

‘They got oppressed all day and now they’re angry’: neurodiversity, rage, and solidarity

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We would like to begin by acknowledging the Dakota and Anishnaabe people as the original caretakers of the occupied territory where we are gathered. This is Indigenous land and the treaties and other means that colonizers have used to try to claim it have perpetuated genocide, theft, and deceit. As white settlers, we are committed to decolonizing research practices and frameworks, and calling attention to the ways in which colonial knowledge systems and institutions continue to disable and to pathologize people. In terms of disability and sensory access, we welcome all bodies and movements, so please feel free to move around, stim, leave and enter the room, or whatever you need.

From the very end of 2019 to the very beginning of 2021, the Neurodiversity Matters team interviewed 60 people about neurodiversity in Southern Ontario, Canada. The first 25 of these interviews were done in person, and the final 35 moved online due to the impact of the COVID-19 pandemic. In these interviews, we asked people to share their understanding of what neurodiversity meant to them, how they had learned about and developed their beliefs, what they thought people should do with it, and how they felt about it. We also asked whether they had found that other people had different ideas. The interviewers and larger research team included people with a variety of identities, including Autistic, neurotypical, neurodivergent, living with mental illness/ Mad, living with brain injury, people with chronic illness, otherwise disabled folks, family members of neurodivergent people, educators, and social workers – most with more than one of these identities at a time. This work was funded by a grant from the Social Sciences and Humanities Council of Canada as well as through funds from the University of Waterloo and Renison University College.

Throughout these interviews, the definition of neurodiversity was generally a settled matter. People mostly agreed about the foundational premises of neurodiversity as a needed alternative to dominant social beliefs that people who sense, communicate, learn, act, or think in normative ways are “healthy” or “functional”, and that people who diverge from the neurotypical are “broken” and “pathological”. Instead, neurodiversity offers a politicized approach that values the differences between people, and responds to neurodivergence through an analysis of oppression – an understanding of neurodiversity that is largely consistent with the ways in which it was described by Judy Singer at its inception in 1998, and as it has been refined by bloggers and activists since (Kapp, 2020; Singer, 1998; Walker, 2021).

The neurodiversity paradigm, as it is often called, led many participants to a lively examination of social and political power, exclusion, and capitalist mandates of “productivity”. Some of the people who participated in our interviews had been talking about and working with neurodiversity for years, but some were very new to these ideas, and hungry to discuss them. Indeed, we were surprised to find that some people volunteered to participate in the study with the hope that they could learn more about neurodiversity from the interview experience.

So, what did we find? We learned that neurodiversity travels in particular circles, so that those who regularly take part in online or activist communities where an Autistic or disability justice focus prevails have heard a lot about neurodiversity and its nuances. However, those who were not engaged in social media or activism struggled to learn about neurodiversity, often in relative to total isolation. The 2015 bestseller *Neurotribes: On the history of autism and the future of neurodiversity*, by Steve Silberman, was a central text that a number of participants said had initiated their interest in the topic, and there has been a recent explosion of related publications. And yet, discourses of pathology and intervention continue to dominate across professional and

social landscapes, and neurodiversity remains more of a buzzword than a fundamental challenge to most organizations, often being mainstreamed into what Shain M. Neumeier dubbed “neurodiversity lite” (Neumeier, 2018).

The people we spoke with had different positionalities; indeed, we set out to interview people from 3 groups. The first group was people who identified with neurodiversity, most commonly as Autistic (as applied to 30 participants), but people also volunteered for the study through identities such as ADHD, dyslexia, Mad, intellectual disability, learning disabilities, giftedness, PTSD, depression, epilepsy, psychosis, and “brain weird” but not subscribing to diagnosis, and often also “neurodivergent”, occasionally “neuroqueer”. The second group we invited to the study was people who used neurodiversity in their work with others: as educators, counsellors, social workers, crisis workers, probation officers, clergy, and so forth, or as trainees across these fields. The third group was people who used neurodiversity in their relationships with family members: as siblings, parents, daughter/ sons/ adult children, cousins, partners, and so forth.

What we learned quite quickly was that these groups, while often conceptualized as very separate, instead overlapped extensively. So we spoke with 44 people who identified with neurodiversity, 34 who identified as service providers, and 31 who were family members: we can see that this total goes well beyond 60. Providers also identified with neurodivergence. Family members also worked as providers. Neurodivergent people worked in professional roles and cared for and about neurodivergent kin. It was more common for our interview participants to be a part of two or more groups than just one.

Even as people had overlapping memberships across these groups, they also described stark lines of tension, disagreement, and misunderstanding when it came to discussions of neurodiversity. For example, many people talked about having family members who held

pathologizing and shameful beliefs about neurodivergent people. Many talked about having experienced discrimination and harm in service systems. A primary source of conflict that people discussed was between neurotypical parents of Autistic people and neurodivergent adults; these often occurred in online spaces. But conflict and tension also occurred within groups too. Providers who used and promoted a neurodiversity ethos described conflict with official mandates and trainings, as well as with most of their colleagues. Parents described tensions with other parents, often around what practices are ethical and helpful for neurodivergent children. Neurodiversity-identified individuals described conflict within neurodivergent groups around terms, practices, and beliefs.

These discussions of disagreement often shifted into the affective realm; they became conversations about anger, rage, fear, disappointment, shame, joy, hope, and so forth. Feelings shaped not only what people experienced, but also what people did. Feelings were at the root of why a neurodiversity paradigm was important.

As bell hooks explained, we need rage in the face of oppression: *“Confronting my rage, witnessing the way it moved me to grow and change, I understood intimately that it had the potential not only to destroy but also to construct. Then and now I understand rage to be a necessary aspect of resistance struggle. Rage can act as a catalyst inspiring courageous action”* (hooks, 1995, p. 16). Rage at injustices faced by neurodivergent people swirled through our interviews as a call for resistance. For example, people raged at the use of bleach and other toxins by some parents and professionals to “cure” or “treat” autism in children, listing this as only the one of a range of horrifying abuses inflicted on neurodivergent young people. Many spoke of their rage at people’s (mis)treatment in psychiatric units and systems. The widely acknowledged inadequacies of diagnostic frameworks and practices, the meagre and punitive

policies of social services, the powerful misapprehensions of providers and employers, the rigidity and non-responsiveness of educational systems -- all inspired anger and a desire to create change. Rage got people to volunteer for the study. They wanted us to know how it felt to be excluded by others when they raised unfamiliar concerns or even mentioned the idea of neurodiversity. They wanted to talk about why their perspectives and experiences were needed and why neurodiversity mattered, to them.

But this rage became layered and complicated as people also thought about how to spread the ideas and practices of a neurodiversity paradigm to broader and different audiences, including those with greater levels of social power. Many participants described the affective modalities of neurodiversity conversations as something that might limit their scope and effectiveness. A few said that they avoided online groups, in particular, because they found them so contentious. However, for most neurodivergent participants, it was not as simple as rejecting social media as a difficult or even toxic space, since the online world was widely seen to be the best place to learn about neurodiversity politics and develop community.

Instead, participants tried to put “angry” or “harsh” responses from neurodivergent adults into some context. For example, one white Autistic woman explained:

I don't always agree with how autistic people approach the issue, and again, I understand because they are tired. They are devastated. They are traumatized. I'm not going to tell them to be nicer, but it frustrates me that they can't be. I know that the problem is oppression. The problem is not that they're not nice enough. The problem is that they got oppressed all day and now they're angry.

This speaker challenged us to see anger in the context of oppression. This is not about being “nice” or “appropriate” or even “empathetic” individuals or community members. Indeed, neurotypical dominance has often coasted upon the assertion that neurodivergent people lack social and communication skills, and that their assessments can’t be trusted. As long as people are seen as unreliable narrators, not only in the content but also in the form of their contributions, then the reasons behind their anger are more readily ignored. Even as this person might prefer that others communicate differently, she insisted that their anger is really about injustice, and that she can’t ask people to put it aside. The language of oppression allows for rage to be understood, to be framed as reasonable even if it might, at times, also alienate others.

The pressure for participants to present themselves and their communities as “reasonable” and to communicate their experiences and beliefs in palatable ways was thus a conundrum. Responding in measured, “less angry” ways required resources, time, energy, and a finely honed set of relational and communicative skills. For example, the same participant talked more about her hopes for communication between autistic adults and “autism moms”, proposing that we also need to address the larger context of patriarchy:

So, do I want for more [Autistic] people to maybe reach out to autism mommies with a little more patience? Yes. Do they have the emotional resources to justify me asking them to do so? No. Absolutely not. No. So, I’m not going to tone police them, but I wish that they could be nicer, but if they were in a position that they could be nicer, we wouldn’t be in this mess [laughs] because autistic people would be more widely understood, so they wouldn’t be so tired all the time. The mommy issue is also very fraught with a bunch of other political problems, where there’s a reason autism daddy isn’t a term. That’s because parenthood and the expectations of parenthood are very divided depending on whether you’re a mother or a father. (156)

As this quote indicates, gender is at play. The people we spoke to often brought a hard-won gender analysis to their thoughts on neurodiversity. In contrast with the bulk of research in the area of autism or developmental disability, in asking about neurodiversity, we heard primarily from cisgender women (32) and non-binary, gender fluid and trans people (18) – and almost all of the (12) cisgender men we spoke to were engaged in parenting or work that is generally feminized (e.g. teaching, social work, counselling).

Patriarchal assumptions that mothers should be the guardians and enforcers of neurotypicality weigh heavily on all interactions between parents and providers, parents and other family members, parents and broader society, creating the ubiquitous categorizations of “autism moms” and “mommy bloggers” even as fathers and other family members may also engage in related practices (Douglas, *). The larger social structures and professions that espouse beliefs that childhood is the primary or even the only time to “improve” the lives of neurodivergent people, that mothers need to take on the role of “warriors” and “advocates” (probably to the exclusion of all other activities), and that interventions need to be unrelenting and only sporadically supported, conveniently recede from view (Gibson, 2018).

However, in the moments where they gestured to larger structural pressures, interviewees floated aspirations of solidarity. When people talked about rage as a cue to oppression, anger became a starting point and an opportunity to give more space and time and understanding, to stretch an initial framing of sides and positions. Rage was a sign of oppression, and many cuts of oppression could be acknowledged without mutual denial and diminishment. The very idea and language of neurodiversity can serve as a call to support diverse social justice movements. In many interviews, people were thinking out loud about how their lives connected with disability, race, class, gender, and sexuality. At the same time, many said that neurodiversity conversations

often exclude and minimize racialized experience, in spite of the central contributions of neurodivergent BIPOC scholars and activists such as Lydia X. Z. Brown, Kassiane Asasumasu, Morénike Giwa Onaiwu, and Leah Lakshmi Piepzna-Samarasinha (and many others).

Critical disability and gender studies need to be in conversation with each other, and to some extent this has already been happening in neurodiversity scholarship. For example, the development of “neuroqueer” identities and activism have used feminist and queer questioning of stable categories to challenge neurological categorization in more radical ways (Egner 2019; Walker 2021; Yergeau *). We would like to see more discussions of how feminist scholarship can work across divided movements and groups to build solidarity in these polarized landscapes. Scholarship that invites connections across social groupings, that asks people to reflect on the affective impact of social movements, creates the opportunity to hear about interrelated struggles. Neurodiversity discussions need to continue to interrogate rage not only to identify injustice, but also create the relational connections and political solidarities we need to fight it.