



Dr. Temple Grandin, Ph.D, diagnosed with autism at age 3, advocates for others with the disorder.

Autism in Academia

Colleges are applying a variety of approaches to help students with the disorder succeed on campus.

BY JACKIE JONES

Freshman year of college can be rather confusing. There's the roommate to get used to and figuring out where the classrooms are, when the dining hall closes, where to get help if your financial aid is messed up or how to talk to a professor who seems indifferent. Many students may not know where to go to resolve these issues, but they usually know enough to ask.

"You talk to somebody," said Felicia Hurewitz, an assistant professor of psychology at Drexel University and founder and director of the Drexel Autism Support Program (DASP). "You go to your roommate or your R.A., so we tend to socially address these problems."

For students on the autism spectrum, the simple act of asking for help can be overwhelming.

"If you're a person with autism, that social interaction is not there," Hurewitz said. "You might not ask."

DASP provides professional development and technical assistance to make the postsecondary experience more

accessible to autistic students, including a Peer Mentor program in which they are paired with students who not only show them the ropes for practical help, but also help to increase social engagement. Currently, 16 students are matched with peer mentors. The volunteer peer mentors are trained, supervised and matched with students. The pairs meet two to four hours a week, and the mentors are supervised once every other week.

Students with autism also are invited to attend a seminar that will help them address issues in which they themselves have expressed an interest, Hurewitz said,

including “social skills, how to initiate conversations. How do I get organized for academics? How do I make small talk? It’s geared toward what students want.”

New Data Would Help

The program is just three years old, so it is too soon, Hurewitz said, to gauge its effectiveness for student retention and postgraduate outcomes. “There’s no college or study that can show that,” said Hurewitz, who estimated it would take about five more years to track a critical mass of autistic students to determine how beneficial the college experience has been.

Marjorie Solomon, an associate professor of clinical psychiatry in the Department of Psychiatry and Behavioral Sciences at University of California-Davis, agreed that more data are needed.

“There really isn’t a lot of good research out there, but there should be, and there will be in the next couple of years,” said Solomon, who also is on the faculty of the MIND Institute and of the postdoctoral Autism Research Training Program.

The UC Davis MIND Institute (Medical Investigation of Neurodevelopmental Disorders) is a collaborative international research center committed to the awareness, understanding, prevention, care and cure of neurodevelopmental disorders. The institute was founded in 1998 by six families, five of whom had sons with autism. The goal was to bring together experts from neuroscience

to education, from molecular biology to developmental pediatrics, from occupational therapy to psychiatry, to work toward finding cures for neurodevelopmental disorders, starting with autism. Their research has expanded to cover other syndromes including Tourette’s and attention deficit/hyperactivity disorder (ADHD).



Felicia Hurewitz is founder and director of the Drexel Autism Support Program.

Autism is being diagnosed earlier and treatment options begin earlier, experts say. At the same time, public awareness of the autistic spectrum is growing and more students with some form of autism are being prepared for and admitted to college.

“There’s a growing recognition that the autistic spectrum is broader,” Solomon said. “Some affected individuals with cognitive abilities in the average and below-average range are attending community colleges. Then, there are the intellectually gifted with autism-spectrum disorders going to four-year colleges and universities.”

By definition, Solomon said, “people with the Asperger’s disorder diagnosis must have average IQs or above and normal language development. Thus, they always are

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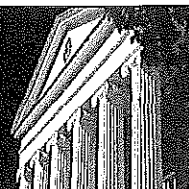
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verbal —sometimes precociously so.”

“There are postsecondary opportunities for all,” she added. “They differ based on the cognitive and adaptive functioning level of the individual.”

What’s not clear and what research has not revealed so far is whether there are certain types of jobs in which autistic adults fare better. In fact, Solomon said, most research into autism-spectrum disorders has focused on high-functioning adolescents and young adults up to age 18. The data on what happens to them after that are harder to find.

Skills Vary Widely

According to Autism Speaks, a science and advocacy organization that funds autism research, autism-spectrum disorder (ASD) and autism are general terms for a group of complex disorders of brain development. Symptoms occur in varying degrees and range from problems with social interaction, verbal and nonverbal communication and repetitive behavior. Problems also can include issues with physical health, intellectual disability and motor skills. The spectrum includes a number of categories including autistic disorder, pervasive-developmental disorder and Asperger’s syndrome. People on the autism spectrum can range from some who can barely communicate to others who excel in visual skills, music, math and art.

According to the federal Centers for Disease Control and Prevention (CDC), an estimated 1 in 110 children has

an autism-spectrum disorder. Autism appears to have its roots in very early brain development. However, the most obvious signs and symptoms of autism tend to emerge at 2 to 3 years of age.

Although high-functioning people with Asperger’s syndrome are considered the most likely college candidates, some researchers say it may be possible for students with average and above-average IQs on the autism spectrum to navigate college successfully.

“Until pretty recently, a lot of kids with Asperger’s weren’t really going to college, so this is kind of the first wave,” said Allison Gilmour, director of programs and community outreach at the Organization for Autism Research (OAR) in

“Until pretty recently, a lot of kids with Asperger’s weren’t really going to college, so this is kind of the first wave.”

— Allison Gilmour, Organization for Autism Research

Arlington, Va. “It’s really hard to track the outcome because once they are out of the public school system, they don’t have to identify as having a disability.”

The organization did fund a small study that looked at the experiences of 19 students at Oakland University



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in Rochester, Mich., with Asperger's syndrome who self-identified as autistic. The study, led by principal investigator Janet Graetz, Ph.D., asked the students questions to gauge how they dealt with stress and managed their time and what support systems were available for them. The participants and their parents or guardians were asked to assess the students' social, emotional, and psychological strengths and coping skills.

The students were asked about their participation in on- and off-campus social events, such as visiting the recreation center, meeting with counselors, going to the academic skills center or meeting a friend for coffee or lunch. About half the students surveyed said they never met with a friend socially. Fifty-five percent also said they never participated in an off-campus activity, but 45 percent said they went to the Disability Support Center. That could indicate, Gilmour said, that once students identified the center as a place to go for help, it essentially became one-stop shopping.

Social Issues Are Crucial

The common experience reported in interviews is that once autism-spectrum students learn how to navigate the things that most people take for granted, the better the college experience.

"It's not a comprehension issue; it's a social issue," said Bradley McGarry, director of the Asperger Initiative at Mercyhurst University in Erie, Pa. "We do everything we can

to give our AIM students as much support or independence as they need."



Brad McGarry works with the Asperger Initiative at Mercyhurst University.

He meets with the freshmen once a week to assist them with social-skills training. The Asperger's students are encouraged to live in housing set aside for students with learning differences. (Not all have Asperger's.) Students have their own bedrooms, an uncommon luxury at Mercyhurst, but share apartments. The idea is to help them learn how to interact with others but provide a safe space by letting them have their own bedrooms. On average, 16 to 20 students participate in the

program, which started with just four students four years ago.

"We continue to monitor them to make sure that (a) it (the social component) doesn't completely overcome their academic experience and (b) they advance their skills and mold into the college community with their peer group," McGarry said.

A letter is sent to all faculty stating that AIM can provide assistance in dealing with Asperger's students who may be in their classes.



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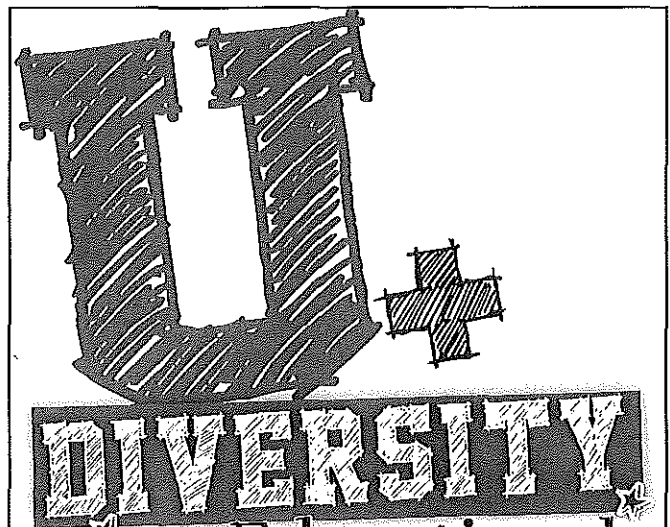
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"It's funny," McGarry said. "More and more I'll get a call from a professor saying, 'I'd like to talk to you about Ben,' and I'll say, 'I'm sorry but Ben is not in my program. I was talking about Suzy.' Maybe Ben has Asperger's and hasn't been diagnosed or identified to us."

McGarry said some faculty are uncomfortable dealing with the issues because they have not been trained to interact with students with Asperger's, but "once they are educated on what it is, I haven't had anyone say yet 'I can't relate to this.'"

Like Actors in a Play

It is the direction, focus and repetition that helps many autistic students succeed, said Temple Grandin, a professor at Colorado State University, a best-selling author, and, as a person with high-functioning autism, a noted advocate for the autistic. Grandin said that in preparing any and all students, but especially students with autism, for the rigors of college life, the value of old-school, 1950s parenting — like the upbringing she experienced — cannot be overstated.

She was diagnosed with "brain damage" at age 2 and diagnosed with autism at age 3.

"They didn't even know what it was, and I was put in an old-fashioned, small, structured nursery school," said Grandin, now 64. Her mother hired a nanny who played board games with Grandin and her sister. By elementary school, Grandin was functioning well with supportive mentors and teachers, as well as a mother who kept her focused.

"One of the problems is that many kids are not learning enough basic skills, like being on time, how to shop for groceries, how you do laundry," Grandin said. "Today's parents are so much looser, and it hurts autistic and Asperger's children more. They've got to learn it's (being in college is) like being in a play."

She explained that dealing with college requires learning by rote and repetition — the way an actor learns lines and practices movement on the stage. Grandin also recommended teaching children board games as she was taught at an early age so they learn how to follow the rules and how to take turns as they work up to performing chores and developing a work ethic.

"They've got to learn work skills like walking dogs, doing PowerPoint presentations, updating church websites," Grandin said in a straightforward, no-nonsense way.

It was learning similar skills, Grandin said, that helped her develop academically and, eventually, socially. Middle school and high school, however, were miserable, Grandin said. She was seen as socially awkward and was teased and made fun of by peers who mimicked the way she spoke, especially because she repeated what she heard (not uncommon in those with autism) and nicknamed her "tape recorder."

"What saved me was my science teacher" who believed in her intellectual capabilities, Grandin said. "If I hadn't had my science teacher, I would have been nowhere."

She went on to earn a bachelor's degree in psychology, a

master's and Ph.D. in animal science and became an expert and consultant in the animal-welfare industry. She said there were awkward moments in college initially.

"I did have a lot of social problems, roommate problems," Grandin said, but she was able to forge relationships by talking about common areas of interest with other students.

The key to a successful collegiate life, Grandin said, is to help students develop an area of strength and encourage

"I did have a lot of social problems, roommate problems."

— Temple Grandin, author and professor

them to focus on getting better at it. Once they succeed, they can translate that ability to mastering other things.

Muddling Through

In fact, it appears, others have for generations. According to the National Institutes of Health, Asperger's syndrome is being increasingly diagnosed in adults seeking help for depression, attention deficit/hyperactivity disorder (ADHD) and other mental-health conditions.

As with Grandin, many adults were considered as eccentric or odd, but may well have had some autism-spectrum disorder that was never diagnosed and they simply found a way to muddle through. While there is greater awareness of the possible outcomes that autism-spectrum students can achieve, it does not mean achievement was not possible before now.

Solomon said a Dutch colleague, Dr. Hilde Geurts, recently received a grant to study senior citizens with autism-spectrum disorders. While reading Dr. Hans Asperger's original work written in German, Geurts realized how many of Dr. Asperger's patients had carved out a niche for themselves in college and the working world long before there was a name for what they had.

"There wasn't such a tendency to label people" Solomon said. Thus, students who appeared to have extreme eccentricities or who struggled in a lot of areas, but were extremely talented or gifted in others, attended college and went to work.

In her book *Thinking in Pictures: My Life with Autism* (Vintage, 2006), Grandin points out that high-performing people with autism can make significant contributions to society.

"In an ideal world the scientist should find a method to prevent the most severe forms of autism but allow the milder forms to survive," Grandin wrote. "After all, the really social people did not invent the first stone spear. It was probably invented by (someone with autism) who chipped away at rocks while the other people socialized around the campfire. Without autism traits, we might still be living in caves."

— Jackie Jones is an independent journalist based in Washington, D.C., a career-transformation coach as director of Jones Coaching, LLC and a journalism lecturer at Howard University.