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Editorial

Reclaiming Research for the Autistic Adult Community

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TWELVE YEARS AGO, I recoiled from my then-new friend Christina Nicolaidis while she was trying to explain the typical course of a National Institutes of Health study. As the autistic codirector of our fledgling community-based participatory research collaborative, the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), I was curious how our group's work on autistic adults and health care would develop. Christina, AASPIRE's academic codirector (and now editor-in-chief of this journal), had just explained, ''First you do an exploratory study to understand what's going on. Then you use what you learn to develop and test an intervention.''

''Wait, WHAT?'' That was me, recoiling. ''No interventions! We don't want interventions!''

As most services researchers would be, Christina was baffled by my terrified reaction. ''But you want to do something to improve healthcare for your community, don't you? That's what we've been talking about doing with AASPIRE's research. That's what an intervention does.''

Except, to many of us autistic people, improving health care was definitely not what an ''intervention'' did. An ''intervention'' aimed to remove or remediate our autistic traits, depriving us of necessary coping skills, or erasing things that were a fundamental valued part of our identity. Like other ethical breaches of trust between science and disability communities,[1] harms caused by conducting research on us instead of with us had poisoned even general scientific terminology.

I remember Christina trying to convince me, as I breathed through my panic, that an ''intervention'' was not about erasing the appearance of disability, so nonautistic people could feel more comfortable in our presence. She finally got through to me by showing her own intervention research to give health care providers more empathy toward patients who have experienced violence,[2] which not only had nothing to do with disability but was also targeted toward changing the behavior of people of privilege.

Now, 12 years later and after obtaining a terminal scientific degree, a faculty appointment, and associate editorship of this scholarly journal, I introduce myself as an intervention researcher. Intervention research is as much a part of my identity as my neurodivergence. I use scientific methods and approaches to explore, develop, and test programs designed to affect specified outcomes. The difference between the work I do and my incorrect assumptions about what ''intervention research'' was 12 years ago is that in my work the outcomes have been specified by the disability communities I work with—not by an outsider who does not understand our priorities and has not bothered to ask. The outcomes in our intervention research are not ''behave indistinguishably from nonautistic people no matter the cost.'' They are outcomes like successful and sustainable employment,[3] improved health and health care,[4–7] reduction of autistic burnout,[8] and increased self-determination.[9]

Science is powerful, whether it is being used in the service of the adult autistic community or at odds with it. We talk about knowledge and power in a Foucaultian sense,[10] and, yes, I do mean it in that way. The authority and privilege of scientific knowledge shape discourse, policy, and culture. But I also mean power in a less socio-political-economic way. Science has a lot of power as an instrument to discover hidden truths. An enhanced understanding of those truths can, in turn, lead to targeted effective change. Science is a powerful tool for modifying the world through its systematic rigorous methods, and through its fiery creativity and curiosity. Science is why we have Internet, agriculture, and effective public health.

Sadly, the power of science has too often been used to justify oppressive practices and further marginalize disenfranchised populations, such as the adult autistic community. Researchers who are not also members of the community need to understand that trust between autistic adults and scientists has been broken repeatedly in the past, and that there will be landmines—such as those around the term ''intervention''—that must be navigated. Trust requires effort to rebuild—and the majority of that effort must be made on the part of scientists (both those of us who are also autistic and those of us who are not) by listening to the community and following through on its direction every single time.

For my part, as a scientist and as an autistic person, I aim to reclaim the power of science to further what autistic adults want better understood and changed about the world. This journal, with its inclusion of autistic adults as editors, authors, and peer reviewers, is one of the many vehicles for meeting that aim. My presence as associate editor of a scholarly autism journal is significant. Our work on this publication can help autism researchers better understand community issues and priorities, and mend trust with the autistic adult population by demonstrating a continuous willingness to privilege our knowledge. For the autistic community—and those like myself who stand at the intersection of both worlds—it illustrates the potential to reclaim the power of science to meet our priorities.

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In this third issue of *Autism in Adulthood,* I am thrilled that we are publishing an array of articles across disciplines, domains, and modes of inquiry that use science in the service of the adult autistic community, and that privilege autistic adults' experiences, priorities, and values.

Improved physical and mental health outcomes have long been a community priority. Hallet's perspective article and Todd et al.'s emerging practices article examine the health benefits of exercise interventions: Hallet's by reviewing and identifying gaps in the current literature regarding health outcomes and Todd's by asking autistic adults directly about their experiences participating in an exercise health improvement intervention in a higher education setting. Hallet, notably, calls attention to the need for more exercise research that represents the autistic adult community and its interests. Dawn et al.'s article takes a look at loneliness by surveying autistic and nonautistic adults and includes a discussion of autistic adult perspectives and priorities, including their direct experience of barriers and facilitators to socializing, their ideas about strategies to decrease loneliness, and their definitions of what they (not nonautistic outsiders) want out of socializing. Benevides et al.'s article on case identification in Medicare (U.S. government-funded health insurance) data paves the way to better understand how health care is used by autistic adults in the Medicare population, a step in future research to further improve that population's health care.

The autistic adult community has also had a long time priority in postsecondary education and increasing young adult independence. Capozzi, Barmache, and Cladis et al.'s insight essay on their experience as nonspeaking autistic peer mentors to other nonspeaking autistic people transitioning into postsecondary education highlights the importance of our role as support for each other, and challenges mainstream narratives of who should be attending universities and who should be mentoring and serving as a role model for autistic students. Myer et al.'s research on what instructors and parents can do to teach driving to autistic young adults focuses on an important milestone in young people's journey toward independence. Sheef et al.'s research directly asks autistic college students what supports they most value in succeeding in college, and Hassenfeldt et al.'s brief report surveys graduate teaching assistants about supporting autistic students—a first step in identifying a potential area for future improvement to autistic college students' success.

Lastly—at least for what is covered in this issue—the autistic adult community desperately craves improvements to employment outcomes. For us, this is not just about getting jobs but also about entering fulfilling and sustainable careers. This issue's round table discussion on employment includes two autistic scholars on the panel (spoiler: one of them is me). In that discussion, which covers wide ground, there is ample conversation regarding what the autistic adult community wants and needs out of employment research, and programs for improving employment outcomes. Nicholas et al.'s research on employment support for transition age adults emphasizes recommendations that are ''needed and desired by autistic adults.''

And yes, a good number of the articles in this issue are about interventions. But the good kind—the kind that seeks to make the kinds of changes in the world that we, autistic adults, want to make.

Science has substantial power to improve our lives; let us reclaim it to meet our aims.

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