Alien No More

For years, Scott Robertson felt different from everyone else—but didn't know why. Then he learned he has Asperger's Syndrome. Now, even as he devotes his career to helping others with the condition, he's still learning to cope with being autistic in a non-autistic world. BY LAURA WEXLER '93 LIB • PHOTOS BY CARDONI

ON A LATE FALL MORNING, as students at University Park revel in the first snow of the season, Scott Robertson is behind a glass door in a 20-foot-by-40-foot cubicle in Rec Hall, playing racquetball alone. He hits the ball softly, waits for it to bounce off the backboard, then runs after it. At 6-foot-1, he is all arms and legs, gangly like a 13-year-old boy who hasn't yet grown into his limbs, even though he's 28. He hunches over and grasps the racquet awkwardly, batting at the ball instead of swinging through it. He focuses his ice-blue eyes intensely, as though he must plan each action—bend knees, pull back arm, connect with ball—before executing it. Even though he's been coming here two or three times a week since he started at Penn State in 2004 as a Ph.D. candidate in information sciences and technology, he plays as if the game is foreign to him.

Foreignness is a familiar feeling for Robertson, and not just on the racquetball court. All his life, he's felt different—different from his brother and sister growing up in Pines Lake, N.J., different from other kids at school, different from every other person he knew. And, as is often the case, differentness made him an easy target. At elementary school, kids called him "retard" and taunted him for the odd way he raised his hand in class; instead of shooting it straight up and holding it there, he'd keep raising and lowering it, unable to hold it steady. One boy told him he was so weird, he shouldn't exist. Another punched him in the face, sending his glasses flying. In seventh grade, he and his classmates were watching the movie *Cujo*, and Robertson raised his hand to ask if two characters in the movie were friends. The whole class laughed at him—the two were a romantic couple, something obvious to everyone but him.

During his K-12 years, Robertson existed in an almost continuous state of confusion, frustration, and loneliness. "More than anything," he later wrote, "I longed to know why I was so very different from others and why I couldn't act like they did no matter how hard I tried."

Then, when he was a freshman at Rensselaer Polytechnic Institute, in a class called "Minds and Machines," students were assigned to write a paper about autism. As part of his research, Robertson stumbled onto a discussion of Asperger's Syndrome—a developmental disability often known as high-functioning or mild autism. He printed a list of Asperger's characteristics and checked off each one that applied to him: heightened sensitivity to noise and light; problems with physical coordination and fine motor skills; difficulties in social interaction. That list explained so much: why, as a child, Robertson felt bombarded by sights, sounds, and smells during trips to the grocery store; why he struggled to learn to ride a bike and wasn't able to master driving a car. And, most painfully, why the social skills that came naturally to others—making friends, conversing—eluded him. Five years later, after he started grad school at Penn State, he underwent 18 hours of testing at the Psychological Clinic on campus that confirmed his self-diagnosis. He had Asperger's.

For the first few years after he diagnosed himself, Robertson concentrated on teaching himself the social skills he needed to survive. But these days, he's focused on helping others. His doctoral dissertation explores how online communities can make higher education more welcoming to people with Asperger's and other disorders on the autism spectrum. He's active in a number of advocacy groups. And he often gives talks on Asperger's and autism. But he still struggles every day to negotiate life as an autistic person in a non-autistic world.

COMPUTERS WERE ROBERTSON'S first obsession—his engineer grandfather had introduced him to them when he was 8 or 9—but Asperger's Syndrome, and autism, became his second. As a student at RPI, he spent hours online and at the library, reading everything he could. While it was a relief to finally have a name for why he was the way he was, he learned quickly that few hard facts about the disorder exist. Though Asperger's became part of the American Psychiatric Association's Diagnostic and Statistical Manual in 1994, experts disagree both about the criteria for diagnosing it—largely because no two people with the disorder are likely to show the same behaviors—and whether it should be classified separately or simply be known as a disorder on the autism spectrum. And the cause of Asperger's, like that of all forms of autism, remains a mystery.

What was no longer mysterious, however, was why Robertson had struggled socially all his life: People with Asperger's don't learn essential social skills naturally, as

When Robertson first saw a list of the symptoms of Asperger's Syndrome, "everything I was seeing was the picture of my life."

most people do. They don't instinctively make eye contact during conversation; they don't read body language and other nonverbal cues; they don't have an innate sense of how to behave in socially appropriate ways. Jo-Ann Cohn, a psychologist at Penn State's Counseling and Psychological Services who specializes in learning disorders, recalls attending a freshman orientation at another university in which a young woman with Asperger's blurted out and then kept repeating, "There are a lot of black people sitting around me." "People who don't know about Asperger's would interpret that as potentially hostile or challenging," says Cohn. "But for this young lady, it was interesting and exciting to her. She was just blurting out that she was noticing that the people around her were different. These kinds of things can get misconstrued and cause a lot of tension."

These days, structured programs and books—and even online virtual communities like Second Life—offer social training to people with Asperger's, but back in 1999, Robertson created his own crash course. When he watched TV, he studied characters' expressions, using the context to decipher the emotions behind them. When he listened to the radio, he noted how people conveyed emotion by changing their tone of voice. When he was in line at the movies, he observed the way people around him talked to each other. He became a sort of amateur anthropologist, examining the unwritten social rules of a culture that felt alien to him. He taught himself these things not only because he was tired of being bullied and ostracized, but also because he craved human relationships. Even as his awkwardness, his monotone voice, his failure to make eye contact often sent the signal that he wasn't interested in intimacy and connectedness, he hungered for it.

To encounter Robertson today is to conclude that his self-education has been a great success. Yes, he's fidgety during conversations with those he doesn't know well, and, no, he doesn't modulate the volume or inflection of his voice in the way most people do. But that's less noticeable than the fact that he's articulate, genial, and warm, with a lively sense of humor and full-throated laugh. He recently signed up at the online dating site eharmony.com and jokes that the service's communication rules are so structured it's like "someone on the autism spectrum set them up." And he's stone cold crazy about sports—hockey, football, and especially Yankees baseball. "He's somebody that people really do enjoy being around," says Joshua Gross, a close friend.

But even with the adaptations Robertson has taught himself, the fear of doing something socially inappropriate still travels with him constantly, like his shadow. When he runs into someone he knows, he sometimes

SELF-TAUGHT: Robertson has had to train himself on the social skills that come naturally for most people—how to make eye contact, how to read body language and tone of voice.

panics and can't greet the person. Before he orders at a restaurant, he rehearses what he'll say. He carries a card in his wallet explaining that he's autistic and may behave oddly when he's anxious, which he'll pull out in case he ever has a run-in with law enforcement.

So much of Robertson's energy goes into adapting to the world that at times completing his Ph.D. seems undoable. The usual hurdles of being a grad student—working with advisers, studying for the comprehensive exams, planning his dissertation research—are even more challenging for him because of his difficulties with planning and organizing (often called "executive functioning"). And things other people may shrug off as minor frustrations can unhinge him. People with Asperger's are "easily overwhelmed," says **Michael Wolff '90 Lib, '06 PhD Edu,** assistant director of Penn State's Psychological Clinic. "They don't have an ability to predict their emotional responses and manage them. There's often no ability to 'pull it together.'"

"When I'm under stress or physically ill," Robertson says, "I can't do my adaptations—they fall apart. I can't concentrate. It's like a computer crashing.

"People say I'm high-functioning because they see one glimpse into my life," he adds. (In fact, Robertson won a Teaching Assistant of the Year award from IST two years ago.) "But they don't see that I'm often at the point where I'm just barely getting things done."

Of all his challenges, Robertson says the most daunting are low self-esteem, depression, and anxiety, which, he says, come from being autistic in a non-autistic world. He's very clear on this point: To him, it's not the actual neurology of Asperger's that creates the brunt of

Living with Asperger's in College

Jo-Ann Cohn is a psychologist with Penn State's Counseling and Psychological Services who specializes in learning disorders. She's familiar with the challenges that college students with Asperger's face. *—LW*

WHAT ARE THE ACADEMIC HURDLES FOR A STUDENT WITH ASPERGER'S SYNDROME?

In the classroom, we take for granted that we can understand, from professors' tone of voice and body language, what they're highlighting as important and what's not that important. Students with Asperger's can't make that distinction. On an exam they may have difficulty understanding questions that involve turns of phrase or idiomatic expressions, because they tend to be very literal. Professors are encouraging more and more group work these days; the assumption is that everyone in the group has the same ability to interact. Because they have difficulty reading social cues, it's not easy for students with Asperger's.

WHAT ABOUT OUTSIDE THE CLASSROOM?

We take for granted that we can manage and be OK with tons of stimuli all around us, going into new buildings and finding our way around. But for folks with Asperger's, even a small school would be overwhelming. They would need someone to ride with them one time on the bus they'll need to take to and from classes. Once they have help, they can do it on their own.

Because folks with Asperger's are so awkward socially, it can be really hard for them to adjust to being in dorms and to make friends. It works best if there are people who act as social mediators and introduce them to people, invite them to things, coach them on how to approach others. Without that, students with Asperger's can end up marginalized and very lonely.

WHAT IS PENN STATE DOING?

We have services for students with learning disabilities. We have counseling services for all students. There are opportunities on campus for students to get coaching and time-management help. What we need to do is pull all that together to address the students with Asperger's.

the disability—it's living in a dominant culture designed by and for people *without* Asperger's. Sometimes he wishes the real world were a little more like Autreat, an annual conference in Bradford, Pa., run by and for autistic people. There, attendees can place a red, yellow, or green badge into their name-tag holder to indicate the level of social contact they want. A red badge signals that the wearer does not want any interaction; a yellow badge says the wearer would like to interact with people already known to him or her, but not strangers; and a green badge communicates that the wearer wants to interact, but would like others to initiate the interaction. At Autreat, Robertson usually wears a green badge, reveling in a clarity that's rare in the non-autistic world.

WHEN ROBERTSON FIRST diagnosed himself with Asperger's at 19, he didn't tell many people. But by the time he got to Penn State, he had "come out of the closet," as he says. In recent years he's taken on leadership roles in such disability organizations as the Pennsylvania Bureau of Autism Services, and he's vice president of the international Autistic Self-Advocacy Network. He speaks regularly to groups, sometimes addressing audiences as large as 2,000, as in 2007, when he gave the opening address to the National Autism Conference at Penn State. He mostly tells his own story—his difficulties growing up and the ways he's found to adapt. He talks about his "speed laces," plastic sliders that help people who have problems with fine motor skills tie their shoes. He talks about his guinea pig, Lucy, which he was able to have in his State College apartment after providing documentation that Lucy was an emotional support animal. He talks about his online community of friends "on the spectrum" and about his struggles and successes in academia.

In speaking so personally and openly, Robertson is seeking more than healing; he is advocating for all people with autism. "If you ask people on the street about autism, they'll think of children, as though we must disappear as adults," he says. He wants to change that.

When Robertson was young, he believed everything about him was wrong. These days, he and others in the autistic self-advocacy movement passionately argue that autistic people aren't wrong, just different. And, taking cues from the deaf culture and disability rights movements, they're promoting that uniqueness while also demanding that mainstream culture become more welcoming to autistic people. "I don't want a cure for autistic people," Robertson says, explaining his belief that autism is part of a naturally occurring "neurodiversity" in the human population. "A lot of things people see as weaknesses [in autistic people] can be strengths, like the ability to concentrate on one thing to the exclusion of everything else."

But to capitalize on their strengths, he says, autistic adults need services that aren't widely available: housing options, job coaching, coaching for social relationships. They also need accommodations in college. "We can take a test in a quiet room, get time-and-a-half for tests, and get class notes, like other students with learning disabilities. But it's not adequate," he says. "We need social support groups. We need help with planning, sensory management, motor skills, executive functioning."

Until recently, such services weren't needed, because people with autism generally didn't get the help as young children that would allow them to contemplate college, much less graduate school. But now many do. Few firm statistics document the incidence of autistic students in higher education—partly because of the stigma of the disorder, and partly because it can be difficult and expensive to diagnose. But Robertson estimates there are at least a hundred among the 43,000 students on the University Park campus, and thousands at institutions throughout the United States.

Robertson speculates about creating a personal digital assistant, or PDA, that would offer social guidance or help with planning and organizing. Already, he says, e-mail and instant messaging allow autistic people to communicate without the stress of having to be face-to-face. "Online communication is to autistic people what American Sign Language is to deaf people," he says. "It levels the playing field."

Robertson acknowledges that even with the adaptations he's learned—and even with the benefit of support services and assistive technologies—he'll never feel completely at home in the non-autistic world, just as he'll never be a social butterfly or a great racquetball player. "It's important to be accepting of myself instead of pushing against it and trying to make myself 'normal.' I'm not normal. My brain is always going to be atypical," he says. "The difficulty that I've had in life is how to work on adapting but hold onto myself at the same time. I want to preserve what makes me, me."

Laura Wexler is a writer and editor in Baltimore.