

DEEP DIVE

# Meet the autistic scientists redefining autism research

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*Illustration by Sam Chivers*

One paper from 2005 likened autistic children to **great apes**, and another from 2016 stated that language problems in autistic people stem from “a **failed domestication** of the human brain.” Linguist Steven Pinker famously compared autistic people to robots.

**Monique Botha** felt nauseous reading these descriptions. Botha had dug up these papers several years ago as background for a master’s thesis at the University of Surrey in the United Kingdom. Botha was investigating why people with autism have a **high incidence of mental health problems** — and hypothesized that stigma had something to do with it. Botha was diagnosed with autism at age 19 and thought that having the condition provided an important perspective as a member of the group being studied. But in diving into the scientific literature on the topic, Botha realized the field suffered from some fundamental problems.

The slights went beyond ugly parallels to apes and robots. Some reports said autistic individuals are **incapable of having moral selves** or that they are **inherently selfish and egocentric**. Several described them as **economic burdens** to communities. And one posited that people with moderate to severe forms of autism are unable to experience features of a “**good life**,” including close relationships. Most of the articles had been published within the past decade. “Imagine waking up one day and reading a book dedicated to arguing why you, and someone like you, doesn’t actually count as a person,” Botha says. “It was all this really horrific stuff.”

Far from discouraging Botha, these ignorant statements only solidified Botha’s resolve to change the scientific conversation about autistic people. Now associate lecturer in psychology at the University of Surrey, Botha studies the effects of stigma and discrimination on autistic people. The importance of Botha’s mission goes beyond principle. Autistic people are at risk for numerous **mental health issues** and **suicide** — much of it likely propelled by prejudice. Amid the coronavirus outbreak, some doctors in the U.K. have pushed for blanket ‘**do not resuscitate**’ **orders** for autistic adults without their or their family’s consent. As long as the scientific literature

casts autistic people as less than human, “it facilitates maltreatment of autistic people,” Botha says. “It legitimizes violence.”

Botha is part of a growing community of autistic scientists who are studying the condition, swapping stories and sharing opportunities. These scientists do so through two closed Facebook groups, each of which has more than 150 members; and on Twitter, using the hashtags #AutisticsinAcademia and #ActuallyAutistic. They meet over drinks at conferences and mentor students between talk sessions. “I get a very clear sense that there is this big — I wouldn’t say a big family, but a big connection,” Botha says. “It’s like being connected to all these other people who are doing the same thing as you.”

These connections were practically nonexistent 10 years ago, when few researchers were open about being autistic, and even fewer made efforts to recruit autistic scientists to the field. “There’s a growing voice,” says autism researcher **Damian Milton**, chair of the **Participatory Autism Research Collective**, which promotes autistic people’s involvement in science. “I think in the future, there will be a lot more of us coming through — or trying to.”

Already, autistic academics are making a significant contribution to discoveries about autism. They regularly publish papers in leading academic journals, and they serve as editors of at least four autism journals and as board members and reviewers. Last year, they spearheaded the founding of an autistic researchers’ committee at the **International Society for Autism Research**, the professional group that organizes the world’s largest annual autism conference. And they have established groups such as the **Academic Autism Spectrum Partnership in Research and Education** to help autistic people partner with scientists on research projects.

These autistic scientists hope they will eventually become a major force in autism research. But obstacles to their academic success abound, from sensory overload at conferences to difficulties communicating with colleagues. Researchers may dismiss autistic scientists as ‘too autistic’ to produce quality science or, conversely, ‘not autistic enough’ for their insights to be useful. Slowly, though, these biases are fading, Botha says: “For every high-quality piece of work an autistic researcher puts out on autism, the more the autistic perspective will be valued or recognized.”

## Community ties:

The idea of autistic researchers leading studies on autism is a natural extension of ‘participatory research,’ an approach **first developed in the 1940s** to ensure that studies of minority communities were not harmful, offensive or inaccurate, and that they were in line with that community’s needs. Researchers who practice this approach collaborate directly with individuals who are part of the community. They work together to define all phases of a research project,

starting with which questions are asked and how to ask them, to interpreting and applying the results. In the past decade, the nonprofit **Patient-Centered Outcomes Research Institute** has helped lead the charge in funding participatory health science. The work it supports, which includes two dozen **studies related to autism**, puts communities in charge of setting research agendas and determining how research is conducted, says **Lisa Stewart**, a senior engagement officer at the institute.

Involving the community in research goals is important because the types of autism research that get funded often differ from what autistic people want. For example, **more than half of all autism research** in the U.K. focuses on the underlying biology of autism — yet most of the 125 autistic people surveyed in a 2013 study said greater priority should go to research on public services, and almost half called for more research on improving life skills among autistic people. A 2015 survey of nearly 300 autistic individuals in the U.K. identified mental health as the **most pressing research issue**. And in a 2018 study conducted in the United States, 485 autistic individuals and their family members said they value research on **health and well-being**, the **transition to adulthood** and lifespan issues more than **basic science research**. “The outcomes that matter most [to people with autism] tie to improved quality of life,” Stewart says. Participatory research can give these preferences sway.

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Autistic partners have been crucial to prioritizing research in these areas. They were essential, for example, in the development of an **online healthcare tool kit** for autistic adults and primary-care providers. Surveys and interviews with autistic adults revealed the main barriers to care. But the autistic partners were important for insuring that the tool kit would be as useful as possible for them and others like them. “As a physician and autism researcher, I certainly had plenty of ideas of my own, but I never would have been able to create a tool anywhere near as useful as we did as a team,” says **Christina Nicolaidis**, a health services researcher at Portland State University in Oregon who helped develop the tool kit. The contributions of one autistic partner in particular, the late **Mel Baggs**, “are infused through every aspect of the tool kit and are a big part of why it’s accessible, respectful and useful,” Nicolaidis says.

Community involvement may also help eradicate hurtful descriptions of autistic people in the scientific literature. “I can’t count the number of times I’ve had to read papers that are talking about how much I cost society, how much of a burden I am, how difficult I am for the people around me, how awful life is for my parents and siblings — all those things,” says **Jac den Houting**, a

postdoctoral researcher in education at Macquarie University in Sydney, Australia. “There’s still a lot of research coming out that unfortunately doesn’t take into account the fact that autistic people are going to read what you’re writing.”

Sometimes these offensive views come up in person. Years ago, at a meeting at Oregon Health and Sciences University in Portland, one senior researcher lamented that girls with **Rett syndrome** have no soul and said it was his deep passion to restore their souls, recalls **Dora Raymaker**, assistant professor of social work at Portland State University, who was at the meeting. “He had no idea what he said was in any way offensive,” says Raymaker, who is autistic. Participatory research helps prevent such situations by requiring scientists to interact directly with the people they are studying and get their input, or even their sign-off, on the research.

Having a researcher from the autism community lead a study can bring additional benefits. For example, the scientist may have a good rapport with participants. “Autistic participants can talk to me more comfortably because they know I’m autistic,” says **Kana Umagami**, a graduate student at University College London who studies loneliness among autistic adults, and who founded the university’s first **autistic peer group** for students in January 2019. “I feel like I can be empathetic towards them, and we can connect on a deeper level.” This connection could prevent **serious misunderstandings** between autistic and nonautistic people that could derail research.

Autistic researchers may home in on various phenomena that autistic people know to be true from experience, says **Steven Kapp**, a lecturer in psychology at the University of Portsmouth in the U.K. For example, last year, Kapp and his colleagues showed that self-stimulatory **behavior known as stimming** — hand-flapping, rocking, spinning, verbal repetition and the like — is soothing for many autistic adults. The adults he interviewed objected to any treatments aimed at curtailing this behavior, a finding that suggests investing in such treatments is not useful. “Nonautistic researchers and people might not be aware of these phenomena or take them seriously until they are reported as scientific evidence,” Kapp says.

The experience of being autistic may also bring a unique perspective to the science. For his undergraduate thesis, **Elliot Keenan**, an autistic psychology graduate student at the University of California, Los Angeles, decided to look into a connection between depression and **repetitive thinking or behavior**, because he had noticed that this type of rumination seemed tied to his own bouts with depression. “My mentor jokingly accused me of being a me-searcher,” Keenan says, referring to someone whose work is informed by personal experience.

Autistic researchers can also change the perspective of neurotypical scientists in important ways. Psychiatrist **Laurent Mottron** of the Rivière-des-Praries Hospital in Montreal, Canada, has spent much of the past 15 years working with **Michelle Dawson**, one of the first openly autistic

researchers. Mottron wrote in a 2011 *Nature* commentary that Dawson had “helped the research team **question many of our assumptions** about autism — including that it is a problem to be solved.” As a result, Mottron has come to view autism as a natural variant within the human species, rather than “an error of nature that should be corrected.”

## I don’t flap enough:

Bias against autistic people may nevertheless impede progress on certain projects. In 2010, Raymaker submitted a grant proposal for the healthcare tool kit she eventually developed with Nicolaidis. Reviewers rejected her initial proposal with a comment suggesting they did not believe autistic people are self-aware enough to participate in science: “There is not adequate evidence that the self-reports of individuals on the autism spectrum are valid or reliable,” the review stated.

This kind of thinking has gradually become less common as the ranks of autistic scientists grow and people warm to the benefits of involving autistic people in studies. Still, autistic researchers say they are commonly accused of bias because people believe that their diagnosis makes them too close to the topic.

But every scientist relies on subjective experiences, thoughts and observations, Botha says. “When someone who is nonautistic develops research, they base their questions around their perspective of what autism is.” The objectivity that comes with being an outsider also comes with drawbacks. “We tend to have this focus in science on objectivity and distance,” Botha says. “But when you’re working with a community that has been vulnerable to things like discrimination and stigma, that distance isn’t necessarily a good thing.”

Paradoxically, autistic researchers also may be accused of being not autistic enough to relate to the population they are studying. “That might mean maybe I don’t flap enough, I don’t talk in a robotic-enough voice. Who knows?” says **Stephen Shore**, clinical assistant professor of special education at Adelphi University in Garden City, New York. Often, the criticism relates to the capacity to conduct research relevant to autistic people with high support needs, because autistic scientists may seem to have little in common with someone who needs a great deal of support, Shore says.

In some cases, autistic scientists are told they must not be autistic at all. In a job interview, Umagami was told that she could not possibly be autistic, she says, because she was making eye contact. Many autistic researchers have learned to brush off such comments. “For those who don’t believe I’m autistic, or [say that I am] not autistic enough, I just tell them to stick around with me for a while and you’ll see,” Shore says.

## Glaring lights:

Scientists like Shore may not seem autistic in part because certain aspects of academia bring out their talents. Botha, for example, found Ph.D. work to be surprisingly easy and enjoyable because it involved prolonged focus on a topic. “This is part of autism,” Botha says. “We have intense interests and can devour information regarding those interests at an incredible rate.” Den Houting loves the type of public speaking that scientists do. “For me, giving a presentation is much easier than having an off-the-cuff conversation with someone,” den Houting says. “It’s scripted; it’s a monologue; it’s on my special interest.”

On the whole, though, academia is hard for anyone to break into — and autistic researchers may face additional difficulties. Most people with autism have **sensory sensitivities**: They are **unusually sensitive** to sound, sight, smell or touch. Nowhere is this more of a problem than at scientific conferences. “They’re just an autistic nightmare,” den Houting says. Many conferences are loud and crowded, with glaring lights and a crush of people. Poster sessions — which are usually held in huge, echoey rooms brimming with people — are especially problematic. At best, this type of environment is exhausting and draining; at worst, it produces panic.

Milton says he regularly misses talks he would like to attend because he needs to leave the building to unwind. In February, Shore walked into a conference on student mental health organized by Harvard University and the Cambridge Health Alliance, only to turn around and walk out. “The presenter had just told the audience of about 800 people to turn and talk to their neighbor about the concept she just mentioned,” he says. “Imagine the noise. In such a situation, you just leave.”

Just leaving, however, may mean missing out on important scientific advances, fresh ideas and chances to connect with colleagues. These lost opportunities can be particularly detrimental for students and early-career researchers. Recognizing this problem, some conference organizers are trying to create a more welcoming atmosphere for autistic participants.

Umagami has attended conferences organized by Autistica, a U.K.-based charity, in which audiences are supposed to refrain from clapping — a noise that bothers some autistic people — and instead use ‘jazz hands’ to show their appreciation, a technique pioneered by the deaf community. The International Society for Autism Research annual meeting has also **encouraged jazz hands**, also known as ‘flappause.’ In addition, that meeting, among others, offers quiet rooms where attendees can go for a break from the buzz. “I’ve been at conferences that have and don’t have quiet rooms, and that’s made all the difference, in my experience,” Botha says.

Sensory complications can also dog everyday situations and get in the way of new ideas — at least until autistic researchers find a way around them. When Shore teaches, he arrives at the classroom a few minutes early to set up. A few students are usually already there, often talking among themselves. During his first few years teaching, Shore found their chatter to be extremely annoying. “It seemed like they were talking really loud,” he says. “It hurt my ears and seemed like gratuitous social interaction.” Back then, he shushed them. But one day, it occurred to him to listen to what the students were saying. He realized they were discussing the class material, and as a result, he decided to incorporate guided discussions into his lessons, rather than just lecturing to the students. “That helped my teaching style,” he says.

“I’m very invested in there being more of us.” Dora Raymaker

Autistic researchers may also find it difficult to navigate the politics and conflicts that are an inevitable part of most academic settings. Many do all they can to simply steer clear. “I’m not going to lie, I think there’s a lot of nuance that probably goes straight over my head,” Botha says. When relationships do go wrong for autistic people, they can go very wrong. Within a year of starting work toward a Ph.D., for example, Milton says he and his supervisor could no longer be in the same room together. Milton had to withdraw from that Ph.D. program — and start another one, years later.

Keenan has also unwittingly wandered into interpersonal minefields. In 2018, progress on a paper Keenan was writing with several neurotypical colleagues ground to a halt because, Keenan says, his collaborators found his directness offputting. “I’ve been told the main problem was the email tone,” he says. In one email, for example, Keenan wrote, “There’s no point in me doing either of those [research tasks] at the moment, because I am not medically well. However, you or anyone else are completely capable of doing either or both of them without me.” Keenan’s supervisor at the time, psychologist **Matthew Lerner** of Stony Brook University in New York, says that Keenan was learning to be honest about when he was stretched too thin. Keenan could sometimes be too blunt in his approach, Lerner says, but the effort showed Keenan’s willingness to grow.

Autistic researchers may be more prone to dwelling on **relationships that go sour**, and they may also be more sensitive to rejection and criticism — another unavoidable staple of any academic career. Den Houting has learned over the years to reframe negative feedback as a way to improve work. Yet if you are autistic, there is a strong chance you have had to deal with rejection your whole life, Botha says, and that can be a strength, in a way. “You tend to build up some form of resilience to the stressors you have to face day in and day out,” Botha says.

There are still the sheer demands of the job to contend with. The academic environment is fast-paced and competitive. Keeping up with research, administration and family or home life can be a challenge for anyone, but autistic people may find managing their time particularly difficult. In February, Umagami made the difficult decision to leave London and return to her parents' house in Japan to finish her Ph.D. Although she was excelling academically, she says she was struggling to keep up with mundane tasks such as cooking and paying bills. She is managing her life better now but is all too aware she is missing out on chances to connect with her colleagues. "Sometimes I really, really wish that I was a little bit like everybody else," she says.

Some senior autistic scientists are working to help younger scientists like Umagami overcome these challenges. Raymaker has mentored numerous autistic students and early-career professionals. Among other things, she talks to her mentees about what it is like to be an 'insider' researcher — where there might be pushback, where it can be a strength and how to use it as such. "I have a strong interest in helping the next generation of autistic researchers get here with less hassle [than I had]," Raymaker says. "I'm very invested in there being more of us."

And Botha, who has long looked up to more senior researchers such as Milton and Kapp, is now regularly approached by students whom Botha inspired to pursue psychology. "They're like, 'I'm autistic, and I want to do something like this, and you're showing me it's possible.'"