



Dora Raymaker (left) and Christina Nicolaidis edit the new journal *Autism in Adulthood*.

SOCIAL SCIENCE

Autistic people take the helm of studies

Trend brings new focus on well-being of autistic adults

By Emily Willingham

Professional burnout is all too familiar: Go at something too hard for too long, and the motivational tank empties. But burnout for an autistic person isn't always about overwork, Dora Raymaker, an autistic systems scientist at Portland State University (PSU), found in a study of autistic workers. Instead, the need to mask autistic behaviors through a workday with nonautistic people can cause chronic exhaustion, reduced ability to tolerate stimuli like light or sound, and loss of skills, the study showed through interviews and a survey of social media comments.

The work, which Raymaker's team published last month, highlights a new trend in autism research. Raymaker and colleagues are part of a small but growing number of research teams with autistic members. These groups are shifting the focus in autism research from cause and cure to practical steps, including ones that help autistic people in settings such as the workplace. And they're publishing some of their findings in a new journal, *Autism in Adulthood*, which is dedicated to including the perspectives of autistic people in what it publishes.

Interest in those perspectives is "skyrocketing," says Christina Nicolaidis, a co-author on the burnout study. Nicolaidis, a professor in the School of Social Work at PSU, has an adult son who is autistic. Although much research on autism has focused on children, autistic adults who came of age in the 1990s and

early 2000s are joining the field and bringing a focus on their own experience. One member of that cohort is TC Waisman, a doctoral candidate at the University of Calgary studying how faculty and staff can improve autistic students' college experiences. Waisman says she sees researchers increasingly "respecting us as our own self-determined culture and foregrounding our needs in studies."

Before the burnout study, Raymaker says, "There was literally no research ... even though it's been talked about in the community forever." In interviews with dozens of autistic people, Raymaker and colleagues found that having an autism-friendly workplace requires not expecting workers to mask autistic traits and come across as neurotypical. Too often, says Raymaker, who uses they/them pronouns, "The burden gets put on the autistic person to fix the problem." Instead, they say in their *Autism in Adulthood* paper, workplaces should make accommodations, such as accepting autistic people for who they are and providing flexible work arrangements.

Medically oriented studies of autism still dominate the field and draw most of the millions in research funding. Such studies usually involve searching for autism-associated genes or trying to recapitulate behaviors of autism in mouse models. Yet many researchers who do such work "have never even seen the condition," says Connie Kasari, a psychologist at the University of California, Los Angeles, who notes that she has autistic people on her research team. "They don't understand that social development in a mouse

doesn't look like social development in a human of any sort."

Many of the new studies grow out of social science practices established for other marginalized populations. Still, the shift toward including autistic people's perspectives has not been painless. Some scientists worry about introducing bias when someone with the condition under investigation is on the research team. But Nicolaidis says, "You are not more biased by being autistic than by being nonautistic."

To address another concern, that including autistic people in research could decrease its rigor, Nicolaidis points to work she's done using survey instruments that autistic people helped her modify. Among suggested adjustments to ambiguous response options was using percentages, such as "I do this activity ____ percent of the time." But autistic people with co-occurring intellectual disability, she says, expressed discomfort with percentages. Nicolaidis's team substituted images of cylinders shaded to reflect percent values.

Had she surveyed autistic people with an instrument for a general population, she argues, she would have wound up with unreliable results. Failing to get input from autistic adults would have been "like doing research in Spanish and not having anybody who's Latino on your team."

A similar philosophy underlies *Autism in Adulthood*. The peer-reviewed journal released a preview issue in spring 2018 and started to publish quarterly last year. Nicolaidis is editor-in-chief and Raymaker is one of several self-identified autistic members of the editorial team.

Researchers can be surprised by some of *Autism in Adulthood's* policies, including using the identity-first phrase "autistic person," which the journal favors over "person with autism." Language that is medical in nature is verboten, for instance calling autism an "impairment." And every submission gets at least one autistic reviewer. Autistic reviewers often comment on manuscripts' language, including whether information is understandable. "I don't think most authors are used to getting a review from an autistic community member, but for the most part they have responded very positively," Nicolaidis says.

For Waisman, it's about time. "Autistic voices should be heard and acknowledged first and foremost," she says. Autistic adults, she adds, "have the right, and perhaps the duty, to speak for ourselves." ■

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