

Let's Talk About Autistic Autism Researchers

Sandra C. Jones, PhD

Zachary Williams: I hope that we as a field can work to remedy this and ensure that there are many more seats at the table for autistic people in the future.

Sara M. Acevedo: I want us to build the table.

Dora M. Raymaker: The shape of the table needs to change too.

AS A SENIOR UNIVERSITY ADMINISTRATOR and an experienced researcher in the later stage of my academic career, I have watched the autism research landscape change dramatically over the past few decades.

I grew up in an era when autism research was research conducted *on* autistic people. Over time I have seen the field evolve to include research conducted *with* autistic people (recognizing that our lived experience could contribute to scientific knowledge, but seeing that lived experience as our main contribution), and now to include research conducted *by* autistic people (recognizing that our contribution goes beyond “being” autistic to the strengths that we bring as professionally trained researchers).

Autism research conducted *with* autistic people, positioning those with lived experience as partners in research, is increasingly becoming the norm and the expectation in high-quality autism journals, and is particularly visible in studies published in *Autism in Adulthood*. Genuine participatory research takes time and requires researchers (and research systems) to adjust to different ways of seeing and undertaking research. It includes recognizing the value of autistic perspectives and seeing autistic people as equal partners not as token partners or research equipment.¹ A recent article in *Autism* provides practice-based guidelines for the inclusion of autistic adults in research and should be the starting point for anyone considering undertaking participatory research related to autism.²

Autism research conducted *by* autistic people—from doctoral students to senior professors—is a growing if somewhat hidden resource for improving the lives of autistic people. It is no surprise that the two studies mentioned in the previous paragraph were conducted by teams that included autistic autism researchers. As is the case for research conducted with autistic people, research conducted by autistic people needs to be truly collaborative. The autistic researchers need to be equal members of the academic team, valued for both their expertise in autism and their skills in research. We need to ensure that autistic researchers, and

particularly those in training such as doctoral students, are not seen as a token inclusion to tick the “collaboration” box. Doing so is not only disrespectful to those talented individuals, but also deprives the autism community from the benefits of their expertise and their insightful approaches to research that can really make a difference to our lives.

This issue of the journal features a roundtable discussion with a group of autistic autism researchers. These are not “token” collaborators; they are extremely competent and influential researchers and future research leaders, changing the landscape of autism research and outcomes for autistic people.

Although the roundtable participants come from a wide range of discipline backgrounds, countries, and life experiences, they share some common perspectives on the benefits and challenges of being an autistic person researching autism. Autistic researchers bring both the insight and experience of being autistic *and* autism-related skills that are important for research such as attention to detail, intellectual curiosity, and passionate focus. In the roundtable, Brown (who recently published on the importance of diagnosticians avoiding framing autism solely as a deficit³) notes that “We understand the values and the traditions of our disciplines and we understand the lived experience of being autistic.” Nachman (whose recent research focuses on the experiences of autistic college students^{4,5}) adds that “My autistic identity enables me to conduct research with a strong attention to detail and with enhanced consideration toward alternative ways of processing and relaying information, as well as to empathize with participants and colleagues through having certain lived experiences that may resonate in a system cultivating trust.”

The roundtable participants also report shared challenges, demonstrating that the field still has a long way to go in truly recognizing and engaging the strengths of autistic researchers. Some of the common concerns include tokenism, challenges with Institutional Review Boards, and debates around terminology and perspectives. Participants also discussed the need for participatory research to be encouraged and required by those in power. As Williams comments, “I think it would be excellent if funders, especially, would go out of their way to encourage or perhaps even require people to simply engage in the community with every sort of project that they do: at the very least to simply survey people and ask whether or not the goals of the project itself are even important to them.” An important caveat from Grapel is to ensure that we recognize our place of privilege, “we really need to broaden where we look for autistic research, because it really tends to be our

group, our subset of verbally-fluent people without intellectual disabilities, because it's easier to collect data from them. All that means we're missing a huge, big picture, and I think I'd like my non-autistic peers to get to figuring out how we're going to account for that and actually learn about the entire population."

The roundtable concludes with the panelists offering suggestions for more meaningful and sustainable inclusion of autistic researchers. My own suggestions include being willing to make the environmental, structural, and social changes that enable us to survive and thrive in the university environment. As I note in the roundtable, "There's a lot that our non-autistic colleagues can do to support us, but only if we actually educate them on what these things are: simple things like putting dimmer switches on lights; limiting the number and duration of meetings; not having meetings in noisy cafés; understanding that we're not being rude or unfriendly if we decline to attend after-work functions; making it easier for us to participate in meetings by accepting that we might need to stim or to fidget, that we might not want to make eye contact, and that we might need to turn the video off during online meetings." Dwyer—roundtable facilitator and autistic researcher—provides a useful summary of the group's recommendations at the end of the roundtable article.

The growing body of published autism research undertaken by autistic researchers is rapidly expanding our understanding of autism and how to better support autistic people. In addition to the articles already cited, recent examples of this research include:

Autistic burnout: Although autistic people have long been familiar with the experience of burnout, there has been a marked absence of research on autistic burnout. In 2020, a team led by autistic researcher Raymaker undertook and published ground-breaking research on autistic burnout, identifying characteristics and causes of autistic burnout and confirming that it differs from depression and occupational burnout.⁶

Autism-specific anxiety: It has long been known that anxiety is a common comorbidity with autism. A body of research undertaken by a team led by den Houting has developed a tool for assessing autism-related anxiety in children and identified that autistic children and their parents have different perceptions of the anxiety symptoms experienced by these children.⁷

Autism and employment: Research led by Hayward has explored the experiences of autistic adults in obtaining and maintaining employment. Key findings include that autistic adults desire stable employment and a fulfilling career but low hopes of finding a fulfilling career.⁸

Community knowledge and autistic people's experiences: Our research has identified significant gaps in the community's understanding of autism and discrepancies between community perceptions of their knowledge of autism and the experience of autistic people and their families.^{9,10}

As an older academic what I find *inspiring* is the increasing visibility of young autistic researchers. Over the past few years I have met so many talented autistic doctoral students and early career researchers, and being awed by their insightful research and their contribution to the field.

What I find *concerning* is the continuing lack of visibility of older and more senior autistic researchers. Although this is in some part due to the improvements in diagnostics over time (many autistic people of my generation remain undi-

agnosed), it is also due to the perceived risk of the stigma that hovers around an autism diagnosis and inhibits disclosure. Unfortunately, it is also related to the reality of that stigma, with autistic researchers being welcomed for the credence they bring to research articles ("we collaborated with autistic researchers") but not for their meaningful contributions to the rigor and quality of the research. I have seen too many young autistic people awarded scholarships to join research teams, only to find themselves looking for a job elsewhere on completion of their doctorate as they were not seen as competitive applicants for research positions (against neurotypical applicants).

My own decision to disclose was driven by a young autistic academic who commented to me: "If you can't disclose at your career stage because of the risk of discrimination, then what does that say for those of us who are just starting out in academia?" He was right. I did not have to fight the prevailing stereotypes to be given the opportunity to prove that I could be a good researcher. I could demonstrate a track record of success as a researcher and a leader and hopefully help people see that my success was in large part *because of* (and not *despite*) my autism. If I am able to contribute to making academia a little more autism friendly and just a little bit easier for autistic researchers to climb the ladder, I will retire with a sense of satisfaction.

If you have an interest in the field of autism research, I encourage you to seek out and read articles by autistic autism researchers and to share these with others in the field. I did a "quick search" in preparing this editorial and identified more than 100 articles. The list of academic researchers and their published autism research is available on my website <https://www.autisticprofessor.com/autisticresearchers> and will be updated regularly.

If you are an autism researcher, I encourage you to seek out opportunities to collaborate with autistic researchers—not as nominal representatives, but as equal collaborators and co-authors.

If you are an autistic researcher, particularly a senior researcher, I encourage you to reach out to other autistic researchers, to promote and support their study, and to mentor junior researchers. Those of us with seniority and tenure have an obligation to lobby loudly for the changes that are needed to enable the next generation of autistic researchers to thrive.

If you are a university administrator or research leader, I encourage you to seek out and employ autistic researchers—not as token equity targets, but as highly skilled and insightful researchers and future research leaders—and to proactively and willingly make the necessary environmental adjustments to enable them to participate fully and be their authentic selves.

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Address correspondence to:

Sandra C. Jones, PhD
ACU Engagement
Australian Catholic University
115 Victoria Parade, Fitzroy VIC 3065
Melbourne
Australia

Email: sandra.jones@acu.edu.au