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Being, Knowing, and Doing: Importing Theoretical Toolboxes for Autism Studies

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Abstract

The aim of this article was to think with and elaborate on theories developed outside of autism research and the autistic community, and through this support the production of new autistic-led theories: theories and concepts based on autistic people's own embodied experiences and the social worlds we inhabit. The article consists of three different sections all of part of the overall umbrella, *Being, knowing, and doing: Importing theoretical toolboxes for autism studies*. In each section, we import useful concepts from elsewhere and tailor them to autism studies. Throughout, we mingle our own autoethnographic accounts and shared discourse in relation to research accounts and theories. Illustrating *being*, we explore and discuss the possibilities of critical realism in autism studies. Illustrating *knowing*, we explore and discuss the possibilities of standpoint theory in autism studies. Finally, illustrating *doing*, we explore and discuss the possibilities of neurocosmopolitics including epistemic (in)justice in autism studies. Our proposal here is for an epistemic shift toward neurodiverse collaboration. We are inviting nonautistic people to work *with*, not *on*, us, aiming at to make autism research more ethical, breaking down bureaucratic structures, and questioning poor theory and shoddy methodology. Acknowledging intersecting axes of oppression in which an individual seeks to renegotiate and reimagine what it means to belong also means to understand what needs changing in society, as it is and how we might do things differently.

Keywords: neurodivergent, autistic-led theories, knowledge production, epistemic justice, critical realism, standpoint theory

Community Brief

Why is this topic important

People are starting to realize that good autism research should include autistic people (as researchers, participants, co-designers, for example), which means working in neurodiverse teams (teams that include autistic and non-autistic people). So far, a lot of ideas that researchers have had about autistic people have said that they (we) are impaired, which is hurtful and can make it hard to work together. If we are going to create better research, and better spaces to do research in, we need to find new ideas and ways to work. It is important that these new ideas are based on how autistic people see themselves and the world around them (us).

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What is the purpose of this article?

In this article, we (a group of neurodivergent researchers) look at how we can apply ideas about how knowledge is made, how we use knowledge, and how knowledge impacts people, to creating better autism research. We use ideas from philosophy and think about how they can help us to share our experiences with each other.

What do the authors suggest?

We start by exploring how a theory called ‘critical realism’ can be used to understand differing autistic experiences, by taking into account how our identities and experiences are shaped by different social environments and affect we think about the world. Next we apply standpoint theory, which looks at the importance of acknowledging the impact of a researchers own identity in research. Finally, we explore ‘neurocosmopolitanism’, which hopes for a future where our differences can be celebrated and accepted. We also think about ‘epistemic injustice’, where research that is done ‘on’ instead of ‘with’ leads to inaccurate or harmful knowledge about us. We argue that by applying ideas such as these to autism studies, we can create spaces where fair and just autism research is created. We argue that these ideas will help both autistic and non-autistic researchers to understand each other better, because they are based on what it is like to be autistic, and not what being autistic looks like to non-autistic people.

What do the authors think should happen in the future?

The authors think that more researchers should think about what they say about autistic people. Autistic people should be recognized as the people with the most knowledge about what it is like to be autistic. We think that this will create a kinder way of working for both autistic and non-autistic people and research will be more useful and ethical.

How will this study help autistic people now and in future?

This research will help autistic people in two ways. First, it will make sure that autistic people’s ideas and experiences will be taken more seriously by non-autistic colleagues. Second, it will lead to better autism research, benefitting autistic people who are not just researchers. This is because the ideas will be more closely related to the experiences of autistic people, instead of outside interpretations of what it is like to be autistic.

Background

FERGUS MURRAY¹ HAS NOTED, “for non-autistic psychologists, there is no lived experience of autism out of which to build a theoretical model and so experimental data have to come first. This could be another reason why autistic-led theories, drawn at least in part from internal observations, struggle to make a big impact in mainstream research.” The notion of autistic-led theories, and concepts and theories developed “part from internal observations” refers to a rapidly developing academic sphere. Among the more frequently cited are the theory of monotropism,² autistic space and autistic sociality,³ double empathy problem,⁴ and flow states.⁵ However, recent autistic autism research has also borrowed and developed concepts initially developed within the autistic community, such as autistic inertia⁶ and autistic masking.⁷

Neurodiversity studies scholars⁸ aim to develop “ways of producing knowledge, ways of looking and talking back to power”⁹ within critical autism studies. The aim of this article is to think with and elaborate on theories developed outside clinical autism research and that are not specific to the autistic community but that may have utility for elevating autistic scholars’ voices. We propose that the theories embrace the inclusion of voices that are otherwise neglected due to intersecting axes of oppression.

It is important to draw on theories outside of clinical autism research because it can foster wider intersectionality, encourage growth in otherwise neglected or siloed areas, and, further, create links to vibrant research communities who have

also struggled with autorepresentations. Through this, we aim to support the production of new autistic-led theories: theories and concepts made and grown from home, based on our own embodied experiences and the social worlds we inhabit.

The article consists of three different sections all of part of the overall umbrella, *being, knowing, and doing: importing theoretical toolboxes for autism studies*. In each section we import useful concepts from elsewhere and tailor them to autism studies. Throughout, we incorporate our own auto-ethnographical accounts, illustrating how writing is itself a way of thinking about neurodivergence collaboratively. The autoethnographic process was unstructured to allow for the different types and ways of thinking and working within this neuromixed group and came from individualized memos and shared discourse in relation to research accounts and theories that we find helpful.

The process was iterative, built on reciprocity, discussion, and done from the ground up. The quotes that appear in the article started as comments or discussions with each other in the development of this article, and are used to illustrate key points, positioning this text as an intersubjective dialogue.

We have chosen to refer to our own autoethnographic voices in the text through the collective “One of us.” This is a way of stressing the text as written in a neuromixed collective space, obscuring the singular “I.” “One of us” is also used as an expression of “joint action,” which feminist researchers Francis and Hey¹⁰ have explained is “core to feminist action over the years.” Joint action provides an opportunity to “counter-narrate” the position of the “individual expert” through the collective voice.

Applying this to the present context, the figure of the “sole” or “lone” neurodivergent is challenged, and collaboration and cocreation are foregrounded as vital components of our methodology. Lastly, joint action provides a level of mutual protection and solidarity from the neuro-normative confines of academia, which we do not experience when writing individualized accounts.

We have chosen to prioritize a small selection of theoretical frameworks, applying them to autism studies, adopting the structure *being* (ontology), *knowing* (epistemology), and *doing* (ethics). The particular theories have been chosen based on our interest-based desires, and what we find relevant to our own study, while not losing the collective focus of the article. Throughout our Zoom discussions and writing rounds, we discovered that the various and multidisciplinary frameworks we each use in our study resonate with each other, especially in their critique of majority discourses. Illustrating the question of *being*, we explore and discuss the possibilities of critical realism (CR) in autism studies.

Illustrating the question of *knowing*, we explore and discuss the possibilities of standpoint theory in autism studies. Finally, illustrating the question of *doing*, we explore and discuss the possibilities of neurocosmopolitics including epistemic (in)justice in autism studies. Although loosely separated by the article’s structure, they are all interconnected/entangled, and, taken together, provide an example of an ethico-onto-epistemology for autism studies.

Being: CR Within Autism Studies

CR¹¹ provides a philosophical position from which to conceptualize and incorporate the many similar and disparate experiences and knowledges that may arise from existing as a particular kind of human in the world. CR posits that an actual material reality does indeed exist; however, reality is more complex than what is often described as the “thin” reality described by positivists (it is not unidimensional). Instead, to critical realists, reality is ontologically stratified and emergent from many layers, which cannot be reduced into one another, but that might jointly constitute or create phenomena or experiences.

These layers are defined as the “real” layer, the “actual” layer, and the “empirical” layer. The real layer is all phenomena, structures, and mechanisms that can generate events. The actual layer is specific events generated by real mechanisms that may or may not be observed. Lastly, the empirical layer is experiences and events that have been measured or observed. What is important is that these layers cannot be reduced or subsumed by one another, even if they are determined by it.

Furthermore, what *is* is distinct from what is or can be *known*. This is knowing (epistemology) is relative to our context, culture, and society, making it transitive and fallible (epistemological relativism). This epistemological–ontological divide means that we cannot access “the real,” only our constructions of it through events and experiences (untying epistemology from ontology, without sacrificing a singular reality). Causality is not reduced to individual entities but, rather, taken as complex inter-relationships mediated by the agency of individuals within such complex systems.

CR identifies distinctive strata to reality, whereby there are levels of explanation that cannot be reduced to each other. As

Kourti¹² highlights, all animals and planets are bound to the laws of physics (with physics being the most fundamental stratum of reality), and yet, physics alone cannot explain all the behaviors of plants and animals. Although lower level (fundamental) strata (physics or chemistry) can have elements tested in experimental conditions with as much outward influence removed as possible (closed systems), the involvement of humans, society, or culture creates open systems (systems open to influence) because of the complexity of reality from which phenomena emerge.

Similarly, epistemic humility is important: we need to acknowledge and engage reflexively on our representations of reality, and with the fallible nature of processes involving the creation of knowledge. This avoids what Bhaskar terms *the epistemic fallacy*—the practice of answering a question about ontology with an answer of epistemology (i.e., conflating reality with measurements of it, without accounting for its fallibility).^{11,13}

Acknowledging this epistemic relativity means engaging in a process of judgmental rationality¹⁴ in determining the trustworthiness of representations—we parse out what we can conceptualize as being more accurate representations of reality and what evidence is required of that claim. For example, making a claim about what it means to be autistic cannot necessarily be answered by research methods that center upon the experience or lens of nonautistic people. Both quantitative and qualitative explorations are key to building a full understanding of a phenomenon, and each can only answer certain questions that jointly provide a fuller more comprehensive image.

For autism research, quantitative large-scale data can address important material outcomes for autistic people (such as the prevalence of autistic people living in poverty, early mortality, or suicide), whereas experiential qualitative data illuminate the phenomenon in a way that large-scale quantitative, or experimental data cannot—for example, numbers cannot tell us about experiences of navigating a predominantly neurotypical world, as an autistic person.¹⁵ When mass-scale disharmony abounds between the perspectives of target populations and scientists, it should perhaps be taken as an invitation to explore whether the large-scale quantitative science is a poor representation of the underlying reality.

Recent theorizing has applied a CR approach to autism.^{12,16} Kourti¹² has argued that knowledge about autistic people through the lens of CR takes into account that a person’s experience of being autistic is specific to them, but the embodied experience of being autistic allows a closer understanding of other autistic people than that of a nonautistic person. This study addresses the tension of who has a *relative advantage* in speaking of the experiences of autistic people more generally.

Kourti¹² suggests that it is through our collective experience as autistic people that we create credible knowledge of autism and what it is like to be autistic, despite our differences, which are closer to an underlying reality than the knowledge of outside observers. Here nonautistic researchers should acknowledge that their outside observer knowledge of autistic behavior will never reach the same level of understanding—much in the same way that an autistic person could not access that level of knowledge about what it is like to be a nonautistic person—due to their lack of an embodied experience of being autistic. However, we may develop expertise at communicating with those who are differently embodied (such as autistic people).

This links both to Milton's⁴ "double empathy problem" and Hillary's¹⁷ notion of cross-neurotype communication, and concordantly the importance and challenges of "cross-neurotype translation," and potential for oppression through cultural imperialism.^{18,19} Milton⁴ proposed the "double empathy problem" to provide a more nuanced theoretical explanation of the "social communication breakdown" between autistic and nonautistic people. Milton argued that communication is bidirectional, whereby the interlocutors draw upon their own contextual knowledge and norms. As the embodied experiences of autistic and nonautistic people differ, so do their communication styles.

This can lead to mutual misunderstandings, which should not be attributed to autistic "social impairment," but take into account the mismatch between both parties. Similarly, Hillary¹⁷ frames cross-neurotype communication within a cultural context, which acknowledges the responsibility of both neurodivergent and neurotypical parties to learn about the other's cultural and communicative practices. The application of CR to autism knowledge frames "lived experience" of being autistic as a more epistemologically sound standpoint for understanding the embodied manifestation of autism.

This, in turn, provides a more equitable platform from which to advocate for emancipatory and neuroculturally compassionate work. Yet, often it is not simply miscommunication, but the specific cultural imperialism of dominant experiences being valued or trusted above and beyond differing minority experiences that are disregarded as inaccurate for failing to triangulate with perspectives of ontology generated by those with the epistemic "power" of being the majority.^{18,19}

A CR perspective fosters multidisciplinary, acknowledging that complex relationships demand multiple approaches and tools, aiming to facilitate research that is emancipatory and works to improve society. Thus CR is compatible with epistemological frameworks such as standpoint epistemology and neurocosmopolitics, serving as a philosophical home from which we can explore the value of both situated knowledge, and diversity of thought, communication, or expression. Importantly, for those who themselves work across methods, it provides a framework that allows for the possibility of employing differing methods to capture different levels of phenomena.

Most importantly, regardless of the kind of knowledge generation (qualitative or quantitative) in which a researcher is partaking, a constant reflexivity is required, not only of those who embody the closest experiences, but also by everyone responsible for knowledge generation, making it more equitable than expecting autistic people to do the heavy lifting of reflexive thinking.

Critical realism eased the tension for me as an autistic making autism knowledge, because it put a distinction between representations of reality, and reality—I am not created of the dehumanizing accounts of me that have been held up as value-free evaluations created by nameless and faceless scientists, who are upheld as paragons of objectivity, even if these accounts spill into my life to create barriers or to relegate me into an unreliable narrator of my own life. Autism isn't mindblindness, dysconnectivity, a lack of reciprocity, a failure of neural pruning, nor an epidemic, or tragedy. I could untangle myself from how others narrated me, and begin to narrate myself—as, at minimum, an equal in the creation of autism knowledge. Within CR we then share the responsibility of transparency, interdisciplinarity, and reflexivity. To me,

CR invites all parties to the table, with the knowledge that we are positioned differently, and that we are constructing something precarious—reality. But, it is shaped in such a way, that the position of the marginalized is key to any robust understanding. We cannot hide behind a guise of objectivity, nor rest on the concept of numbers as value-free—we must constantly acknowledge ourselves and others. (One of us)

Knowing: Envisioning Alternative Positionings, the Possibilities of Standpoint Theory

For all of us, science is never neutral, but that does not mean that science can necessarily never be objective. Feminist philosophers such as Harding²⁰ have argued for more than three decades that knowledge needs to incorporate the standpoints of marginalized groups to be truly objective. They argue that in fact marginalized groups have access to parts of knowledge and understanding that may be missed in dominant approaches and discourses. The field of autism has a long-standing history of dehumanizing discourses about autistic people, and narratives are presented as epistemologically transcendent of all social and cultural values by virtue of their quantitative and/or experimental nature (which as an action is somehow said to ensure objectivity).¹⁵

We argue that for autism research to be rigorous, we need to engage the standpoints of autistic persons themselves, who have been traditionally marginalized in research. Such autistic marginalized standpoints offer unique insights that make science about autism better. Harding²⁰ has argued that "strong objectivity" in research requires both democratic inclusivity and reflexivity so that investigators "recognize realities about nature and social research practice that could not be detected in earlier era," so "one must take advantage of the distinctive kinds of knowledge that can be produced from previously disregarded starting points."

The emergence of an international and highly diverse and interconnected adult autistic community offers huge amounts of intersubjective knowledge about many aspects of autistic experience, including those that come from being labeled as autistic: what it is like to be positioned as cognitively, socially, and emotionally "other," what it is like to be the recipient of care. This means identifying questions that may be overlooked by nonautistic researchers, as well as providing knowledge about multiple factors that support autistic or human flourishing.²¹

Since autistic and otherwise disabled people across various global contexts are also more likely to be subject to other kinds of domination, as a result of their gender, sexuality, class, or race, they are also likely to offer insight into mechanisms that exacerbate chauvinism, including inequality and poverty. At the same time, currently, the autistic community is often seen as simply a source of "data," rather as partners in research.

For strong objectivity, we require investigators to reflect on any biases that come from dominant social positions, such as those that cast minority groups as "other," or which allow us to reflect on the demand for a future that is not simply a continuation of the present. However, Harding²⁰ has also suggested that incorporation of these starting points may require different methods. So, if autistic autism researchers say that autism is a condition of embodiment, sensory experience, and perception, this calls for distinct methods of investigation to those that position it according to dominant cognitive paradigms, being conceived either as a lack of social motivation or a faulty mode of sorting through sense data.

If we make our knowledge production more democratic, this may not only be an epistemic virtue but also of benefit to all in a moral sense. From an ethical perspective, the 20th century philosopher Arendt²² offers a perspective on understanding how judgments in the public realm depend on a plurality of perspectives producing the “enlarged mentality” rather than on moral or logical imperatives. For Arendt, this capacity is a shared common sense, or imaginative perception of other people’s perspectives when we encounter their actions, so that we may judge based on what we share with others: “[t]o think with an enlarged mentality means that one trains one’s imagination to go visiting.”

Arendt sees this kind of activity as essential to the creation of a “shared world” that is inhabitable for all.²³ As a contribution to this, research on autism might be informed by a judgment of what autistic people share with the rest of humanity (as a capacity for suffering and, equally, for flourishing) rather than how they fall short of normative subjectivity. Furthermore, research could look for measures of flourishing that go beyond economic productivity and the absence of mental ill health. In any domain of enquiry, but especially when the object under investigation is people, it is important we learn from each other’s viewpoints to understand a specific phenomenon more fully, and to overcome biases.

What does it mean to take someone’s experiences seriously on the part of the researcher or clinician or ethicist for that matter? How do we create collective spaces for knowledge creation where people with different neurotypes can flourish and contribute as equals? This goes far beyond being able to check the “stakeholder” or “community engagement” tick box on a project proposal. It needs an openness to let go of all kinds of biases and willingness to take the other for granted.

When I talk about realising that I am autistic, I often wish I had a simple story, or anecdote that I could recount with ease. But the truth is a series of fractured memories, of small ‘hmmms’, of ‘surely not’s’, of ‘but am I sures’, of ‘am I just looking for a place to fit’, and a gradual and ongoing realisation that trying to understand yourself through the lens of 80 plus years of a neuronormative gaze is never going to produce meaningful self-knowledge. I think about an ex-partner mocking my ‘little obsessions’, of growing to expect the ‘eeeh you’re dead funny aren’t you’ when I met someone new, and the idea that ‘Everyone carries a minimum of everyone else within themselves.’²⁴ I am a psychologist, an autism researcher, and I knew these things before I knew I was autistic. My understanding of autism came from two very disparate places: from journal articles and textbooks, but also from my relationships with my brother, and with the children in the school I volunteered at as an undergraduate student. My experiences and my academic reading didn’t align, but I was unable to see the reason for these inconsistencies at the time—faulty paradigms built upon a fundamentally flawed starting point. (One of us)

And further they writes:

Ironically, my understanding of autism as a disorder of cognitive deficit and ‘mindblindness’ prevented me from being able to situate my own experiences, despite finding personal resonance in the writing of autistic people. I didn’t have ‘sensory issues’, I just found it difficult to walk around certain supermarkets without a lot of planning. I didn’t have ‘an insistence on sameness’, I just didn’t like change. Much later I realized that my lack of understanding stemmed from not

having the right shared language to be able to conceptualize what I was experiencing or had experienced throughout my own life. I only had the language of deficit, and whilst I felt like a somewhat deficient human, I also knew that other people viewed me as at least partially competent and ‘good with people’. I learned very little about my autistic self from textbook definitions of autism, and outsider views of our ‘traits’. Hearing about the experiences of autistic others, first hand, and hearing others talk about experiences that were so similar to my own, helped me to finally make sense of my own experiences, my own life, and provided me insights that continue to contribute towards my own flourishing. (One of us)

The issue is not only the existence of problematic models for interpreting autism but also skepticism toward the validity of situated knowledge. Autism as cognitive “otherness” does not offer a starting point from which to tell a story. Counter discourses, such as monotropism,² may be helpful to start from, but will themselves need enriching through time by new stories that recognize the interactions between subjectivity and social arrangements.²⁵

Ideas from the 1940s about what was “normal” childhood behavior have depicted autism as a tragedy, in which someone who could be a “contributing” member is a lost cause without intense intervention.²⁶ This has been echoed in portrayals of autistic people in mainstream films, books, and TV shows, where autistic people are either cold, and unknowing or uncaring of what goes on in the minds of others, or else a tragedy, a burden, and a plot device for others to show personal growth. We started from an assumption of deficit, therefore, limiting any specific understanding of autistic people.

The tradition of regarding autistic people as “lesser” is rooted in mainstream eugenic practices of 19th century Britain and America, and 20th century Nazism, which led to the assumption that societal problems originated in individual biology and “racial deterioration” rather than external inequalities or inadequate support. This resulted in legislation aimed at segregation and sterilization of those who were considered mentally or socially “deficient.” Eugenic thinking endures in institutional racism, homophobia, and transphobia, leaving autistic people at these intersections even more vulnerable to violence and cultural erasure.

I used to think psychology was fragile because of the replication crisis, the lack of conversation about meta-theory, the lack of consistency, the ‘science wars.’ I know better the longer I am in this institution. We focus on replication, registration, open-science, and quantification, because it means we do not have to deal with the legacy of violence and harm that we have perpetuated against disabled people, queer people, gay people, intersex people, trans and or non-binary people, or Black people, people of color, or indigenous communities. We [Psychologists] are borne out of the bell-curve, IQ, conversion therapy for curing ‘homosexuality’ and trans-ness. We focus on methods to absolve ourselves of a failure of ethics, theory, and to ignore that we are an institution built on the values of white supremacy, classism, ableism, misogyny, transphobia, and homophobia. It is not fragile, it is unchanging for a reason—its ability to maintain the status-quo. (One of us)

How might a more encompassing idea of autism be achieved?

I am haunted still by the portrayal of us as a lifeless puppet on the West end, being handled, mishandled, and passed between frustrated, angry, and sad parents, who are striving for their normal kid to ‘return.’ I am reminded of the psychologists, doctors, and mental health specialists who talked like I wasn’t there. The concerned glances. The comments about what I would and wouldn’t become. I am objectified into how other people tell the story of my future, passed between adults. No one asks me what I want, or what my normal is. I think my normal might be different. Maybe the puppet haunts me because it is an accurate reflection not of autistic people, but of the non-autistic people around them. (One of us)

Discontent with shoddy autism research and theory has gained more traction among autistic and nonautistic researchers alike, and the idea of community involvement has become normalized. However, some nonautistic academics have approached autistic attempts to be recognized as curators of our own experiences as a “debate” or a “tension,”²⁷ at odds with those who want to “help” autistic people. This is disingenuous for many reasons, but not least because it creates artificial “camps” that we are meant to separate ourselves into to indicate our epistemic authority and positionality, lest we be considered “biased” for having insight into our own experiences.

At the same time, we are frequently told that our participatory input into projects run by nonautistic people is “crucial.” Participatory research is often detrimental to “practical identities,”²⁸—the sense of who we are based on our own sense of what is normal, valuable, and practical—since it means behaving as though others have greater understandings of our experiences than we do.²⁹ Here, our differing epistemologies are emphasized, with those “least affected” by outcomes seen as more objective. It has also led to the tokenistic inclusion of autistic people in autism research,³⁰ often seen as a panacea for issues around community involvement.

As some researchers seek to stratify autistic people into smaller and smaller subgroups to confirm theories that do not hold up in the face of heterogeneity,³¹ many autistic people seek community knowledge that acknowledges heterogeneity as part of the human condition while still allowing us to find ourselves in each other’s stories to learn more about ourselves. Taking an intersectional lens to the experience of being autistic acknowledges that, though many of us might consider being autistic a core part of our identity, our identities are multifaceted and comprised many fluid and interacting aspects, which shift with context.

I am never just—I am never just autistic, or an ADHDer. I am interwoven with identities which co-construct each other. I am working class, Trans-non binary, queer, and neurodivergent. I am disabled, and a migrant from a family of migrants. My story is never just about neurodivergence, or autism, or ADHD, as neatly parceled clinical classifiers. My body, mind, and upbringing are a constant scene of public discourse, and often an ideological battleground. Autism is appropriated to deny gender inclusive language, affirming care, or as evidence of my own lack of authority to know or describe myself. ‘It’s just restrictive repetitive interests’, ‘they won’t understand if you use language beyond binaries—male and female—keep it simple’: when seeking emancipation and agency, it is not just as an autistic. (One of us)

Our proposal here for an epistemic shift would go some way toward remedying these issues, as we are inviting non-autistic people to work *with*, not *on*, us. Botha³² and Pearson³³ have pointed out that autistic people are often those doing all of the “heavy lifting” to make autism research more ethical, breaking down bureaucratic structures, and questioning poor theory and shoddy methodology. As situated researchers, autistic researchers always have to recognize that our interpretations might be impacted by our experience, and we are constantly reminded of our positionality as both insider and outsider, as knowledge creator whose knowledge is supposedly questionable and yet as someone who is directly impacted by other people’s understandings.

But this does not mean that we believe nonautistic people should not participate in autism research: instead, we propose to work with nonautistic people to make a better space for all. This does, of course, require transparency around beliefs and positionality, for example, where researchers are situated in hierarchies of power and authority, including access to funding and acclaim that has been entrenched within traditional biomedical deficit-driven narratives.

It seems that some people take making space for ourselves as a threat—if we have agency or equity or parity of narratives, then what happens to the status of those who continue to speak over us? It feels like we ask for a space at the table, and they hear us burning down the entire room. (One of us)

In summary, the standpoint firstly allows us to identify everyday “hidden” or “minor” harms (such as the long-term effects of bullying, isolation, or dehumanization), in the way that feminism has remained concerned about the everyday (as opposed to the exceptional events of patriarchal politics). For instance, it allows us to consider the events that lead to autistic suicide rather than to seek to explain the “strange phenomenon” that is autistic suicidality; it allows us to recognize the “privileges” that some autistic (and nonautistic) researchers have (in racialized, gendered, or class normativity) and how this may be mitigated against by creating more diverse research teams.

This ensures that the research does not simply replicate itself by narrowing the object under investigation. Second, the standpoint offers knowledge of how class-based, gender-based, and racialized subjugation works in combination with other axes of oppression. Third, it can provide a framework to consider the centrality of care that is an overlooked aspect of everyday academic life—from the concern we have for neurodivergent students and research subjects to the acts of recognition and solidarity we undertake.

Doing: The (Neuro)cosmopolitical and Epistemic (In)justice

Standpoint epistemology’s perspective on “better science” can be linked to neurocosmopolitanism. Asserting the moral neutrality of all neurotypes means embracing neurocosmopolitanism: a concept coined by Walker and Raymaker³⁴ and, elsewhere, by Savarese.³⁵ Like neurodiversity, its premise is that humankind is neurocognitively diverse, and there is no “correct” way for a mind to function. However, although one’s neurodivergence is “neutral” with respect to one’s inherent value and potential contribution,

neurocosmopolitanism recognizes the political value of openness to other “neurotypes” and forms of embodiment.

As Walker states: “[a] neurocosmopolitan individual accepts and welcomes neurocognitive differences in experience, communication, and embodiment in the same sort of enlightened way that a cosmopolitan individual welcomes cultural differences in dining habits.”³⁴ As with Walker’s example of cross-neurotype encounters, where each group benefits from the shared meal and the shared customs and conversation that comes with it, neurocosmopolitanism enables a mutually beneficial relationality between people of different neurotypes.

Therefore, although neurodiversity enables autistic people to work, create, study, or socialize alongside their non-autistic counterparts, the neurocosmopolitan paves avenues for active collaboration, enriching the experiences of all involved, and producing better outcomes in research, creativity, and broader culture. This nonhierarchical collaboration is at the heart of both joint action and standpoint epistemology. This can also be linked to the role of diplomats as have been theorized by Stengers.³⁶

Diplomats aim to give a voice to those who define themselves as threatened, in a way likely to cause the experts to have second thoughts, and to force them to think about the possibility that their favorite course of action may be an act of war. For those who cannot or do not want to speak for themselves, witnesses can make them present, conveying what it may feel like to be threatened by an issue that one has nothing to contribute to.

Envisioning an alternative academia, including both neuromixed and neuroseparate research cooperation, based on a collaborative ethos, there seems to be a deep-rooted fear of (for want of a better word) “messaging up” despite being “well-intentioned,” and neurodivergent people being unwilling to forgive these transgressions.

‘Messing up’ what? The things they are asked to do by funders? What they are asked to do by parents of autistic people? Or the research community? Lots of possibilities that would be helpful to clarify. We invite not just ourselves, but also non-autistic autism researchers to narrate themselves differently, but also to recognize privileges of certain cognitive positions and to be willing to give some of that up. (One of us)

Maybe we are asking people to build a bigger table and more chairs? We are in the room, and we are talking—but we are also on the fringes often. We are here forming fields like neurodiversity studies, critical autism studies. But we are always standing on the edges of rooms, carving out space and agency, in ways that other people don’t. There are people who knock on the door, walk in, and are given a chair, because they speak, move, and create stories within that legacy. (One of us).

Even in 2022, we are sometimes confronted with autism researchers who question why autistic engagement in research is important or why we seek to question work within a pathology paradigm. So-called community engagement is at the same plane as “ethics approval” seen as an administrative burden that funders are increasingly demanding and that requires resources, time, and diplomatic knowledge that one just does not have in research consortia.

But the unease sometimes even goes deeper: science is typically regarded as neutral and impartial. In this view, it is irrelevant who does the science: researchers are conceived as neutral spectators²³ who have a privileged vantage point on reality. The enshrinement and association of objectivity with numbers and neutrality often sideline autistic people by virtue of being autistic, leaving no room for an appreciated knowledge production.¹⁵

This perspective should be challenged. We can confront this skepticism using different types of arguments: a moral one (epistemic injustice qua Fricker³⁷; or ontological agency qua Lucas),³⁸ a scientific one (standpoint epistemology), and one that combines the two (cosmopolitical). The first type of argument is a moral one and is concerned with justice. It is now generally accepted, although sometimes it is met with reluctance, that the community must have a say in research concerning them. We all know the saying “nothing about us, without us,” no research on autism without the autistic experience. Neglecting the voices and opinions of those we are talking about is a form of epistemic injustice.

Epistemic injustice was framed by philosopher Fricker³⁷ to refer to the injustice that is done to someone when they are not believed because they have a particular social identity, for example, being a queer person or a person of color. Autistic people, we believe, have experienced epistemic injustice in many social arenas, including research, as they have been ignored as valuable partners in research that is about them. Certain theories about social functioning, such as the Theory of Mind hypothesis, and the lack of theory of own mind, have perpetuated the idea that autistic people are unreliable narrators about their own experience of themselves and others.

Included in this are the autistic autobiographers who have been relegated through a hermeneutic injustice.³⁹ Much has been said, also by autistic researchers, about the many flaws of the mentalizing and theory of mind account of autistic minds and minds in general.⁴⁰ Still, we cannot deny that much injustice has been done in research. Moreover, the victims of such injustice risk seeing themselves as people who cannot participate in dominant discourse.

Psychology among other disciplines is marked by a ‘universalizing’ impulse towards single ways of being and doing that will be bad not only for people but also for the planet. A psychology rather informed by a sense of the cosmopolitical and the different nature-cultures that people occupy, is partly about epistemic justice—the creation of a more just society for all—but it also recognizes that psychological practices of pathologizing individuals erodes recognition for the inherent dignity of all life ‘Community psychology’ may offer something here—again something Monique [Botha] has written about. (One of us)

Conclusions

The aim of this article was to think with and elaborate on theories developed outside of autism research and the autistic community that may have utility for elevating autistic scholars’ voices (voices that are often relegated in knowledge production). We aim to foster a wider intersectionality, new growth in otherwise neglected or siloed areas, and, further, create links to vibrant research communities who have also struggled with autorepresentations by adding to these complex conversations. These theories, as well as the exploration

of joint action in a neuromixed and otherwise diverse space, should add to the growing conversations about what it means to produce knowledge about autism.

In the Global North and minority world, the ideology of “independent self-construal”⁴¹ dominates the practices and institutions of psychology, the humanities and the social sciences, making this joint action all the more radical. The independent self is defined by static attributes and dominance of the social and material environment, through the dominance of the mind over the body. And yet what many of us, autistic and otherwise, talk about when we are asked to describe the meanings of our lives are the “interpersonal,” and the relational, as well as the embodied and affective—as a relational self who is constantly emerging as we develop new passions and skills.

These relationships can be both enabling and disabling, as demonstrated by the autistic life writers who have sought to explore who they are in the context of being subject to other people’s ideas about who they are, or are deprived of the opportunity to pursue our passions, in a culture that demands a coherent story of our triumph or failure to navigate the world (see e.g., Williams⁴² and Miedzianek⁴³). If our relationships do not conform to normative expectations—if they are facilitated by technologies or other persons—human or nonhuman—or if we enjoy things for no practical purpose, then they become unintelligible, thus undermine our ability to articulate who we are.

These intersecting axes of oppression will provide a unique context in which an individual seeks to renegotiate and re-imagine what it means to belong, and also to understand what needs changing in society, as it is and how we might do things differently. Neurodiversity or autism and Blackness or queerness are stories that are typically seen as a kind of move too far into inclusion, to be of interest to many, instead of to few.

But when you look at how autism combines with other types of highly marginalized identities, you see the world in a different way, and this helps us to understand what it might be to be genuinely inclusive, rather than inclusive just for those who give us an immediate competitive advantage. It also shows that independent creativity and dependence are universal traits of all people, in ways that cannot be measured or predicted by statistical measures.

Authorship Confirmation Statement

H.B.R., M.B., K.H., S.O., A.P., and A.S. conceptualized and wrote this article. All authors have reviewed and approved this article submission. The article has been submitted solely to *Autism in Adulthood*.

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