

The rise of peer support for students with autism spectrum disorder

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Accessibility offices are encouraging students with autism to turn to their peers for support through university life.

When accessibility specialist Jamie Penner started at the University of Manitoba in 2009, a series of eye-opening client meetings made him reconsider how the institution was accommodating students with an autism spectrum disorder. “One of my first students on the spectrum had a course in ancient history covering some battle. I asked him what the lectures were like and he really only could remember or focus on the fact that they used a certain weapon in the battles. He was paying attention, he was listening, but he got so sidetracked,” Mr. Penner recalls.

Autism spectrum disorders, or ASDs, are neurobiological conditions that affect various systems in the body and impact brain development. The severity of that impact differs from person to person, which means there isn’t a standard case and symptoms cover a range (which is why autism is said to exist on a spectrum). Generally, people with an autism spectrum disorder may struggle with communication, socializing, and the intensity and scope of their focus.

About a decade ago, disability advisers at Canadian universities didn’t have much to offer these students beyond conventional accommodations like a tutor or a note-taker for lectures. And most universities in Canada, Mr. Penner says, weren’t too concerned about retention when it came to students with autism. “The word was that when you had students on the spectrum, they were going to come for a year, have a good experience, see how ‘other’ students went to school and they’d somehow benefit from that even if they didn’t continue at the university.”

Hearing from this student had convinced Mr. Penner that the usual way wouldn’t cut it anymore. “They have the brains,” he says, but “they don’t know what’s expected of them.” After consulting with a psychiatry lab on campus, Mr. Penner came to the conclusion that a fellow student would likely be the best guide to these new community expectations. In 2010, he launched the peer-to-peer academic [attendant program](#).

The attendant program is a paid service that pairs a student with autism with another U of Manitoba student, generally an education or psychology major, who offers one-on-one support. This support might incorporate some typical accommodations like note-taking or tutoring, but attendants are also trained to help students to “refocus their attention” through organization techniques, and to model appropriate behaviour in academic settings, like speaking with a professor or contributing in class, Mr. Penner says. A few years ago, he added a free mentorship option, which “takes a slight turn away from the academics” to allow for troubleshooting situations like how to join a club.

While attendants are paid \$25 an hour for 12 hours of work a week, mentors volunteer for up to three hours a week. This academic year, the program has seven attendants and two mentors for as many students with an ASD.

At the University of British Columbia, accessibility adviser Sarah Knitter says students on the spectrum “present with unique and new challenges that we weren’t really looking at. It’s pushed us, it’s motivated us to broaden the scope of our role and what our duty is to accommodate these students, to create inclusive and welcoming university communities for them.” Like her colleague at U of Manitoba, Ms. Knitter noticed a widening gap between the academic services her institution offered and the specific challenges that students with autism continued to flag in her office. To bridge it, she created the Mentor Program for Students with ASD in 2011.

Ms. Knitter developed the program with UBC psychiatry professor Anthony Bailey and education professor Pat Miranda as a sort of hybrid tutoring service: a student on the spectrum is paired with another student in a similar academic program and together they might review course content, try out study and time management strategies,

prepare for assignments and exams, or talk through other problems. Mentors, generally upper-year undergraduate or master's students, receive about five hours of training and are paid \$20 an hour for a minimum of two hours a week with their mentees. In the fall of 2016, 12 clients and six mentors participated in the program.

Peer-to-peer approaches like those at U of Manitoba and UBC have become a go-to for many campus accessibility advisers as their offices see the number of students with autism steadily rise. At U of Manitoba, 38 students with an ASD are registered with the student accessibility office, up from 12 students in 2009. This year at UBC, 47 students with an ASD have registered with the accessibility and diversity services office compared to 27 in the 2012 academic year. "A general stat that we use is that maybe half of all students with disabilities do actually register with the disability office," Ms. Knitter says. For the record, UBC has a student body of more than 58,000.

Ballooning adviser caseloads

Although students with autism reflect a relatively small portion of the growing population of students with disabilities, accessibility advisers maintain that the trend has a significant impact on their ballooning caseloads. (Mr. Penner says he went from advising 150 students with disabilities to more than 300 in less than 10 years.) And, according to Ms. Knitter, students with autism tend to struggle throughout their university careers with complex challenges requiring a disproportionate amount of time and support. As advisers do their best to respond to student demand, peer-to-peer models have provided them with a low-cost and relatively high-yield way to offer individualized, proactive support.

"If you're not planning in advance, crises can escalate quite quickly with students on the spectrum," Ms. Knitter says. "One thing the mentorship program has done is now we have these regular check-ins on the ground. We find that when issues come up, we hear about them much earlier because the mentor is having those weekly or biweekly sessions."

The peer-based approach has caught on at several other institutions in Canada. York University is home to one of the longest-running peer mentorship programs for students with an ASD. The nine-year-old [Asperger Mentorship Program](#) recruits, trains and pays mentors to meet one-on-one with mentees, but also to host socials, workshops, training sessions, and to help coordinators develop resources and program evaluation. Mount Royal University and McGill University have both opted for peer-based programs that resemble support groups. At Simon Fraser University, the [Autism Mentorship Initiative](#) doesn't focus so much on academics and tutoring; instead, disability access adviser Suzanne Leach encourages mentors and mentees to spend their time addressing a specific issue. "Part of the process at the start is just getting a sense of what their goals might be, where they might think they'll have some challenges in school: do you want to work more on socialization and communication skills, or is it more self-care, or is it just pure academics?"

At SFU, mentors are often psychology or education students who meet with mentees for an hour or two every week over two terms for a \$500 honorarium. Once a month, all the mentors get together to run any issues that might come up by in-house experts, including psychology professor Grace Iarocci, education professor Elina Birmingham and Mitchell Stoddard, director of SFU's centre for students with disabilities.

"It's a really great opportunity for the mentors to get some experience. It's not clinical work, but it gives them a sense of what it's like to work on a team and gain more skills in working with adults with autism. I see it as a win-win-win," Ms. Leach says. "The mentee – the student with autism – benefits; the mentor benefits and gains some experience; and the university really benefits because we're meeting our mandate to be community-centred and to engage the students to help them have more success while they're here."

Mr. Penner at U of Manitoba estimates that less than five student clients have earned their degrees while participating in the attendant-mentorship program, but "retention has really been high." Only one student with autism participating in the program has dropped out of school while working with an attendant. He notes that students with an ASD pursue their degrees at a reduced pace and that he expects the institution will begin to see graduation rates

increase for students with autism starting in 2018. (One of the largest cohorts of students with autism at U of Manitoba began their studies in 2012.)

The benefits and next steps

For students with autism, peer-to-peer programs offer dedicated time each week for building academic and social skills in a safe environment. Adrian Cheng, a fourth-year environment and sustainability student at UBC, participated as a mentee last year. Working with a mentor helped Mr. Cheng “get more committed to my homework and to not being so afraid of screwing up,” he says. But, more than that, he appreciated the chance the program gave him to open up to his peers about his life.

“I tried to talk a little about having a disability and what that’s like being in university,” he says. Mr. Cheng, who has autism and attention deficit hyperactivity disorder, says the transition to university from high school was hard. “There’s a lot of studies that say that the autistic population gets bullied a lot more than the regular population, and that was true for me. So by the time I got to university, psychologically, I was already really tired. I’d already had a lot of poor social experiences so I’m a lot more cautious because of it, and it does get a little bit lonely.”

Getting involved in activities, like singing in an a capella group and volunteering with local mental health organizations, have helped Mr. Cheng feel more comfortable on campus. As a first-year student in 2012, he even founded the Neurodiversity Pathfinders, a club for students on the autism spectrum. By sharing his story with the two mentors he worked with last year, Mr. Cheng says he “wanted them to know at least one more narrative which I hope would help open their eyes a bit.”

The training and relationships had a major impact on Mollie McAllister, who was a mentor with the UBC program from 2015 to 2016. Though she’d had stints working as a camp counsellor with Easter Seals, she says that the mentorship program opened her up to the possibility of what a career in the field of accessibility could look like. After completing her undergraduate degree in geography last year, she was hired on staff with UBC’s accessibility office.

As disability advisers develop and refine their peer-based programs and continue to reimagine accommodations for students with autism, they’re finding other service gaps that they must eventually fill. “We’re refocusing some of our energy on career development,” Ms. Knitter at UBC says. “A major barrier I’ve found is getting employment experience before they graduate. That’s important for any student but it seems to be a particular barrier for these students on the spectrum.” She’s been collaborating with colleagues at career services on workshops and job placements, and she’s begun training peer mentors in how to address work-life skills with their mentees. “It’s been a bit of my focus this year,” she says.

Developing a broader range of services beyond the traditional academic accommodations for students with autism is not something institutions can delay. As Jack Dobbs, a psychologist at Mount Royal, told a meeting of accessibility advisers in Winnipeg last May, “There’s a tsunami [of students] coming.” Mr. Penner sees proof of this incoming wave of students with an ASD at U of Manitoba’s feeder schools. “I’ve done presentations at three of the four biggest high schools outside of Winnipeg and they’ve all said the same thing. ... The number [of incoming students with autism] could double to 20. If there’s 20 coming from one big school and there are five big schools,” he pauses, “that’s a big swell.”