduate with honors, he confronted another hurdle while pursuing a doctorate in music at Boston. As part of the program he was required to pass a series of tests on genres of music. He could not fathom composition from the Romantic era, however, because it lacked the structure and patterns that were evident in other types of music.

The director of the music department refused his request that the questions be rephrased to compensate for his extremely literal way of thinking. The university's clinical director of disability services, Lorraine E. Wolf, also denied Mr. Shore's request. He dropped out of the program in 1997.

Ms. Wolf says she would have handled the situation "with more compassion" had she known more about the disorder at the time. She has since developed a better understanding of Asperger's and now gives talks about the disorder with Mr. Shore, who is pursuing a doctorate in education at Boston. Still, she says, her decision was "academically correct." Her office provides Asperger's students with assistance on social interaction and time management, but nonetheless requires them to meet the same academic standards as other students.

'Lost in the Dust'

Some students with Asperger's need help navigating life outside the classroom, too. Because social skills are crucial for academic success, it is important that colleges provide such students with guidance on interpersonal skills, says Yale's Dr. Volkmar.

"The problem is, it takes social awareness to pay attention selectively," he says. "You watch the professor to see what's relevant and what's not relevant, to get the big picture, ... but all that nonverbal stuff is happening very fast, so these students get lost in the dust." Some students with Asperger's struggle to control their impulses. Brenda Smith-Myles, an associate professor of special education at the University of Kansas, helped to treat a student from another college who often yelled at a professor during class when she became frustrated at her inability to keep up.

The office for students with disabilities at the college, which Ms. Smith-Myles declines to name, refused to help the student, she says. "It was generally interpreted that she could control what she was doing," says the professor. "No one should treat a professor that way, but she needed support, and the question really was where should it come from. The university did not see how it could provide support, so they didn't."

Some colleges offer lessons in etiquette and social norms for Asperger's students.

Ms. Thierfeld-Brown, at Connecticut, works with students on the basics of interpreting body language. They learn that a person who puts his hand on a doorknob probably wants to leave the room, and that it is preferable to wait until people are facing you before beginning conversations with them. She also sets up "safe rooms" around the campus for the students to visit if they need to calm down.

At Boston University, Ms. Wolf says her office provides similar services, although she contends that colleges are not legally required to do so. "We provide it as a service because if we didn't, these students could be a constant drain on our time," she says. "A lot of them will get in trouble with professors if we don't teach them how not to."

The difficulties faced by Asperger's students reveal a larger question that colleges must cope with: When determining accommodations for students with special needs, how much is too much? If students struggle to accomplish even basic tasks for themselves, is the college responsible for unlimited hand-holding and lessons in common sense?

Most student-disability professionals agree that college life is supposed to serve as the last bridge to the real world, and that students themselves are responsible for learning social and survival skills. With many learning-disability and psychological-counseling offices stretched thin, professionals argue that some services fall beyond the scope of what colleges can, or should provide.

"There are some folks who are just not going to make it under traditional standards," says Keith J. Anderson, a psychologist at Rensselaer Polytechnic Institute. "The problem is that parents start to develop the expectation that we will provide unlimited services -- and that's just not feasible."

For students who need additional assistance, a few programs have sprung up. In Pittsburgh, a program called Achieving in Higher Education with Autism and Developmental Disabilities works with local colleges.

Before the program began two years ago, with a state grant, there was nothing available to young adults with conditions on the autism spectrum, says Carolyn Komich Hare, the program's founder and director. Students with Asperger's and autism are "often served really well in the K-12 public school system, and then they're cut off," she says.

Ms. Komich Hare works with about 15 students from community colleges and four-year institutions, including Carnegie Mellon University. She typically checks in with each of them a couple of times a day to help them schedule their study time. She also talks them through social situations, advising them on appropriate times to ask questions during a class, or how to ask a classmate out on a date.

Since the program started, two students who had been on the verge of flunking out of Carnegie Mellon have turned their grades around, with one earning mostly A's and B's. While the colleges she works with are cooperative, students who require daily guidance must pay an additional \$4,500 per semester for her services because the state grant does not cover the full cost, according to Ms. Komich Hare. Sometimes those costs are partially covered by private medical insurance, she notes, adding that she is in the process of securing a federal grant to further offset the expenses.

Larry A. Powell, manager of disability resources at Carnegie Mellon, says he wishes that his institution could cover more of the cost, but that "with my caseload of 380 students, we just don't have the resources."

As more students are diagnosed with Asperger's syndrome, programs like the one in Pittsburgh could become the new model for colleges. But for now, experts agree that students with the disorder are showing up in droves, whether colleges are ready for them or not.