

An Expert Roundtable Discussion on Experiences of Autistic Autism Researchers

Moderator: Patrick Dwyer, MA^{1,2,1}

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Introduction

HISTORICALLY, FEW AUTISM RESEARCHERS have been openly autistic. Indeed, the institutions, practices, and culture of autism research have largely been shaped by nonautistic people. Insofar as nonautistic people may struggle to understand autistic perspectives and communicate effectively with autistic people, as suggested by the concept of the double empathy problem¹ and by empirical research,^{2–4} this could have serious repercussions for the quality and relevance of autism research. Fortunately, a growing number of openly autistic scholars have begun to make their presence known in the autism field.⁵ For example, autistic researchers are visible in the Participatory Autism Research Collective, in the International Society for Autism Research (INSAR) Autistic Researchers Committee, in social media groups for autistic researchers, and via the #AutisticsinAcademia hashtag, and through numerous other initiatives and organizations, including this journal. Although these autistic autism researchers might be well positioned to act as a countervailing force against the double empathy problem, being autistic in a field shaped and dominated by nonautistic people could also be a source of challenges and tensions. Unfortunately, no academic articles focusing on autistic scholars in autism re-

search currently exist in the literature, which could impede efforts to promote the success of autistic autism researchers. This roundtable discussion provides an initial exploration of this important topic.

This discussion focuses specifically on autistic scholars—such as graduate students, postdoctoral fellows, and faculty—who are conducting autism and disability research. We chose this focus to allow a more in-depth discussion. As such, this roundtable does not focus on the involvement of autistic people in autism research as community partners or coresearchers. Although the involvement of autistic community members in research teams is an important topic for the field, it has been discussed in other publications.^{6–11} Furthermore, while the accessibility of university-based clinical programs (e.g., medical, education, social work, and clinical psychology) does affect the representation of autistic people in occupations that are responsible for providing important services and supports to autistic individuals, this is a distinct and separate topic from autism research. Finally, this roundtable does not explore experiences of autistic people conducting research in fields unrelated to autism. It is possible that being an autistic researcher in nonautism fields may be associated with some tensions and challenges that meaningfully differ from tensions facing autistic autism researchers.

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Mr. Patrick Dwyer: *Today, we have brought together a group of autistic scholars to highlight the contributions that autistic autism researchers are increasingly making to autism research, to discuss the challenges and tensions that autistic autism researchers still face, and to explore and suggest changes that might address those tensions and ensure that autistic people can thrive as autism researchers.*

We strove to ensure that this panel would include a diversity of perspectives. Our panelists are autistic researchers who conduct a variety of different types of autism and disability research, including basic science, applied research, and humanities scholarship. Our expert panelists also come from a variety of career stages, from graduate students through senior faculty. Furthermore, several of our expert panelists not only have personal lived experience of being autistic in academia, but also have experience conducting research regarding, or engaging in service or advocacy on behalf of, the emerging community of autistic people in academia.

We will begin our discussion by asking each of the participants in our discussion to introduce themselves.

I am an autistic PhD candidate at UC Davis, where I primarily focus on researching sensory processing, attention, and hyperfocus in autism. I also do some research regarding other topics, such as neurodiversity and education. I am one of two Co-chairs of the INSAR Autistic Researchers Committee. Finally, I facilitate a UC Davis peer support community for neurodivergent students, and the membership of that group includes both undergraduate and graduate students.

Dr. Sara M. Acevedo: I am an assistant professor of disability studies at Miami University, where I have been on the tenure line for close to 3 years. I am a linguist, anthropologist, and disability studies scholar by training. My work is situated at the productive intersection of spatial politics, self-governance, and transgressive discourse—neurodivergent grassroots organizing is a central topic in my research. I use critical qualitative methods and collaborative/emancipatory research; I identify as a scholar-activist.

Dr. Heather M. Brown: I am an associate professor in the department of educational psychology at the University of Alberta in Edmonton, Alberta, Canada, where I try to help current and future educators understand how to best support neurodivergent students in the regular classroom. My research aims to uncover strategies to support the academic achievement and overall well-being of autistic children, youth, and adults.

Mr. Jordan Grapel: I am currently a clinical research specialist on the neuroscience team for the Duke Center of Autism and Brain Development. I run most of our electroencephalography (EEG) and eye-tracking sessions for a number of different studies that all generally try to identify biomarkers for autism.

Dr. Sandra C. Jones: I am the pro vice-chancellor, engagement, at Australian Catholic University in Australia. My research focuses on autism acceptance and inclusion, primarily the experiences of autistic adults in education, employment, and engagement with the community.

Dr. Brett Ranon Nachman: I am a postdoctoral research scholar at the Belk Center for Community College Leadership and Research at North Carolina State University. I am the director of research for the College Autism Network as well. I am studying higher education, and one of my main areas of focus entails uncovering the experiences and perceptions of autistic college students. Each year I work with my colleagues in developing the College Autism Summit that invites autistic self-advocates, practitioners and scholars, educators, and community members as we address issues facing research and practice related to autistic college students.

Dr. Dora M. Raymaker: I am a systems scientist and research assistant professor at Portland State University's Regional Research Institute for Human Services, in the School of Social Work. I am also the co-director of a community-based participatory research group, the Academic Autism Spectrum Partnership in Research and Education (AASPIRE; aaspire.org). I conduct applied services and intervention research. My current focus is on improving employment outcomes for autistic people in skilled settings, including research.

Mr. Zachary J. Williams: I am an MD/PhD candidate in neuroscience and hearing and speech sciences at Vanderbilt University in Nashville. My research focuses on measuring and predicting the health and well-being of autistic adults, with a specific focus on mental health symptoms and sensory differences. I also serve as the secretary of the INSAR Autistic Researchers Committee and as a member of the Autism Intervention Research Network on Physical Health (AIR-P) Autistic Researcher Review Board, and also a consultant for Roche.

Mr. Dwyer: *Thank you all. Let us move on to the questions. First, how has your autistic identity impacted your research? What led you to pursue autism research? Are there other identities intersecting with autism that have affected your research?*

Dr. Acevedo: Yes. I cannot speak of my autistic identity without simultaneously drawing attention to the fact that I am a Mestiza woman, an immigrant—I was born and raised in Colombia, South America—and someone who lives with chronic illness. I have written at length about the compounding impact that my gendered and racialized identities have as they intersect with my disabilities. I center lived experience and *situated knowledges*¹² in my research—in other words, there is no view from nowhere or decontextualized research method that I think has as much impact as embodied knowing does, at least when it comes to social justice and sustainable transformation. Others will of course beg to differ.

Dr. Brown: I first truly learned about autism as an elementary school teacher in the Canadian educational system. There had been a little boy with autism in my grade 2 class and I soon began to wonder whether my grade-2-self would have looked and acted much as he did. At the same time, I was also a relatively new mother of my own neurodivergent son. After doing a great deal of reading, talking to therapists, and getting a formal diagnosis, I made the difficult decision to leave the classroom and return to grad school. Given my love of psychology and learning along with my new understanding

of my autistic traits and aptitudes, I wanted to explore whether scientific research and academia would be work environment within which I could thrive. And, in many ways, it has been a really good fit. Lastly, although there have been many systemic barriers in my life, I also want to acknowledge that I have had a great deal of privilege to be where I am today.

Mr. Grapel: I would say that out of my many identities, autism has definitely been the one that has been the most impactful on the course of my life. I am also a cis half-White Jewish male, so I like to call myself the worst dancer on the planet. But I was not told about my autism diagnosis until I was about 15 years, and I did not think much of it until a few weeks later, when a club that I was in basically lied to me and tried to have meetings without my knowing, and that was one of the worst days of my life. I basically realized that everything that happened there boiled down to a lack of understanding between both them and me about social protocol: me not understanding social protocol and them not understanding how to deal with me. That experience made me want to help other socially awkward kids with Asperger's, like me, not have to deal with that in the future, and that is why I am here.

Dr. Jones: I first began working in autism research before I was diagnosed, but after both of my sons were diagnosed. I had always been interested in the area, but for a long time I stayed away from actively researching autism, because I bought into the prevailing mythology that people instill in you: my personal connection to the topic would make my research less objective and, therefore, less valid. I certainly do not hold that view now, but at the time I took that on board. I took my first tentative steps as an autism researcher after my children were in their teens, because I was just so frustrated with the issues they experienced and the very scientific and ableist body of literature that was available. I started with researching the media representation of autism, then the experiences of autistic adolescents and their families, and this grew to become a much broader body of research. It was not until my formal diagnosis that I began to identify specifically as an autism researcher rather than a researcher who does some autism-related projects among other things.

Dr. Nachman: In my research endeavors, I always recognize the privileges that I carry as a White cisgender male whose societal status as a recent PhD positions me in a powerful role, so my perspective as an autistic person is truly one of many, and I feel it is my responsibility to broaden conceptualizations of who belongs to this very diverse and rich community. Being gay adds another dimension to my work, and that has enabled me to uncover the nuances of “coming out” within both the LGBTQ and autism communities. I grew to study autism in higher education and later to do work related to LGBTQ+ campus climates as a reflection of my desire to be more connected to communities in which I belong, which I did not do much during my youth. My research aims to elevate autistic college students' perspectives that have long been absent from higher education scholarship until more recently, so I consider it a duty to carry my viewpoints of the world alongside those of autistic participants to the forefront of stakeholders' attention, especially because there are sadly very few autistic voices in higher education research engaging in such inquiry.

Dr. Raymaker: I started out on the activist side. Before I had a disability identity, I go back to the old gay rights stuff in the '80s. That is where my activism started. Later I got much more involved in the autistic rights community. I was doing science before then—my graduate work was originally going to be in computational intelligence. Then I started AASPIRE, and I realized that my science could be activism, and I have never looked back. I see community-engaged research as a way of shifting the system.^{13,14} I see it as a form of activism. I see elevating community voices in science and ensuring “nothing about us without us” in science as a part of all of that. I also think that the pragmatic nature of services interventions could have an impact on people's lives today in terms of advancing justice agendas.

Mr. Williams: I think my foray into autism research was almost an accident. I had decided on the path of going into psychology and neuroscience when I was starting out in college, and then as I started to define the scope of what I wanted to do for research, I just found some of these opportunities in the autism research community at Yale. I was drawn to the topic because of the personal connection, and I really never looked back. I think it has been something that has driven me: as with the rest of you, I definitely feel like my work is both impactful on a scientific scale and to really truly improve the well-being of other autistic people. And I would like to think that by combining a scientific career with the community priorities, that will eventually lead to a generally increased health and well-being for many autistic adults—and children, for that matter.

Mr. Dwyer: *Thank you so much for providing those thoughtful reflections, which I especially appreciate because I realize one's identity is inherently a more personal topic than most academic discussions. Zack, your last reflection also provides a perfect bridge into our next question: what value do you feel autistic researchers bring to your area of autism research?*

Dr. Acevedo: As someone who uses critical pedagogy to decenter dominant epistemologies in the classroom, it has been rewarding to use autoethnography to document how autistic embodiment, which Yergeau¹⁵ describes as “cunning” while astutely reclaiming the term, can truly transform a learning space and a community of learners. Autistic “motioning” (another of Yergeau's terms), which I describe as a form of “neurosomatic expression,” interrupts expectations of linearity and disrupts the focus on productivity that characterizes neoliberal education (as an exchangeable good—“what can this degree buy me?”). This of course comes at a cost for gendered and racialized faculty like myself.

Mr. Grapel: In general, I think that the obvious benefit that autistic researchers have to autism research is just more actual lived experience with autism and consequently being able to understand, instead of viewing autism from the outside looking in. This lived experience can, as Zack was saying, help us figure out how the research that we are doing can help autistic people fit more easily into and be more helpful citizens in the communities we live in. It creates more

of a chance to genuinely contribute to improving quality of life for autistic people. How will what we are studying actually improve our lives in the ways that we see as being valuable? Because what the general world considers important for living life is not necessarily what we want out of life.

Dr. Nachman: 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 beauty in the autism community is its vast diversity in viewing, processing, and relaying new knowledge about the world. Autistic researchers are necessary in higher education scholarship because they provide a distinct stance on issues facing marginalized communities, particularly in relation to helping scholars further disentangle often singular understandings of disability. Through more of us having a more salient role in academia, we can interrogate neurotypical norms, offer a platform for individuals whose perspectives have far too long been overlooked, and provide mentorship for the next generation of autistic scholars.

Dr. Jones: I think that autistic researchers bring a variety of strengths to any area of research, not just autism research. All of the autistic researchers I know are extremely focused on, and very passionate about, their areas of research. They want to know everything there is to know about the topic; they are committed to doing the most comprehensive and high-quality research; they have terrific attention to detail; they are perfectionists. They bring lots and lots of strengths and value. In relation to autism research specifically, I think they also bring a breadth of knowledge about autism that is not found in books, and an insight into areas that are under-researched or poorly researched. They also have a genuine awareness and acceptance of the fact that every autistic person is different, and that everyone has strengths to contribute, not just challenges to be addressed. Unlike many nonautistic researchers doing autism research, they have a commitment to truly inclusive autism research that sees autistic people as collaborators, not just as test subjects.

Dr. Raymaker: Everybody has made some really great points, but I particularly agree with what Sandra just said. I would also add that I think autistic researchers are able to develop better and more effective research designs because we understand the relevant access needs and community priorities. I think that leads to better data collection, better samples, and better research questions. Because of the insights we bring with us, we are in a position to do better research.

Mr. Williams: Like Dora, I think that most of the points that I would have made have already been made by everyone else, though I do think one thing that is particularly worthwhile is the ability of autistic people to, in many cases, become the researchers themselves rather than simply being community partners. Yes, having lived experience is good and certainly contributes to the research endeavor, but I actually think that the most valuable lived experience is that which is combined

with a traditional education in a given field. That can allow us to then question some of the norms in those fields and use new language to actually move the fields forward toward a set of questions and principles that are more in line with the autistic perspective, as it were.

Dr. Brown: I really agree with what Zack just said: the idea that autistic researchers have, much like our indigenous colleagues, a foot in both worlds. We understand the values and the traditions of our disciplines and we understand the lived experience of being autistic. Living as an autistic neurodivergent brain in a world dominated by neurotypical brains is often difficult. Our intense interests, our ways of thinking, and our behavior are often interpreted under a neurotypical lens, which at best means that our behavior is misinterpreted and it often leads to psychological harm.¹⁶ Thus, my autistic brain enhances the quality of my research, because I am much less likely to misinterpret the intentions behind the behaviors of my participants.

Dr. Acevedo: Perhaps we can all agree that autistic people embody resistance just by virtue of existing? Staying alive in a world that has tried to erase us from the human pool is truly revolutionary. That is precisely why our role is invaluable in reclaiming and actualizing our own stories so that we may decenter the epistemic monopoly that nonautistic professionals have historically held over our *embodiments*¹⁷ experiences.

Mr. Dwyer: *Thank you all for describing those numerous different ways in which our presence could enhance the field of autism research. Sara, your last comment about our survival in a world dominated by nonautistic people also provides a perfect bridge into our next question: do you think that there are tensions or conflicting expectations and goals that can particularly affect autistic researchers, especially given that the autism research field has been predominantly shaped and inhabited by nonautistic researchers?*

Dr. Acevedo: I am often asked for resources about—and I quote—“ASD” in various spaces. This is of course unpaid labor that comes with added microaggressions that begin, but do not end, with wording and terminology choices. My responses, depending on context and on how comfortable or safe I find myself in those situations, often touch on our community’s language uses and choices. I make it a point to explain that generally, although not always, neurodivergent activists and scholars tend to refrain from using the language of disorder. It does not really align with our views, ideologies, or cultural approaches to neurodiversity, which is considered an integral part of the human experience. As a bonus, my comments always include a list of sources to encourage independent research that does not bank on the intellectual and affective labor of an oppressed group. I guide people to survey literature coming from either critical autism studies or critical disability studies, if they wish to truly learn from our own process of knowledge production and overall cultural kinship systems. Mind you, the topic of autism, theorized by autistic scholars—which is fairly new due to the monopoly of the medical and therapeutic establishment over our lived experiences and ways of knowing.

Mr. Dwyer: *Thank you. I suspect that many people here have similar experiences of being asked to provide our insights as additional unpaid labor. I certainly have, and yes, I am seeing several of our panelists nodding in agreement.*

Mr. Williams: As someone who primarily works in the biomedical field and in a clinical program, I think I do encounter a lot of the medical model, and I am probably a bit more tolerant of it than many of autistic people. I do think generally that it is very interesting to see how researchers over the past several years who have listened to the social justice movements of autistic people have tried to incorporate neurodiversity principles into what is still relatively a medical model-heavy field. Indeed, I really think that we are in a point of transition right now in many of the more psychological brain sciences. On the one hand, many people are still engaged in traditional research, that is, “Let’s look at cause, prevention, cure,” but I also think many more people have now shifted toward asking, “Okay, what are the actual outcomes that matter?” developmental milestones, quality of life, etc. In some ways the tensions between these two different research agendas seem to reflect differences in the goals of many younger early career professionals versus the goals of older established professionals.

Mr. Grapel: I agree with a lot of what Zack said. I am definitely noticing much more of a shift away from a cure and more toward effective treatment. For example, one thing that I really love about my laboratory is that I have not personally experienced a lot of tension in terms of cure versus where we practically go from here, because I feel like many people are starting to understand that the idea of a cure is problematic. What would “cure” actually mean? What are we curing? So the goal is not necessarily about trying to get rid of the autism. It is about figuring out what things about autism are actually problematic for executive functioning and daily living, and how to train and teach the skills necessary to live without sacrificing the things that make your autism an advantage.

I will also say, and this might be a slightly unpopular opinion: I have never been a huge fan of the way that some people tend to focus on identity and specific language. I can see its value in terms of people and how they view themselves and how they talk to each other, but as an autistic person in a research laboratory, there have been occasions where I have been asked how I feel about a certain language that is used, like person first versus identity first versus all the other different ways we could write about autism in the article. Every time that question comes up, it kind of bugs me because I get that we are trying to be respectful, but it seems like it is detracting from the research we could be doing to actually improve people’s lives. It feels like that kind of stuff can come later. But I do not know. I am sure that there are people who disagree with me.

Mr. Williams: Jordan, I tend to feel the same way. I have definitely seen some people dismiss entire articles because of their use of language rather than their scientific merit, and that bothers me.

Dr. Acevedo: My view is that language is a technology of power that works to create compliance and homogeneity.

Everyday language use is not exempt from the logic of normative social arrangements built on multiple exclusions. Discourses that sustain said arrangements manifest through practices and policies that affect our lives in very tangible ways. I am very interested in challenging the idea that language is not as important an issue to address.

Mr. Dwyer: *I think it is definitely okay for us to disagree and have friendly controversy and debates between ideas.*

Dr. Brown: I agree! There are important points on both sides.

Dr. Acevedo: Yes, absolutely! And the fact that we do not agree about everything reflects our plurality as autistic people and as researchers.

Mr. Grapel: I would not say that language is not important. I would just say it is not the most important thing, especially when we are talking about research that can affect people’s lives.

Dr. Acevedo: Materially speaking, language affects people’s lives, though. To clarify, I did not mean to suggest you said it does not affect people’s lives, but rather that it is a common argument that people express by saying we have “bigger fish to fry,” and I simply disagree with the idea that language orbits outside other systems of oppression.

Mr. Grapel: Yes, but I would argue that effective research has a larger impact in people’s lives, and I would personally rather see an article with an outdated term make it to publication than see an article be killed because of the language when it has got strong merit and can help people right now. I have seen articles stalled for that very reason and it is infuriating to me.

Dr. Acevedo: I respectfully agree to disagree.

Mr. Grapel: Agreed.

Dr. Nachman: I will also follow-up on what Jordan said. Personally, I tend to not get as offended if someone uses person-first or identity-first language to describe me, but I also believe it is important to recognize that there are many nuance and other factors playing into how other individuals want to be described. In the work that many of my colleagues and I do, I think it is important for us to try to position the individual in the autism community to directly share, in the research study, how they would like to be identified, so we can use their wording. Crucially, this includes trying to erase deficit-based framing of autism. It goes without saying that everybody who is part of this panel is an advocate for wanting to discuss autism in a strengths-based format, and I would also add we have to recognize that everything is contextualized. Much like any identity, any experience, or any opportunity, there are both challenges and opportunities, and I think looking at this holistically is extremely important to illustrate the complexities and true richness of being a member of the autism community.

Dr. Jones: I think there are dozens of tensions and conflicts, but due to time, I will just mention three.

First, the primacy of nonautistic researchers in the minds of universities and professional organizations can make it very difficult for autistic researchers to secure funding for research that is not aimed at treating or curing autism, but rather at addressing societal and environmental barriers.

Second, I think that many researchers experience frustration working with colleagues who have been trained by the system to use language and perspectives that we might find offensive, and that creates this constant conflict—and others have touched on this—between: Do we openly challenge them, which a lot of the autistic community wants us to do, but which could risk ending the collaboration? Or do we accept where they are coming from and slowly work to educate them, which leaves us quite open to criticism from others in our community that we are allowing the problematic terminology and perspectives to continue? I think that is a real conflict, and certainly one I experience.

But for me, perhaps the most significant and disturbing of the conflicts within our community is that I see many autistic people and families of autistic people who are deterred from asking questions or participating in groups or activities because they are attacked for using the wrong terminology or expressing a nonmajority perspective. And that prevents them from interacting. I think we already face so many challenges from those who do not have any lived experience of autism without battling each other.

Dr. Raymaker: Everybody said such important things that I am just going to respond to just a couple of thoughts that you all made me think.

First, getting back to what Sara said about our embodied presence, and how our being here can help break down some of these ableist structures—even the things that we have to do with the IRB (institutional review board) to include autistic collaborators butt up against ableist systems—the fact that we exist and that we have these needs is going to make the rest of the field change to accommodate us and make room for us for what we are doing. That makes this tension between us and the institutions of academia a good one, with potential for positive change. I am not sure whether I could say anything here better than Sara, but I very much agree with that.

I also wanted to return to the conversation about language. A decade ago, the ARC refused to give our recruitment flyers out because we had used identity-first language that the autistic community wanted, so we neutralized all of our language for a while—person on the autism spectrum. But our work, the science, gets disseminated back out into the autistic and broader communities, so although it might not seem like making concessions in one place matters very much, if we actually want to make change, it matters. I think that we have a role in making social justice happen, so you cannot draw a clear line between where the science ends and where its impact on society begins.

Dr. Brown: I agree with many of the points that have been made so far. I often feel a great deal of anxiety about trying to ethically balance the needs of the autistic individual and autistics as a group; and the needs of parents, families, educators, clinicians, and the wider community; while also needing to meet the rules, regulations and financial constraints of policymakers, funding agencies, and governmental organizations. Another tension that has been quite difficult

for me to navigate in academia is the need for self-promotion and having a public persona. I am quite introverted and I have a great deal of social anxiety because I was bullied throughout high school for being different. As a result, intense flashes of shame often crash through my nervous system whenever I notice that my behavior *might* be interpreted as odd, rude, or socially naïve. To cope, I try to mask my differences and appear just like everyone else. The use of compensation and masking strategies, also known as camouflaging, is often used by autistic people to blend into their social surroundings by mimicking the behavior of others.^{18–20} However, it is incredibly draining to continually suppress obvious autistic traits and mannerisms (like fidgeting, pacing, or stimming) or to pretend that everything is fine when the sensory environment is impossible to tolerate.

Mr. Williams: One point that I wanted to bring back that I think is a very very important one is that Sandra was talking about the sort of infighting in the autistic community and even autism communities in general. There are many people in these communities with very different perspectives and very different lived experiences who all get together and for the most part argue about things via the Internet. And I think that in many cases, the animosity that comes between these different factions of people with varying opinions can often make the autistic spaces or these autism-focused spaces somewhat hostile. And that can be problematic. I do not know that this really extends to research, just because I think that many folks in academia have a level of professional decorum that has been instilled in them: you know, if you are going to ask a snarky question, you do it as a comment after someone's talk. But I think that generally, nevertheless, there are still kind of these undertones of, "Oh, I dislike this person at their base level, and this infuriates me, and I want to destroy their work" underneath a lot of disagreement.

Dr. Raymaker: I agree with the concerns about internal infighting, but there is another tension related to the community that I feel all the time, which is a need to do right by the community. I have very strong feelings around needing my research to actually do right by my own community. This can sometimes make me terrified, actually: I worry that if I mess something up, I am betraying what I care about and the people I care about. I think that researchers who are not also members of the community do not feel that as much. The intensity and impact of these feelings are another important dimension of community-to-researcher tension that I feel.²¹

Dr. Acevedo: I totally agree with you, Dora, and I just want to piggyback on what Zack was saying before. I completely agree that there is a tendency toward hostility in online activist spaces to the point that I have left these places entirely, and I know of many others who have done the same; gatekeeping is certainly an issue and it happened to me personally when I first joined what I thought/hoped would be community-building spaces. I do not mean to say there should be no room to discuss across different perspectives and experiences because those are necessary to cultivate plurality within our communities. What I encountered often, however, were plenty of interactions based on *ad hominem* attacks against people whose views differed from more commonly held views or shared stances. Some argue that

interactions of this nature are fueled by trauma and, although I certainly agree with that, I neither condone perpetuating personal trauma nor thrive in that type of online culture. The fact is that our community deals with so much external pressure already that the infighting is simply detrimental to our common goals and political agendas. Overall, there is certainly a need for understanding and recognizing that we are plural and that we espouse multiple and often conflicting views, but I do not think that those differences should be weaponized within our communities and against each other.

Mr. Grapel: I just want to very quickly piggyback on what Sara was saying to point out, yes, there is a lot of diversity in the group in terms of both online forums and reality in the real world, and I feel like it is important that we also mention that we are all coming from a place of privilege within our own community, insofar as we are able to even be here working in research and able to actually communicate effectively how we feel. That is, frankly, a luxury that not everyone with autism has, and I think it is really important that when we do talk about the society and the community as a whole, we remember that there is a whole subset of the community that cannot really, as of yet, speak for themselves. I do feel that we have a bit of an obligation to those people to try and help to get them what they need to become their own self-advocates.

Dr. Jones: I want to jump back to the point Dora made earlier about IRBs. For me, one of the biggest conflicts or tensions I find is between our desire to do studies that are informed by authentic autistic voices, and an IRB's perspective is that this is a vulnerable group that we have to protect. There is a tension there because it can be so hard to get a study through an IRB that is about actually talking to people. It seems to be easier if you want to put electrodes on their heads. But if you want to actually have a conversation with them, talk about their experience, you risk feedback like: "Oh, this is a very vulnerable group. I don't think you should do that... I think you should write a participant information sheet that's written for a two-year-old, because otherwise they won't understand it." And I think that is a tension that needs to be resolved, so that our voices—all of our voices—can be heard. We need to make sure autistic people are able to actively participate in research: that we are not protected by IRBs so much that we are actually silenced.

Dr. Acevedo: That is so real, Sandra. It happened to me with my dissertation, which was a collaborative emancipatory research-based study.

Mr. Dwyer: *As somebody who sometimes puts electrodes on people's heads, yes! I agree there is truth to what you say, Sandra. And that important point, along with all the thoughtful insights brought up by the panelists, emphasizes that there are many tensions and issues in our fields we need to address. This leads to our next set of questions: What do you want your field to look like 20 years from now? What things would you like to be different? What needs to happen for your vision to become a reality? Are some of these changes already occurring?*

Dr. Acevedo: Institutional and structural changes and reducing ableism in academic settings: these two are inevitably

intertwined. Performative diversity under neoliberalism: there is a lot of virtue signaling and very little infrastructural and cultural support for the "diverse" faculty that are brought on as a sign of good will and benevolence (charity model, anyone?). This illusion of plurality, which is actually used to fulfill a "diversity quota," is not only culturally divisive, but also materially precarious. I want to crush the idea of "diversifying" the workspace or the research community—we are already diverse, so this is a neoliberal ruse to keep us distracted from the processes of sanitation and exclusion that actually come before this focus on what Mitchell and Snyder call "inclusionism."²² I am a disability justice activist and the way in which QTBIPOC [Queer, Trans, Black, Indigenous People of Color] activists have reimagined the term and the practice of access is truly an act of love as Alice Wong, Sandy Ho, and Mia Mingus have explained.²³

Mr. Williams: I think one thing that I would really love to see is the space being made for autistic people to come to the table even if they do not have academic credentials on equal footing with the researchers. I think that people who are doing community-based participatory research such as Dora et al. are obviously leading the way in this regard, but it is still very much a niche thing within autistic research. 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. That could be very useful. And of course, there is always this suggestion that, oh yes, basic science may lead to things down the line that you do not yet know or think are important, and that has merit as well. But overall, I do think that in many cases the consideration of community priorities as research priorities is becoming more standard for autism researchers, and I hope that the field continues to do that over the next 10 to 15 years or longer.

Mr. Grapel: I really resonate with what Sara said, and I want to expand on it. I think she really hit the nail on the head, that this neoliberal idea of "more diversity equals more progress" is really this self-defeating problem. If we really want more diversity in the field of autism research, if we really want more autistic people in the field, then what we need to do is, as a community, have better autism research. Better autism research will lead to better understanding of autism, better treatment of the parts that actually do make it difficult to succeed, and a better understanding of which of those things are socially constructed and thus not areas in which we should be trying to change autistic people. That will, in and of itself, allow for more autistic people to become autism researchers. Ultimately, in response to, "what do I want to see from the field," I most importantly want to see actual progress for autistic people autism, and I think that to get there, we need more consensus among researchers on what we are actually trying to do. We spend so much time arguing about what things mean and politicizing everything, and it makes it hard to just agree on what we are trying to do—which is how we could figure out what works.

Dr. Jones: I would like to see a landscape where all autism research includes collaboration with autistic researchers and

autistic communities. In my ideal world of the future, I would never again read a journal article written by an autism “expert” that reports on a research study that was no benefit to autistic people and potentially harmful for autistic people. What I would not like to see, but seems to be very common at the moment, is token inclusion of autistic people, as Sara mentioned. It is not about ticking a box that there is an autistic person on the team. It is about recognizing that autistic people bring unique strengths and insights to the research, whether that is research on autism or research on aerodynamics or butterflies. We actually bring things beyond just ticking a box.

Dr. Raymaker: I really resonate with what Sara said, and I want to give an example. I was having a discussion with a colleague just the other day about this: about the structural changes that are necessary. We were talking about comprehensive examinations as an inherently ableist structure if what you honestly want to get at is: “Can this person demonstrate a deep and intensive level of competence?” Why is the comprehensive examination the only way to do that? Cannot we offer multiple ways of assessing competence? For example, skills demonstrations. And so when I look to the future, I would like to see structural changes like that throughout the system, where we start thinking about: “How is what we’re doing making assumptions about a particular way of being, instead of getting at what we actually claim to care about?”

And then the other thing that I want to see in 20 years is more of us! An exponential increase in the number of autistic autism researchers in all fields.

Mr. Williams: More than just increasing the number of autistic autism researchers, I want to see more autistic people *wanting* to be autism researchers, clinicians, and service providers. These are the career paths with the most direct impact on the lives of autistic people, and if autistic people do not feel comfortable or welcome working in these areas, there will forever be a significant disconnect between research, clinical practice, and the goals of the autistic community. The field of autism research has become a lot more welcoming to autistic people over the past few years, but there is definitely a long way to go to bridge the gap between researchers and the general autistic activism community.

Mr. Dwyer: *I greatly appreciate Dora’s point about inflexible requirements that are not tied to what we really ought to care about. Building off what Zack says, I also feel like there is some pressure right now for autistic scholars to go into autism research because in some ways it is easier to be “out” here than in other fields. So I would hope people can want to be either autism researchers or researchers in another field.*

Dr. Brown: I agree with the points that many of my colleagues have made, especially Dora’s. I would like to see more autistic researchers leading studies intending to study some aspect of autism. And like many of us, I would also like to see more research aimed at improving the overall well-being of autistic people and their families. Increasing the number of autistic researchers would mean that more autistic adults would be directly involved in the production of

knowledge about autism, knowledge that is about them,⁷ which would, in turn, lead to the use of less harmful and stigmatizing discourse and language about autism. The production and dissemination of more accurate knowledge about such a misunderstood group will help change the current narrative of tragedy, pity, and fear to a less harmful and stigmatizing one that showcases autistic strengths and potential. Indeed, another big difference is that there would be a larger focus on these strength-based approaches. To take education as an example, strength-based education begins with educators discovering what their students do best, and then helping their students leverage personal strengths while learning new or difficult things, so that their students “can reach previously unattained levels of personal excellence.”²⁴ This strength-based approach is a paradigm shift; it is a movement away from a deficit-based approach and it focuses on identification of weaknesses and remediation of deficits.²⁵ Empowering autistic researchers and the broader autistic community to direct autism research ensures that the resulting research will be grounded in a strength-based approach, even when the focus of the research is the challenges associated with autism.²⁵

Dr. Nachman: What more can I say that my colleagues have not said already? I think that I would further push on the point of representation mattering. We need to bring intersectional identities to the forefront, and not just from a tokenistic standpoint but rather from a fully contextualized perspective of the members of the autism community that encompass our world. I hope that goes without saying, but it is certainly important. We need to value the diversity of expertise and knowledge found throughout the autism community. There continues to be some pigeonholing and stereotyping in terms of what individuals’ skill sets and strengths are, and I think we need to recognize that, of course as with any other community, strengths are multifaceted, very rich, and often very nuanced.

What do I think needs to happen, in terms of our environment having a greater autistic researcher presence? I think in terms of my field of higher education specifically, we need our colleges and universities to really be transformed to truly value autistic perspectives. My recommendations for implementing structural changes really stem from the research that I and my colleagues work on: everything from having more inclusive teaching strategies embedded in curriculums in the classroom that enable autistic students to showcase their strengths (and, like my colleagues here today, across many different disciplines), to really offering campus-wide seminars and panels featuring autistic students, who we are learning *from and with*, as opposed to talking *to* and communicating *to* the community. I feel like increasing our collective visibility and supporting strength-based programming better position autistic students to attain their goals. It even makes us more likely to explore graduate school and to pursue similar work to that I and my colleagues here today engage in. If I were to quote a favorite Disney song, “There’s a great, big, beautiful tomorrow just a dream away,” and I feel like we are among the trailblazers and our contemporaries can help shape that vision.

Mr. Grapel: Was that from *Carousel of Progress*?

Dr. Nachman: Sure was, Jordan!

Dr. Jones: What needs to happen: I think academia needs to be a lot more supportive of autistic people. That means being willing to make the environmental, structural, and social changes that enable us to survive and thrive in the university environment. I can see some of these changes coming, but not at the scale or speed we need them to. There is a lot that our nonautistic colleagues can do to support us, but only if we actually educate them on what these things are: simple things such as putting dimmer switches on lights; limiting the number and duration of meetings; not having meetings in noisy cafés; understanding that we are 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. I think there is a lot. I think there is also an onus on senior researchers in the field, though, to drive those changes. It is a lot easier to be brave and vocal when you have tenure and you are at a certain point in your career. And I think that autistic researchers should be mentoring and supporting junior autistic researchers and research students and those who aspire to become autistic researchers.

Mr. Grapel: Yes, Sandra! On that same note, those obligatory meet ups during the interview process that they say are optional but that we all know are not.

Mr. Dwyer: *I think Sandra's answer really resonated with everyone, judging from how it was accompanied by strong nonverbal signs of agreement—vigorous head nodding—from many of us. Thank you so much Sandra and everyone else for drawing attention to so many areas where our fields have a very real opportunity to improve.*

We do have one final question, which I am afraid may fall into the perennial theme of, “You are the autistic voice and we are therefore imposing on your time and energy by demanding that you should share your insights with the non-autistic people.” Sorry in advance about that, but here is the question: what would you most like nonautistic autism researchers to better understand about autism?

Dr. Acevedo: I teach students in the applied professions, and it is pretty challenging to introduce critical disability study theories and methods to students who have spent several years learning about disability (without disabled people) from a deficit or biomedical perspective. I do observe incredibly rewarding shifts in perspective, but again it is evident that students face plenty of personal and professional challenges when first encountering critical disability studies and critical autism study perspectives that fundamentally counter their very core of their fields. There is this fear, I think, of relinquishing the idea that not all efforts framed as “inclusive” are actually beneficial or just and that in many cases they are harmful. They might feel concerned with the thought that to bring a critical look into their field is some form of “betrayal” while others might experience anxiety as they learn that something (a practice/ideology) that they believe in so passionately carries a deep history of harm against disabled people. Ultimately, my hope is that they experience some paradigmatic shifts as they perceive dialoguing with us

(disabled educators and peers) in terms of acceptance and epistemic expansion, rather than a threat to their sense of personal and professional identity.

Mr. Williams: I really do have to agree with what Sara said, and I also think that in general, beyond just listening and dialoguing with autistic people, people need to treat us as peers and as equals. We do not have to be right, and we do not have to have the final word on everything related to autism; we just have to have a seat at the table. In fact, instead of nonautistic researchers deferring to my point of view because I am autistic, I *want* to be challenged. I want my ideas to be held to the same standard of academic rigor as everyone else's, and if people disagree with me, I hope they feel comfortable doing so. I know that my ideas are not going to be right all the time, and it is most important to me that these ideas become part of the larger discourse of autism research. I feel that I have been able to contribute in this way pretty well so far, but I think that it is a lot harder for many other neurodivergent people. 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.

Dr. Acevedo: I want us to *build* the table.

Dr. Raymaker: The shape of the table needs to change too. Maybe instead of a table, a field of flowers?

Mr. Grapel: One thing I would like nonautistic researchers to learn is that autistic adults exist, and we need to have more studies wherein we look at their experience and everything that happens after graduation. I am really proud of Duke, because they are already getting on this, but there are so few studies on outcomes; it is all about early development, which is very important, but I think we need to broaden where we look. In the same way, 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 is easier to collect data from them. All that means we are missing a huge big picture, and I think I would like my nonautistic peers to get to figuring out how we are going to account for that and actually learn about the entire population.

Dr. Jones: When my son was in high school, he wrote a book of short stories, and the title of that book sums up everything that I want nonautistic autism researchers to understand. The title of his book was *Don't Fix Me: I'm Not Broken*.²⁶

Dr. Nachman: I am glad to be living in a space where there are richer conversations about autism in the higher education research pool that I occupy; it is relatively novel. For me, it encourages me to see more scholarship on autism in higher education. I work closely with people—my colleagues and coauthors—many of whom are not autistic, and what I value is openness to listening, learning, and being humble, and the recognition that we are in a constant process of learning and unlearning things. Even as a member of the autism community, my conceptualizations continually change, so I think what I would encourage nonautistic autism researchers to do is to actively engage with members of the autism community and also to really interrogate their own institutions. They

could use the privileges and roles that they hold to be agents of change to further support the aspirations and potential of autistic researchers.

Dr. Brown: I would like nonautistic researchers to understand that my subjective experience is real. Gaslighting occurs when you tell me that my reaction is out of proportion to the event. But in that moment—given how my brain and my body and my mind are responding to the stimuli in my environment—given my history, my trauma, and my neurological differences—in that moment, my reaction is perfectly in line with my subjective reality. So, if you truly want to help, then teach me how to find the calm in the eye of my chaos while fully acknowledging all of the causes beyond my control that put me there.

Mr. Dwyer: *I wish I could yell what Heather just said at my middle school teachers! That is a powerful final thought to end our discussion.*

Thank you so much everybody for contributing such rich, actionable, penetrating, and nuanced insights in today's discussion. I think this roundtable will be very valuable to the field of autism research, so I deeply appreciate your time and your perspectives.

Mr. Dwyer: To summarize some of what we have heard in this discussion, we began by discussing identity. You all clearly expressed that your identities—autism and sometimes other intersectional identities—give you a personal connection to your research. You rejected the idea that this connection is a source of bias, pointing out that everyone has biases **and that personal connections to research can be of value both for scholarship and activism.**

Indeed, you described numerous different ways in which autistic autism researchers can enhance the quality of autism research:

- Although you acknowledged the diversity of autistic people's experiences and the privileges we enjoy as researchers, you also pointed out that **autistic autism researchers are uniquely well positioned to combine experiential knowledge with academic knowledge**—and, I would add, with knowledge of frameworks autistic people in the community use to understand autism, such as the concept of autistic burnout that Dora brought into academia²⁷—**in ways that can lead to critical insights.**
- You pointed out being autistic can **give us insight into important, yet neglected domains**, such as topics relevant to autistic quality of life. Relatedly, you pointed out that autistic researchers are well positioned to **challenge widespread harmful misunderstandings** of autistic people.
- You also noted that our insights as autistic people can help us understand how autistic participants will engage with research studies, **allowing us to develop more accessible, relevant, and methodologically sound projects.**
- Some of you commented that being autistic **can help us connect with autistic people in the community.** Our empathy and shared autistic identity can help us foster trust and build collaborations with community partners.

- Moreover, you noted many autistic people can have important strengths that can be useful in research generally: **our attention to detail and our passionate focus** on our interests.
- At the same time, you noted that our presence in the research field could help **challenge the competitive productivity-oriented culture of academia.** This could benefit many scholars, including but not limited to neurodivergent, gendered, and racialized academics.

Furthermore, you drew attention to numerous tensions and conflicts that we face as autistic autism researchers:

- You pointed out we can feel a **deep sense of obligation and responsibility toward the needs of the autism community, which can put us in the difficult position of being torn between following community preferences, maintaining collegial and collaborative relations with other autism researchers, and adhering to the requirements of institutions such as funders.**
- You also drew attention to **conflicts, hostility, and demands for conformity within the community**, especially online, which can make it difficult or dangerous to engage with the online community as we would like to. Although you embraced the diversity and plurality of the autism world and expressed the importance of hearing from marginalized populations, you felt the conflicts and hostility that so often pervade our communities prevent us from working together on shared goals.
- These community tensions relate to **language and terminology**, where some of you disagreed in a way that emphasizes the diversity of autistic perspectives. On the one hand, some of you pointed out that **terminology conflicts** can distract us from other important issues relevant to quality of life in autism. On the other hand, some of you emphasized that **language and identity are important and related to power and oppression.**
- Moreover, many of you commented on tensions between research agendas grounded in the medical model and those grounded in the neurodiversity approach and the practical needs of autistic people. Although you felt we are gradually seeing more research of the latter variety, you pointed out that **powerful forces, such as funding mechanisms and senior researchers, often favor medical model-aligned research.**
- You also drew attention to ways in which **inflexible institutions and practices**, such as IRBs and qualifying examinations, can impose barriers that restrict autistic involvement in academia. (Isn't it ironic how inflexible neurotypical society can be, despite the traditional focus on autistic inflexibility?) Furthermore, you warned that pressures to self-promote **can lead neurodivergent academics to camouflage** in exhausting and potentially harmful ways. On a more positive note, you also pointed out that the involvement of autistic people in academia can help us confront these barriers and challenges.

Indeed, you articulated attractive and compelling visions of ways in which the autism field can improve and address contemporary tensions and challenges. You suggested:

- **Expanding involvement of autistic people—including those with intersectional identities—in autism research as both scholars and as community partners.**

You suggested funding incentives could encourage this involvement. Although you emphasized that such involvement must be meaningful—it must not be performative ticking of diversity checkboxes—you described how meaningful involvement could challenge widespread misunderstandings of and stereotypes toward autistic people.

- **Making autism research more strengths based and better aligned with community needs and priorities.** This could help bridge gaps between community members and researchers, increasing community trust and confidence in research.
- **Reforming academia to make institutions and practices more inclusive,** such as using more inclusive teaching strategies, finding alternatives to qualifying examinations, considering sensory accessibility, and generally taking a more flexible and empathetic approach. You said that senior faculty in positions of power have a responsibility to drive these changes. You also emphasized the importance of providing opportunities for campus communities to hear the perspectives and insights of autistic people.

In that vein, you provided some very important insights and advice for readers who want to better understand autism:

- **First, to be open and receptive to learning.** You said it is important for people to be open to criticizing traditional or dominant theories and institutions in their fields. This includes being willing to acknowledge harm.
- **To treat us as equals and peers,** who might or might not be correct about something, but whose opinions and insights deserve respect and consideration.
- **To recognize the full diversity of autism, including understudied and marginalized populations** such as autistic adults, those with intersectional identities, those with intellectual disabilities, and non- and minimally speaking individuals.
- **To have empathy for and validate our subjective experiences,** especially when our neurodivergence and past traumatic experiences lead us to become overwhelmed.
- **To refrain from assuming we need to be fixed.**

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P.D. and D.R. planned the roundtable. All authors participated in the roundtable discussion. All authors edited and approved the final manuscript. The content is solely the responsibility of the authors and does not necessarily represent the official views of any of the funders.

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