

## Growing up with Asperger's

**The rate of diagnosis of this milder form of autism is rising, and now post-secondary institutions are learning how to help those with the disorder cope as young adults.**

By Irene Sege  
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Nomi Kaim has just walked 6.8 kilometres from her Brookline home because walking soothes her. She is sitting in her Harvard Extension School course on emotion and watching grainy clips from a 1965 film titled *Three Approaches to Psychotherapy*.

Onscreen, psychologist Carl Rogers leans forward, gently cautions the patient, Gloria, against expecting too much of this initial visit. When Gloria calls him fatherly, he replies she'd make a good daughter.

He's reassuring, says one student. Unintimidating, says another. Kaim disagrees.

"He was too in-your-face, too touchy-feely," she says. "To have somebody do that to me in the beginning would have made me anxious."

Kaim's brain is wired differently from most people's. She has Asperger's syndrome, a mild autism recognized as a disorder only since 1994. Those with Asperger's are verbal and as intelligent or more intelligent than average individuals. They have problems processing the myriad cues around them -- trouble understanding social situations and communicating in social settings, trouble distinguishing what's important from what's not, trouble with sensory overload or understimulation, trouble organizing their lives, trouble, as the saying goes, seeing the forest for the trees.

Where Kaim's classmates interpret Rogers' leaning forward as engagement, Kaim sees him invading Gloria's space. Where her classmates like his open-ended approach, Kaim flinches.

Kaim is 23, fast-talking and slow-walking, smart and curious, serious and self-



Suzanne Kreiter, the Boston Globe

Nomi Kaim, right, talks with volunteers with the Asperger's Association of New England. Kaim, 23, was not diagnosed with Asperger's syndrome until after starting college.

absorbed, bad at multitasking and good at pouring herself into whatever she does. She's uncomfortable socially and comfortable, when not depressed, with solitude. She craves structure and resists uncertainty. She longs for human connection but cringes at being touched and balks at the reciprocity of friendship. She earned As at Bryn Mawr but left after a semester because campus life unhinged her. Only then was she diagnosed with Asperger's. Now she takes one course and worries that's too much.

"The problem with Asperger's," she says, "is you're stupid and smart at the same time."

She's finding her way, struggling with the depression and anxiety that often accompany the syndrome.

For decades, autism was considered a rare condition, affecting two to four per 10,000 children. According to the Autism Society Canada, autism is now recognized as the most common neurological disorder affecting children and one of the most common developmental disabilities. The prevalence of autism nationwide has increased to 40 to 60 per 10,000, which represents about 190,000 Canadians.

About one in 200 children born today have a form of autism.

Asperger's affects about 15,000 Canadians or five in 10,000, according to a 2003 article in the Journal of Autism and Developmental Disorders.

The Asperger's Society of Ontario cautions statistics are generally conservative because so many people are misdiagnosed or diagnosed later in life. The society's latest research shows one in 167 Ontario children between the ages of three and 17, have been diagnosed with an autism disorder. This represents about 18,000 children.

Researchers suggest the rate of increase is so dramatic for several reasons: there is a possibility of a true increase in numbers but also people are being properly diagnosed sooner and there is a growing awareness among parents and professional workers about autistic disorders that cover a wide spectrum, commonly known as Autism Spectrum Disorders (ASD).

As the number of young adults known to have Asperger's increases -- children diagnosed since 1994 are growing up, and others, like Kaim, learn later they have the disorder -- post-secondary institutions are paying more attention to their needs.

In Ontario, members of the Inter-University Disabled Issues Association had its first session on Asperger's at its latest professional development meeting in November. The syndrome is also discussed often on its electronic mailing list, which wasn't the case a few years ago.

Tim Nolan, manager of disability services at McMaster University and member of the association, says 42 McMaster students were registered with disability services when it was first created in 1988.

Today, there are 832, of which five to 10 have Asperger's.

In fact, the number of students with disabilities registered with McMaster's Centre for Student Development has significantly increased each year, nearly doubling from 431 in the 2002/03 school year.

At Mohawk College, students with disabilities account for 11 per cent of its student population. Eleven students have Asperger's.

"There's no doubt the need is great. We're seeing more and more complex disabilities," says Martha Fox, Mohawk's manager of disabilities.

Kaim illustrates the challenges that, to varying degrees, face students with Asperger's. She has strategies to navigate her neurological detours, as well as an appreciation of the perspective Asperger's provides, of the "individuality and working hard and being loyal" that she values.

Dressed in sweatshirt and sweatpants, ignoring anything as superficial as style, Kaim had left home 90 minutes before the evening class started. She walks everywhere -- to school, to her part-time job sorting photographs at a university library, to the Asperger's Association in Watertown, to her therapist in Cambridge. At home, she paces.

"I get so exhausted and overstimulated just talking with people and doing the things that I need to do," she says. "Walking calms the body and the mind both," she adds. "It's just really a way of becoming myself again and separating myself from an overwhelming world."

In Coolidge Corner, she winced and instinctively covered her ears when a trolley rumbled by. "It hurts my ears," she says. "I often close my eyes, too, because you can't have all your functions going if one function is getting overwhelmed."

Kaim focuses on small things, not the whole landscape, on bark patterns, for instance, that others might overlook. She likes to gaze at the earth beneath her. "It's composed of smaller pieces," she says. "Fewer and smaller." Before the discussion section, a classmate wonders about the function of emotion. "Fear," Kaim replies, looking at her, "evolved so you would have a way to get away."

This seemingly unremarkable exchange swells with connections, both social and intellectual, to Kaim's condition.

Looking at someone during conversation is a convention Kaim forces herself to follow. "Usually I'll pretend I'm doing something else when I'm talking. When I'm listening I'll make eye contact," she says. "Trying to talk to someone and look at them. That's too much. I can't focus on the two things at once." Here she was sharing information, which made the looking easier. "And I knew it would be short," Kaim adds.

"I feel people's eyes are always saying something," she says. "It's very intense for one thing, so it's overwhelming. The other thing is I don't know what they're saying."

As a child, Kaim seemed different. "A little more intense," says her mother, Susan. "A little more fragile. A little more serious. A little more articulate. A little more anxious." She did well in school but badly with transitions. She loved imaginary play -- she still fantasizes about the secret life of rocks -- and had friends. "She never enjoyed them, we found out later," Susan says. Her first-grade teacher suggested she be tested; nothing significant was found.

Kaim was a perfectionist still earning As in high school, but as the work got harder she began to crumble. "You look back at it as the triumph of determination over biology," says her father, Robert.

She was diagnosed with depression at 15. She shunned sleep to do homework. Then came senior year, with expectations of college and the future. "I'd never had so many choices before," she says. She was hospitalized. Still, nobody discovered the Asperger's, which is most often diagnosed in males.

After a year off, Kaim headed to Bryn Mawr, where the long lag between classes proved too much, as did living away from home. "There were all these requirements at once," Kaim says. "Mail coming in every day, and trying to determine what's junk mail -- it was hard."

Dormitory life was unbearable. Had her parents known she had Asperger's, they'd have requested a single room. Even that, they believe, wouldn't have been enough.

"You go to the dorm and people are not talking about classes. They're talking about their boyfriends. I felt really ungrounded. There was no home to go to," Kaim says. "I really want to be liked. I would put on my social face and be nice and polite and listen. Then my roommate would leave, and I'd be exhausted, and I wouldn't know when she was coming back. I found it impossible to manage. I didn't know when I'd have to put on my social face."

She was hospitalized again after leaving Bryn Mawr. Her mother, carrying a list of "Nomi's Neurological Eccentricities," brought her to a neuropsychologist, who diagnosed Asperger's. Kaim takes medication to ease her depression and anxiety.

Social situations. School. These are Kaim's main sources of stress.

"When I'm sad, I really want another person to comfort me, but when I'm not sad, I don't necessarily want it," she says. "I hate to say it, but I've never had that much interest in discovering other people's lives and their worlds because I get so preoccupied with my own. It takes up 150 per cent of my energy. Sometimes it doesn't even occur to me that other people have inner lives. It occurs to me, but it doesn't feel real because my own is so big it's bursting at the seams."

The closest Kaim comes to friendship is with a 63-year-old fellow Asperger's Association member. "She is an older figure who can let me do all the talking," Kaim says. "I'm getting better at listening to her, but it's not in balance."

In school, Kaim has been plagued by fear of failure. "I can tell you everything that's going on with a character very well, but how do you pull out a theme?" she says. "I miss that, and it's really humiliating."

She first took three Extension School courses a term, then two, now one. In the discussion section, she grows anxious when she has questions and finds scant reassurance when classmates have them, too. She considered dropping this course, but the teachers persuaded her to stay. "She can integrate her ideas with other people's and engage with other people in a way that's better than most people in the class," says section leader Christine Soutter. "I'm not saying it's not hard for her, but she's acting contrary to what might be the limitations of her diagnosis."

Kaim's unsure about next term.

"I'm so torn. The panic in the beginning is so enormous. The transition can take half a semester. By the end, I love it. I go around briefing people on what I've learned," she says.

"I think about how I got As in everything for so long and how everybody told me I had so much potential and all the windows were open and all the other metaphors I didn't quite get. Now I think I'm completely held back by my obsessional tendencies."

Class over, Kaim boards the T for the ride home. On the Red Line, she covers her ears and tenses as a train screeches. Several young people board the Green Line at Boylston. They crowd her. They chatter. Kaim cowers and mutters the Indigo Girls song *The Girl With the Weight of the World In Her Hands*.

At 10, six hours after she left for class, Kaim arrives home.

"Now to sleep," she says. "Things do get a little better with practice."

-- with files from Carmelina Prete, *The Hamilton Spectator*

In a 1944 paper published in Vienna, Dr. Hans Asperger first described the neurological disorder that bears his name, but it wasn't officially recognized as a psychiatric diagnosis until 1994. Asperger's syndrome is at the high-functioning end of the autism spectrum and is four times more likely to affect males than females. People with Asperger's are verbal and as intelligent -- or more intelligent -- than average, but often seem odd or eccentric. They have trouble reading non-verbal cues and forming age-appropriate relationships. They may be overly sensitive to sound, light, smells, or touch. They could have trouble setting priorities because of trouble determining what's important, and they have trouble with transitions. They may develop an intense interest in one particular area. For more information: Autism Ontario, Hamilton chapter: 905-777-1100 [What is Asperger's syndrome?](#)

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