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“The refusal to fit into boxes”: Interview findings on ADHD and neurodiversity

« Refuser d’entrer dans des cases » : Résultats d’entrevues sur le TDAH et la neurodiversité

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Abstract

What do people with Attention-Deficit Hyperactivity Disorder (ADHD) think about neurodiversity? How does it affect what they do? While a burgeoning body of scholarship has examined the concept of neurodiversity, this work has often restricted its focus to autism, or addressed more general ideas about neurodivergence. Little existing research explores what neurodiversity means to people with ADHD. This paper presents a subset of findings from a multimethod project on how people use the language and concept of neurodiversity. We examined 11 interviews with diverse participants living in Southern Ontario who all identified as having ADHD, which we analyzed using an institutional ethnographic approach. Participants shared a diverse range of ideas, feelings, relationships, and experiences with neurodiversity. For some, neurodiversity was an integral aspect of their identity or provided useful language to advocate and educate, while others expressed uncertainty or discomfort with adopting this identity. Diagnosis was highlighted as a particularly complex issue without clear agreement. We found that people understood neurodiversity through their experiences of community, especially within online and activist circles. Those who did feel connected with neurodiversity

described it as an empowering lens with which to organize their lives. People with ADHD have important insights to share about neurodiversity that can inform needed changes across social domains such as education, employment, identity, and activism. We consider the implications of these findings for future research and practice.

Résumé

Quelles sont les perspectives des personnes ayant un trouble du déficit de l'attention avec ou sans hyperactivité (TDAH) sur la neurodiversité? Comment cette notion influence-t-elle leurs parcours? Bien qu'un corpus de travaux en pleine expansion se soit penché sur le concept de neurodiversité, ces recherches ont souvent limité leur portée à l'autisme ou abordé des idées plus générales sur la neurodivergence. Peu d'études existantes explorent ce que la neurodiversité signifie pour les personnes ayant un TDAH. Cet article présente un sous-ensemble de résultats issus d'un projet multiméthode portant sur la manière dont les personnes mobilisent le concept de neurodiversité et le vocabulaire qui lui est associé. Nous avons analysé onze entrevues menées auprès de participantes et participants vivant dans le sud de l'Ontario, toutes et tous s'identifiant comme ayant un TDAH, selon une approche ethnographique institutionnelle. Les personnes ont partagé une diversité d'idées, de ressentis, de relations et d'expériences en lien avec la neurodiversité. Pour certaines, celle-ci constituait un aspect central de leur identité ou offrait un langage utile pour militer et sensibiliser, tandis que d'autres ont exprimé de l'incertitude ou un malaise à l'idée d'adopter cette identité. Le diagnostic a été mis en évidence comme une question particulièrement complexe, sans consensus clair. Nous avons constaté que les personnes comprenaient la neurodiversité à travers leurs expériences dans la communauté, notamment au sein de cercles militants et d'espaces numériques. Celles qui s'identifiaient à la neurodiversité la décrivaient comme une lentille émancipatrice leur permettant d'organiser leur vie. Les personnes ayant un TDAH apportent des éclairages précieux sur la neurodiversité, susceptibles d'informer les transformations nécessaires dans divers domaines sociaux tels que l'éducation, l'emploi, l'identité et l'action militante. Nous examinons les implications de ces résultats pour les recherches et les pratiques à venir.

Keywords

neurodiversity, ADHD, ethnography, interviews, services, diagnosis

Mots-clés

Neurodiversité, TDAH, ethnographie, entrevues, services, diagnostic

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Introduction

There is a surge of writing and discussion about neurodiversity across popular, professional, and academic settings. At the same time, little of this has focused on people with Attention-Deficit Hyperactivity Disorder (ADHD): what they understand neurodiversity to be, and how they want it to be used. While most people contributing to conversations about neurodiversity identify ADHD experiences as a part of what neurodiversity discussions should address, little research engages with the ideas and experiences of people with ADHD on neurodiversity directly.

This paper presents findings from interviews with people who identify as having ADHD about what they think and feel about the concept of neurodiversity and how it affects what they do. By focusing on how people who identify with ADHD use the language and ideas of neurodiversity, we can broaden our knowledge of neurodiversity as a paradigm and a social movement, and also learn about possible ways to change our social frameworks and activities – without being limited to any one institution, discourse, or sector (e.g. healthcare, education). Our approach builds upon critical ADHD and disability studies critiques that understand disability and related identities as socially structured, and demand research practices that put the marginalized experiences and ideas of disabled people at the centre of research processes and analysis. This work has implications for how we organize systems, research studies, and everyday practices.

Background

Over the past decade, the term “neurodiversity” has become an increasingly popular way to understand and describe human differences. The concept of neurodiversity was developed collectively by Autistic communities in the mid 1990s (Botha et al., 2024). There continues to be significant discussion of what neurodiversity means, who it should include, and what kinds of social changes are called for by a neurodiversity paradigm (livingstone et al., 2023). However, there is generally a consensus that the concept of neurodiversity offers an alternative to medicalized, pathologizing, and deficit-centered approaches to differences in thinking, being, and communicating. Neurodiversity advocates instead view these differences as a natural and often beneficial part of human diversity (Chapman, 2020; Kapp, 2020; Walker, 2014). Increased scholarly interest in neurodiversity has lagged behind longstanding discussions of neurodiversity in activist and disability justice communities (livingstone et al., 2023). Nevertheless, as more academics are talking and writing about neurodiversity, and increasing emphasis is placed on research to learn more about neurodivergent individuals, there has been a growing question as to what the language and concept of neurodiversity encompasses.

While ADHD is typically included in definitions of neurodiversity (Armstrong, 2010; Bertilsdotter Rosqvist, Stenning, & Chown, 2020; Zaneva et al., 2024), discussions of and research related to neurodiversity continue to center autism and Autistic communities (livingstone et al., 2023). Comparatively little research has explored the experiences and understandings of people with ADHD as to what neurodiversity means to them and how they want the term to be used. Much of the existing ADHD research instead continues to

frame ADHD as a “burden” (Asherson et al., 2012) or biomedical pathology, and focuses on questions of prevalence (e.g. Espinet et al., 2022), pharmacological or behavioural treatment (e.g. Mechler et al., 2022), educational challenges and interventions among both children (e.g. Daley & Birchwood, 2010) and adults (e.g. Varrasi et al., 2023), and employment challenges and outcomes (e.g. Fuermaier et al., 2021).

A select number of other studies have engaged with the ideas and experiences of people with ADHD as a way to understand how our social world and institutions are organized. For example, Bertilsdotter Rosqvist and colleagues (2023) and Hoben and Hessen (2021) used collective/collaborative autoethnography to explore their experiences with higher education and academia as academics diagnosed with ADHD. Schreuer and Dorot (2017) used phenomenological interviews to examine workplace challenges experienced by women with ADHD, identifying both general and gender-specific challenges and drawing on participants’ subjective knowledge to make recommendations for workplace best practices. Ginapp and colleagues’ (2022) rapid review of qualitative research on the lived experiences of adults with ADHD identified the need for research that focuses specifically on racialized communities, adults, and women, and that explores the relationship between ADHD diagnosis and identity. Such findings highlight the necessity of directly engaging with individuals with ADHD to understand the social organization that shapes their experiences and ideas, and consider how these social underpinnings can be addressed and managed.

Scholars in disability studies and critical ADHD studies (eg. Jackson-Perry, Bertilsdotter Rosqvist & Brown, 2025) have highlighted mainstream researchers’ limited

perspectives on ADHD. Such writers note that, to date, much of the literature involving ADHD has been in the biomedical realm, viewing ADHD through a lens of deficit. In mainstream writing, ADHD is discussed in neurological and pathologizing terms, with a focus on symptoms (such as executive dysfunction, impulsivity, and emotion regulation) that require medical treatment through medications and behavioural therapies (Brown, Bertilsdotter Rosqvist, & Jackson-Perry, 2024). Such limited models restrict their focus to the challenges individuals could experience if these symptoms are left untreated. Brown, Bertilsdotter Rosqvist and Jackson-Perry's (2024) analysis of the research field calls for "relearning" how society conceptualizes and pathologizes ADHD. There is growing criticism of the dominant framing of ADHD as purely a biomedical issue, with recognition of the need to continue exploring approaches across methods, disciplines, and fields (Marley, 2023; Wheeler, 2010; Visser & Jehan, 2009).

Methods

This research is part of the larger project, *Neurodiversity Matters*, led by principal investigator (PI) Margaret F. Gibson at Renison University College, affiliated with the University of Waterloo, in Waterloo Ontario, Canada. The overall project included co-investigators, collaborators, students, and research assistants who brought a range of identities and experiences to the topic of neurodiversity. Many of the team members identify as disabled and/or neurodivergent, including three authors on the current paper who identify as having ADHD.

The larger project used a combination of methods to investigate how the language and concept of neurodiversity have been taken up and put into practice by different people, across different social domains. The study included a combination of discourse analysis and critical ethnography, and was informed by institutional ethnographic methodology (Smith, 2005). The ethnographic side of the project included interviews with 60 individuals in Southern Ontario as well as observations of online events. Methods and findings from the discourse analysis and ethnographic observation parts of the project have been published elsewhere (livingstone et al., 2023; Gibson et al., 2024; Gibson et al., 2025). A full description of the interview methods, sample, and findings are available in other forthcoming work. We followed ethical protocols approved by the institutional research review boards at the University of Waterloo, University of Toronto, University of Guelph, and Brandon University.

Participants were recruited through organizations and networks including mental health and disability service organizations and providers, university groups that focused on disability, networks of the research team and community collaborators, disability rights organizations, self-advocacy/activist groups, and social media (primarily Facebook/Meta). Potential participants were given more information on the study and screened for eligibility by email or telephone. To be eligible to participate, people needed to be at least 18 years old, be able to provide informed consent for and participate in an interview in English (with the option to type if this was more accessible), and live in the geographic region for the project (an area including the Greater Toronto Area, Hamilton, Waterloo, and London, Ontario). We set out to recruit participants from 3 different groups with numerical targets

for each: people who saw the concept of neurodiversity as related to their identity (usually described as being “neurodivergent”) whether or not they had a formal diagnosis (25); people who used neurodiversity in their work as service providers such as counsellors, teachers, or social workers (25); and people who used neurodiversity in relation to a neurodivergent family member (10). Our screening process also asked about demographics such as race, gender, and socioeconomic status, and we used this information to select participants with a wide range of experiences. We noticed that our initial participants were mostly cisgender, White women, and we did a second, more targeted round of recruiting for people who identified as men and/or as racialized (including biracial and multiracial participants). As we completed recruiting, we found that many people identified across multiple categories, and 44 (i.e. most) of the participants in our final sample were neurodivergent in some way.

While a total of 60 people were interviewed, this analysis focuses on our 11 interviews with people who identified as having ADHD. Of these 11, 7 also identified with other types of neurodivergence, most commonly autism (5). While most participants were able to afford food, shelter, and basic needs at the time of the study, it is worth noting that 3 reported struggling to afford these basics in the past. A demographic description of this ADHD-focused sample can be found in Table 1.

Table 1

Participant demographics (n=11)

Characteristic	Category	Number of Participants
Additional neurodivergent identity	Autistic	5
	Mental health/Mad	1
	Eating disorder	1
Gender	Cisgender Woman	2
	Transgender, Non-Binary, Agender, Genderfluid, Gender Neutral, Gender Non-Conforming, Queer	5
	Cisgender Man	4
Race/ Ethnicity	White	7
	Mixed or Biracial	1
	Afro-Caribbean	1
	South Asian	1
	Latinx	1
	Not struggling	6

Socioeconomic stability¹	Not struggling because of support from others ²	2
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¹Measured by whether participant reported struggling to afford food, shelter, basic needs

²These participants reported that they would be struggling to meet their basic needs if they didn't have ongoing financial support from parents, partners, or friends. Some lived with family because of this financial pressure.

Interviews lasted between 45 minutes and two hours and were conducted by Margaret Gibson and Hannah Monroe. Participants were offered all interview questions in advance and had the option to take breaks as needed. The first 24 interviews were conducted in person from January–March 2020; the rest of the interviews were conducted remotely, on Zoom, from June 2020- January 2021 due to the effects of the COVID-19 pandemic. One of the interviews in this paper was conducted in person, while the other 10 were conducted remotely. Participants received \$50 Canadian as an honorarium and were reimbursed for any costs incurred in doing the interviews. The interviews were semi-structured, and the interview guide followed practices rooted in institutional ethnographic (IE) methods (Smith, 2005). Interviews were audio recorded and then de-identified as they were professionally transcribed.

Throughout the interviews and the analysis, particular focus was paid to texts, institutional forms and processes, and the everyday work and practices that people did in their everyday lives, from their particular positions. Work was understood to encompass all

activities that require effort and time, including waiting, seeking information, and handling emotions, as well as paid activities and physical tasks (McCoy, 2006; Smith, 2005).

We focused our analysis for this paper on the experiences of participants who identified as having ADHD in recognition that researchers have not paid sufficient attention to the knowledge and perspectives of neurodivergent people - including those with ADHD - even as we also recognize the diversity of experiences within this group. This focus on those most affected by current systems and practices is consistent with our commitment to a disability justice framework (Kafai, 2021; Mingus, 2011; Piepzna-Samarasinha, 2018; Sins Invalid, 2019; Wong, 2020). The present analysis addressed the research questions: What do people with ADHD think about neurodiversity? How does it affect what they do? Data analysis was rooted in IE commitments to “keep the institution in view” as we worked to learn about broader social relations from the specific, everyday experiences of the people we spoke with (McCoy, 2006). This approach is consistent with IE’s larger objective of illuminating power relations (Smith, 2005). Brianna Urquhart and Lauren Chan used a shared document that included all of the de-identified transcripts from the 11 interviews with people who had ADHD. They each read through transcripts and used colour-coded highlighting and comment boxes to identify key elements and passages from the interviews. They regularly met with the project’s PI (Margaret Gibson) – who had conducted most of the interviews – for guidance and to share resources and ideas; they also met on their own for more specific discussions of how they were understanding and responding to the transcripts. After these close analyses, we met to talk about what we were learning about social organization from these transcripts, and developed the findings presented in

this paper. This approach was consistent with recommended practices of institutional ethnographic analysis with a team (Campbell & Gregor, 2002). All co-authors then collaborated on the draft through shared documents.

Positionality

The authors of this paper bring different lived and professional experiences to this research, and some areas of commonality. Four of the authors are cisgender women and one is agender. All identify with disability in some way, and three identify with ADHD specifically. Four of the authors are White and one is East Asian. Margaret Gibson is the principal investigator and the other three worked as research assistants; one of the research assistants conducted screenings and interviews in this project. Three of the authors (including the PI) have graduate degrees in social work, two have master's degrees in sociology, and one has a master's degree in global health research.

Findings

Our interview participants did not share a consistent, unilateral relationship with the concept of neurodiversity and its relationship to ADHD; interviewees' life experiences and intersecting identities brought an important element of diversity to their discussions of the concept and language of neurodiversity. In this section, we will present the key findings from our analysis of these 11 interviews, and how they illuminate the social relations and discourses surrounding ADHD and neurodiversity in the contemporary Canadian context.

Relating to neurodiversity: Community, practice, and identity

This exploratory analysis allowed us to answer our research questions: What do people with ADHD think about the concept of neurodiversity? How does it affect what they do? Our findings show that people with ADHD see neurodiversity as a term that can include them and that can produce a sense of belonging for some – but they don't always see themselves reflected in how other people use it. Neurodiversity as a term and an idea was variable in its appeal or availability to different people, particularly with regard to racism and other forms of marginalization. Most participants found that neurodiversity framings offer a way to address pathologizing language and ideas regarding ADHD, and advocate for and/or expand supports beyond deficit-based understandings of their experience. They identified the concept and language of neurodiversity as a way to open up, create, and adapt practices across different spaces – and underscored that such changes are needed due to harsh socio-cultural beliefs and practices in education, employment, healthcare, social services, and beyond.

While participants did not always agree on who is and is not included under the umbrella of neurodiversity, they did agree that ADHD belonged as a part of this concept and its related conversations. Participants generally described feeling included in discussions about neurodiversity, even though many of these discussions focused primarily on autism. There was notable variability in how engaged participants with ADHD were with the concept and language of neurodiversity. Those who were most familiar with neurodiversity and ADHD as an identity were often connected to activism. These participants described having neurodivergent friends, family members, or romantic partners; many were involved in groups engaging in education or advocacy about issues

related to social justice and neurodiversity. Social media was also identified numerous times as a place for sharing information and resources, and for organizing. Unexpectedly, a few people participated in the larger *Neurodiversity Matters* study in order to learn more about neurodiversity. This was a unique experience for us as qualitative researchers, as participants typically volunteer for research studies in order to share their knowledge or contribute to something they are already invested in.

Several participants were exposed to ideas about neurodiversity through interacting with peers who used this language or identified with ADHD and other diagnostic labels. Connecting with other neurodivergent people created an opportunity for individuals to re-evaluate their own experiences and needs, and learn about different ways of conceptualizing them. Those who reported becoming curious about their own ADHD through community reported a sense of validation as they recognized themselves in the concepts they were learning about, regardless of whether this led to pursuing formal diagnosis or not.

For some interviewees with ADHD, the concept of neurodiversity provided language that could be used as an educational tool to help them advocate for themselves and their needs. Many described it as a validating, empowering framework that helped them tackle ableist assumptions in order to identify new ways of thinking, communicating, doing, and being. Several participants talked about the hope it provided for a more inclusive society for neurodivergent people. One participant describes such positive aspects:

That's why the narrative of neurodiversity is so important, because this is a corner of hope. This is a little anchor that makes me believe there are safer spaces and possible futures. If that didn't exist, then I would never be – I

would always feel like a patient. I would always feel like an imposter. I'm trying to build that space where I'm not. I'm trying to build the space where my difference is valued.

Encouragingly, participants described how neurodiversity can provide a framework for people to think about and approach life differently, regardless of neurotype. A common request echoed across the interviews was for basic compassion, understanding, and kindness. More education and awareness is needed across all fields, as well as throughout society as a whole, in order to recognize the harmful ways that people with ADHD continue to be misunderstood, disbelieved, or excluded. Many participants described neurodiversity as a lens through which they could learn about themselves in order to dismantle and replace pathologizing, rigid, and capitalistic approaches to how they organized their lives.

Some participants did not consider ADHD to be an integral aspect of their identity, and instead focused their discussions of neurodiversity more on other aspects of their identity or on other relationships, such as an Autistic sibling or romantic partner. Some talked primarily about specific challenges or experiences, such as executive functioning. Several participants identified with AuDHD (autism and ADHD), and while they did discuss the role of ADHD in their daily lives, they often focused more on their Autistic identity and experience in relation to neurodiversity language and activism.

Some people who had experienced discrimination or other challenges related to ADHD or autism expressed discomfort at the idea of participating in discussions of neurodiversity and embracing a neurodivergent identity. Some participants who held other marginalized identities, such as racially minoritized people, talked about concerns about

being multiply oppressed. For example, one individual described how racially minoritized people fear taking on “*another identity that will victimize them*”. Another participant, who identified as a Black woman, described how she avoids using the term “neurodiverse” to describe herself. She feared she would be seen as “*weak or a victim*”, in addition to facing racist discriminatory assumptions and stereotypes.

Perspectives on diagnosis

Centrally we found that questions about ADHD and neurodiversity almost invariably introduced stories and ideas about diagnosis. Overall, participants shared experiences related to diagnosis that were diverse, complex, and often fraught with uncertainty. They described how the process of accessing a formal diagnosis can be long, expensive, and arduous. It can require thousands of dollars and extensive documentation from childhood, and involve long waitlists and multiple referrals. Some participants decided against seeking a formal diagnosis even as they understood themselves to have ADHD.

Participants who did pursue a formal diagnosis talked about facing discrimination. Many critiqued the ways that current tests and the Diagnostic and Statistical Manual (DSM-V) criteria are written, particularly regarding larger societal stereotypes about how ADHD “should” present. Participants shared experiences where diagnostic practitioners had difficulty identifying ADHD in anyone who is not White, male, heterosexual, and cisgender. For people who had multiple experiences of marginalization, the diagnostic process was especially challenging, as summarized by one participant:

The stigma that neurodiverse people face, the stigma that queer people face is so deeply embedded in white supremacy and colonialism, and if we don’t

talk about that, we're not making those connections, or if we're not talking about ableism at all, we're missing a fundamental part of the picture.

Interview participants offered broader social critiques of how hierarchies of human value have been assigned. These interviews highlighted the ways in which people's experiences and understandings of ADHD were fundamentally shaped by dominant socio-cultural understandings and institutional expectations.

Interview participants often utilized the language of neurodiversity as a part of self-led research and a means to identify useful strategies. Many described learning about ADHD from friends or online sources, and then finding more information about it from both professionals and those with lived experience. For example, one participant described their formal diagnosis as something they “*actually don't need*” and is “*not that important*” due to their own efforts to set themselves up to succeed. They had learned what their needs are and how best to accommodate themselves, often intentionally designing their life in ways that utilized their strengths and supported their challenges.

Regardless of costs and other barriers, participants underscored that having a formal diagnosis could be necessary in order to access many institutional resources, supports, and services, such as academic or workplace accommodations. The process to receive formal accommodations typically requires documentation outlining the person's diagnosis and its implications. Participants often described the decision of whether or not to pursue diagnosis in pragmatic terms, even as it might also offer other forms of understanding. As one participant describes, “*I don't want to take that away from people because that diagnosis obviously means access to resources, it means access to*

understanding yourself, all those kinds of things, so I understand the value of a diagnosis on that level." Diagnosis could be double-edged as a tool to validate access needs and fight for meaningful inclusion, and it inspired a range of associations and emotions.

Participants often expressed grief and frustration at the lack of support they received from others across relationships and settings. Participants described being shamed, criticized, or judged harshly in terms of their intelligence and work ethic. They discussed the ways that others viewed their ADHD-related challenges as personal or moral failings, often with harmful consequences to participants' mental, educational, and vocational wellbeing. Participants reiterated that "*getting all these messages that you're stupid all the time*", as one participant put it, or being treated differently than their peers was harmful, with long-lasting effects on how a person thinks, feels, and navigates the world. For people who were diagnosed with ADHD later in life, diagnosis was also a way to re-conceptualize their identities and dismantle harmful narratives and beliefs placed upon them by others. ADHD diagnosis was therefore seen as a possible gateway to compassion, flexibility, and understanding.

Interviewer: Do you sometimes wonder if things would have been really different if you had a diagnosis much younger?

Participant: Yeah. That's kind of what the sadness is about, that if I had understood why I always felt like a freak on the outside or whatever, and if that information, that self-awareness or the supports had been there, yeah, life probably would have been a lot easier, but at the very least, [laughs while crying] I figured it out at some point. A lot of people don't.

These findings showed how harsh the relational and institutional assessment of people's normative performance and relative "productivity" can be across childhood and

adulthood, and spanning many different contexts: schools, families, peer groups, workplaces, and beyond.

Workplace experiences and career choices

Interviewees identified workplaces as a site of particular struggle for equitable inclusion. They shared fear and uncertainty as to whether or not disclosing a diagnosis would help or harm a person's professional standing. Some shared stories of experiencing workplace bullying and prejudice once their workplaces were aware of their ADHD. One participant described a noticeable, dramatic change in how they were treated once their ADHD was disclosed: *"Like, from one day to the next, they started speaking very slowly to me, as if I was mentally challenged, which is totally ridiculous."* Some participants decided to risk interpersonal problems in order to obtain workplace accommodations, such as modified work hours, written directions, or assistive technology. Yet workplace accommodations continued to be ignored, challenged or denied, even after the appropriate documentation was submitted. One participant described experiencing frequent and ongoing discrimination and prejudice within her workplace, even after spending the time and effort to educate and advocate.

Interviewer: When you disclosed at the workplace, what happened?

Participant: I was sort of dismissed and shut down. Initially, I thought it was just ignorance; they don't know what neurodiversity is. I stupidly kept trying to bring up the issue and educate them. That sort of general public education, you just talk about it, you're open about it, thinking that would get the Executive Director a little bit more up to speed and maybe get her to understand that I'm not just making stuff up [laughs] or trying to pull a fast one or whatever she thought. Then I turned around and I was like, oh my god,

it's been one year and I still haven't gotten any of the accommodations I asked for, except what I insisted.

This finding is particularly concerning given the lengths that people had to go to in obtaining a diagnosis in the first place, and the existence of legislation in Ontario that requires employers to provide such accommodations.

Several participants also described the numerous ways in which they intentionally organized their lives with their ADHD in mind, such as choosing career paths and daily routines that accommodated their challenges and utilized their strengths. The concept and language of neurodiversity provided them with an alternative lens through which to understand dominant beliefs about effort, value, and capacity. One participant explained, *"What I found, the idea of really finding my own work environment that works well for me is really important. [...] I've got a real gift for some things."* When participants chose careers that they genuinely enjoyed, they were able to implement strategies to engage in the challenging aspects of those jobs in order to fulfil their commitments.

When participants proudly embraced their identities and unique ways of doing and being, they often reported positive impacts on not just their practices, but their overall wellbeing. One person summarized, *"The refusal to fit into boxes is neurodiversity exemplified. The reason why I picked this particular field is so I could find a niche for myself and not just die of invalidation."* Participants described a range of ways that the concept of neurodiversity supported their drive to choose and develop pathways that worked well for their interests and strengths.

Service provision and provider education

Across these interviews, people frequently talked about problems in the education and training that service providers (such as teachers, counsellors, and social workers) receive on ADHD and neurodiversity-affirming practice. Problems ranged from trainings that perpetuated pathologizing stereotypes about people with ADHD and other neurodivergent people, to professional curricula that made little mention at all of neurodiversity or disability. As service users, people often struggled to find adequate services and supports, and sometimes had to educate their providers on ADHD and neurodiversity-affirming practice. For example, one neurodivergent service user and provider discussed his experience of seeking an ADHD assessment and learning that his provider had deliberately told him that his appointment was at an earlier time than it was actually scheduled for. This practice revealed a policy that assumed patients seeking a diagnosis for ADHD would be late to their appointments. Such findings illustrate how deficit models of disability shape the ways in which services are offered.

Many participants were also working as educators and service providers. They offered many examples of ways that we could change how we work with individuals and communities. A common theme was moving beyond just the deficit-lens and current focuses on medical treatment. As one participant said, "*I'm of the thought that people have hobbies and interests, and we need to feed and grow those, too, while also treating the problem, instead of just treating the problem and forgetting about their interests.*" Essential to this process is letting go of many of the rigid ideas about productivity and functioning that society holds. Another participant suggested that "*Basically, we need to do things in a different way. We need to do things in a way that is going to be*

counterintuitive to what normal society will tell you is correct." Participants described the importance of flexibility, open-mindedness, curiosity, modification, and adaptation to tasks, routines, and responsibilities, rather than viewing ADHD as a burdensome disorder that requires treatment to "cure" or "fix". Many interviewees experienced ableist society as the thing that disabled them, rather than their ADHD, and learned to empower themselves and thrive, often with the help of neurodivergent practitioners and community.

Unfortunately, participants who were providers and educators also shared experiences of discrimination that they faced in their respective fields as a result of their neurodivergence, and talked about structural and widespread barriers that neurodivergent people face in these fields. One interview participant explained, "*...we kind of push service users out of the [service provider] profession, even though they have the best reasons to go into the profession.*" Several other participants who were service providers across a range of professions described similar experiences of being dismissed, discriminated against, or otherwise excluded in ways that drove them out of the very spaces that desperately need their perspectives.

Discussion

Participants in this study were eager to participate and to learn more about the topic of ADHD and neurodiversity, and to share their experiences with us as researchers. Our conversations with participants revealed that neurodiversity was not simply a neutral descriptor of human differences, but a complex, multifaceted, and sometimes contested concept that brings with it powerful stories about inclusion, relationships, identity, and

discrimination. Our findings illustrate that people are understanding and using “neurodiversity” through community, and we argue that neurodiversity should not be a top-down domain, divorced from its long activist history and subjected to debate and definition by (often neurotypical) researchers and academics (Botha et al., 2024; Gibson et al., 2025; livingstone et al., 2023). We also call for the continued broadening of the communities and identities we see as included in and relevant to neurodiversity. Specifically, we need to hear more on neurodiversity from and about people who identify beyond exclusively Autistic. As this paper demonstrates, people with ADHD definitely see themselves as a part of this conversation and have important knowledge to contribute. These findings suggest that we also need further research that both engages with neurodiversity paradigms and directly involves ADHD-connected communities.

Our findings also suggest that researchers need to approach diagnosis as a fundamentally contested and tension-filled domain with variable meanings and impacts that exist at the intersection of individual experience, identity, and broader systems of power and oppression. For some people with ADHD, including participants in our study, diagnosis brings with it a sense of validation, belonging, and the option to locate oneself in community. For many, diagnosis is the institutionalized mechanism by which they can access resources, supports, and accommodations. However, rates of and access to ADHD diagnosis are not evenly distributed across different social groups (Shi et al., 2021). Dominant constructions of ADHD (and the neurodiversity movement more generally) are embedded with assumptions about gender, class, and race, that make some people’s experiences legible as neurodivergence while others’ are dismissed or invisibilized (Giwa

Onaiwu 2020; Nair et al. 2024). Specifically, framings of ADHD as a condition that primarily or exclusively affects White, cisgender, boys and men make it more difficult for racialized people, women and girls, and people with other marginalized gender identities to receive a diagnosis of ADHD. On the other hand, the label of ADHD, disability, or neurodivergence can also contribute to increased experiences pathologization, discrimination, and even violence in ways that are similarly organized along lines of social power and marginalization (Giwa Onaiwu, 2020; Nair et al., 2024). If researchers rely on formal diagnoses in selecting participants for their studies, it will directly impact whose voices and experiences are represented in research.

By adopting broad inclusion criteria that prioritized self-identification with ADHD and neurodiversity, we were able to reach a diverse range of participants. Because we did not restrict eligibility criteria to those with a specific, formal diagnosis, we were able to hear from a spectrum of people who experience and relate to neurodiversity and ADHD in different ways. Through the interviews, we were able to better understand participants' relationships to the language of neurodiversity. Specifically, depending on each individual's background and context, the concept of neurodiversity can impose certain restrictions and limitations, and may not always be easily understood or accessible to all.

These findings underscore a pervasive lack of representation and training about ADHD and neurodiversity throughout social services, education, healthcare, and related fields. In order to bridge this gap, neurodivergent people must be hired and supported as service providers across every field. We need to challenge existing stigmatizing ideas about who is and is not neurodivergent, how ADHD manifests, and who service providers or

professionals can be. Unfortunately, much of society still perpetuates ableist stigmas and stereotypes (Baker, Drapela, & Littlefield, 2020). This results in neurodivergent practitioners being denied opportunities to participate in these fields or being actively discouraged from contributing when they do gain entry, even as their insights are needed.

Our findings highlight the need to challenge existing ideas about best practices within the existing frameworks for identifying and “treating” ADHD, practices that some of our participants described as abusive or traumatizing. Participants who were mental health professionals critiqued the utilization of the DSM-V as the primary basis of practitioner training. This echoes a growing conversation in the public sector, disability justice communities, and amongst medical and mental health professionals regarding diagnostic processes (Epstein & Loren, 2013).

This study also showed how people with ADHD face misunderstanding and exclusion across multiple social spaces. Interview participants’ discussions about the concept and language of neurodiversity led them to share experiences across many social domains, including family relationships, education, friendships, employment, social services, digital landscapes, mental health, and activism. Our exploratory, ethnographic approach contrasts with most existing research on ADHD, which has focused on a particular social or institutional domain such as elementary education or adult employment. Our findings suggest that research that has a broad scope and exploratory method allows us to learn about how people interact with systems across the lifespan, and provides an important opportunity to investigate cumulative, interactive, and complex social experiences and identities.

Limitations

The findings in this paper emerged from a subset of 11 interviews that were a part of a larger, multimethod project about neurodiversity; they are not necessarily representative of the broader ADHD community. All participants were English-speakers living in Southern Ontario and therefore had a particular set of systems and discourses available to them in understanding neurodiversity and ADHD. Recruiting methods tended to prioritize people who were engaged with online or activist networks, or engaged in service provider roles.

While there was some diversity within the sample in terms of gender, race, age, and socioeconomic experience, further research is needed to understand a broader range of experiences of people with ADHD. While we did not require that people have a formal diagnosis of ADHD to participate in our study, we acknowledge that the broader institutional context often emphasizes diagnostic verification; it is very possible that people who did not have a formal diagnosis were less likely to participate in the research.

Finally, this research occurred over a period of time when the COVID-19 pandemic was upending many assumptions and practices. While the pandemic was not a formal element of our interviews, it is possible that findings from these interviews were shaped by this context of considerable social upheaval.

Conclusion

There has been a welcome burgeoning of writing about neurodiversity, much of it emerging from the scholarship of disabled and neurodivergent community members. While discussions of neurodiversity and neurodivergent community generally mention ADHD as a

set of experiences that should be included, much of this work has, until recently, been focused on the experiences and scholarship of Autistic communities. Our research highlights an ongoing need for further exploration of how people with ADHD understand the concept of neurodiversity, and what practices they want others to develop and embrace. Through this analysis of a subset of 11 interviews about neurodiversity with people who identified as having ADHD, we learned that members of ADHD communities have crucial contributions to share about neurodiversity and insights into the ways that contemporary discussions and practices could be re-imagined. The concept and language of neurodiversity can be more appealing and useful for some people with ADHD than others, particularly in its associations with gendered and racialized vulnerabilities. We invite others to build from the knowledge of diverse ADHD communities in developing ideas and practices that promote more just relations and practices for our collective futures.

References

- Armstrong, T. (2010). *Neurodiversity: Discovering the extraordinary gifts of autism, ADHD, dyslexia, and other brain differences*. Da Capo Lifelong Books.
- Baker, D.L., Drapela, L.A., Littlefield, W. (2020). *Law and Neurodiversity: Youth with autism and the juvenile justice systems in Canada and the United States*.
- Bertilsdotter Rosqvist, H., Hultman, L., Osterborg, S., Nygren, A., Storm, P., & Sandberg, G. (2023). ADHD in higher education and academia. *Canadian Journal of Disability Studies*, 12(3), 1-26.
- Bertilsdotter Rosqvist, H., Stenning, A., & Chown, N. (2020) Introduction. In H. Bertilsdotter Rosqvist, N. Chown & A. Stenning (Eds), *Neurodiversity studies a new critical Paradigm* (1-12). Routledge.
- Botha, M., Chapman, R., Onaiwu, M., Kapp, S., Ashley, A., & Walker N. (2024). The neurodiversity concept was developed collectively: An overdue correction on the origins of neurodiversity theory. *Autism*, 28(6), 1591–1594.
<https://doi.org/10.1177/13623613241237871>
- Brown, A., Bertilsdotter Rosqvist, H., & Jackson-Perry, D. (2024). An introduction to critical ADHD studies. In H. Bertilsdotter Rosqvist & D. Jackson-Perry (Eds.), *The Palgrave handbook of research methods and ethics in neurodiversity studies* (41-60). Palgrave Macmillan.
- Campbell, M., & Gregor, F. (2002). *Mapping social relations: a primer in doing institutional ethnography*. University of Toronto Press.
- Chapman, R. (2020). Defining neurodiversity for research and practice. In H. Bertilsdotter Rosqvist, N. Chown, & A. Stenning (Eds.), *Neurodiversity studies a new critical paradigm* (218-220). Routledge.
- Daley, D., & Birchwood, J. (2010). ADHD and academic performance: Why does ADHD impact on academic performance and what can be done to support ADHD children in the classroom? *Child: care, health and development*, 36(4), 455–464.
doi:10.1111/j.1365-2214.2009.01046.x
- Epstein, J. N., & Loren, R. E. (2013). Changes in the Definition of ADHD in DSM-5: Subtle but Important. *Neuropsychiatry*, 3(5), 455–458. <https://doi.org/10.2217/npy.13.59>

- Espinet, S., Graziosi, G., Toplak, M., Hessen, J., & Minhas, P. A review of Canadian diagnosed ADHD prevalence and incidence estimates published in the past decade. *Brain Science*, 12(8), 1051. <https://doi.org/10.3390/brainsci12081051>
- Fuermaier, A. B.M., Tucha, L., Butzbach, M., Weisbrod, M., Aschenbrenner, S., & Tucha, O. (2021). ADHD at the workplace: ADHD symptoms, diagnostic status, and work-related functioning. *Journal of neural transmission (Vienna)*, 128(7), 1021-1031. <https://doi.org/10.1007/s00702-021-02309-z>
- Gibson, M. F., Livingstone, B., Easton, S., Monroe, H., & Gruson-Wood, J. (2025). Texts and Effects: Interview Findings on Neurodiversity and Representation. *Neurodiversity*, 3. <https://doi.org/10.1177/27546330251350740>
- Gibson, M. F., Livingstone, B., Monroe, H., Leo, S., Gruson-Wood, J., & Crockford, P. (2024). Observing Neurodiversity, Observing Methodology: Ethnography in Pandemic Times. *International Journal of Qualitative Methods*, 23, 16094069241266200. <https://doi.org/10.1177/16094069241266200>
- Giwa Onaiwu, M. (2020). “They Don’t Know, Don’t Show, or Don’t Care”: Autism’s White Privilege Problem.” *Autism in Adulthood*, 2(4), 270–72. <https://doi.org/10.1089/aut.2020.0077>
- Ginapp, C. M., Macdonald-Gagnon, G., Angarita, G. A., Bold, K. W., & Potenza, M. N. (2022). The lived experiences of adults with attention-deficit/hyperactivity disorder: A rapid review of qualitative evidence. *Frontiers in psychiatry*, 13, 949321. <https://doi.org/10.3389/fpsyg.2022.949321>
- Hoben, J., & Hesson, J. (2021). Invisible Lives: Using Autoethnography to Explore the Experiences of Academics Living with Attention Deficit Hyperactivity Disorder (ADHD). *New Horizons in Adult Education and Human Resource Development*, 33(1), 37-50. <https://doi.org/10.1002/nha3.20304>
- Jackson-Perry, D., Bertilsdotter Rosqvist, H., & Brown, A. (2025). Moving forward: A call for Critical ADHD Studies. *Disability & Society*. <https://doi.org/10.1080/09687599.2025.2458016>
- Kafai, S. (2021). *Crip kinship: the disability justice & art activism of Sins Invalid*. Arsenal Pulp Press.
- Kapp, S. (2020). Introduction. In Kapp SK (Ed.), Autistic community and the neurodiversity movement stories from the frontline (1-22). <https://doi.org/10.1007/978-981-13-8437-0>

Livingstone, B., Gibson, M. F., Douglas, P., Leo, S., & Gruson-Wood, J. (2023). Weighing In: Academic Writers on Neurodiversity. *The International Journal of Disability and Social Justice*, 3(3), 72–98. <https://www.jstor.org/stable/48755797>

Marley, C. (2023). Investigating ADHD across education and health: A critical ethnographic approach. *International Journal of Research & Method in Education*, 46(4), 434-446. DOI: 10.1080/1743727X.2023.2196067

McCoy, L. (2006). Keeping the institution in view: working with interview accounts of everyday experience. In Smith, D. E. (Ed.) Institutional ethnography as practice.

Mechler, K., Banaschewski, T., Hohmann, S., & Häge, A. (2022). Evidence-based pharmacological treatment options for ADHD in children and adolescents. *Pharmacology & therapeutics*, 230, 107940. <https://doi.org/10.1016/j.pharmthera.2021.107940>

Mingus, M. (2011, February 12). Changing the framework: Disability justice. *Leaving Evidence*. <https://leavingevidence.wordpress.com/>

Nair, V., Warda, F., & Boveda, M. (2024). Is Neurodiversity a Global Northern White Paradigm?. *Autism, September*, 13623613241280835. <https://doi.org/10.1177/13623613241280835>

Piepzna-Samarasinha, L. L. (2018). *Care work: Dreaming disability justice*. Arsenal Pulp Press.

Schreuer, N., & Dorot, R. (2017). Experiences of employed women with attention deficit hyperactive disorder: A phenomenological study. *WORK*, 56(3), 429-441. <https://doi.org/10.3233/WOR-172509>

Shi, Y., Guevara, L., Dykhoff, H., Sangaralingham, L., Phelan, S., Zaccariello, M., & Warner, D. (2021). Racial Disparities in Diagnosis of Attention-Deficit/Hyperactivity Disorder in a US National Birth Cohort. *JAMA Network Open*, 4(3): e210321. <https://doi.org/10.1001/jamanetworkopen.2021.0321>.

Sins Invalid. (2019). *Skin, Tooth, and Bone: The Basis of Movement is Our People* (2nd ed.). Berkeley, CA.

Smith, D. (2005). *Institutional ethnography: A sociology for people*. AltaMira.

Varrasi, S., Boccaccio, F. M., Guerrera, C. S., Platania, G. A., Pirrone, C., & Castellano, S. (2022). Schooling and Occupational Outcomes in Adults with ADHD: Predictors of Success and Support Strategies for Effective Learning. *Education sciences*, 13(1), 37. <https://doi.org/10.3390/educsci13010037>

Visser, J. & Jehan, Z. (2009). ADHD: a scientific fact or a factual opinion? A critique of the veracity of Attention Deficit Hyperactivity Disorder. *Emotional and Behavioural Difficulties*, 14(2), 127-140. DOI: 10.1080/13632750902921930

Walker, N. (2014). Neurodiversity: Some basic terms & definitions. Available at: <https://neuroqueer.com/neurodiversity-terms-and-definitions/>

Wheeler (2010). Critique of the article by Visser and Jehan (2009): 'ADHD: a scientific fact or a factual opinion? A critique of the veracity of Attention Deficit Hyperactivity Disorder'. *Emotional and Behavioural Difficulties*, 15(3), 257-267. DOI: 10.1080/13632752.2010.497665

Wong, A. (Ed.). (2020). *Disability visibility: first-person stories from the twenty-first century* (First Vintage Books edition). Vintage Books, a division of Penguin Random House LLC.

Zaneva, M., Coll-Martin, T., Hejja-Brichard, Y., Kalandadze, T., Kis, A., Koperska, A.,...& Zisk, A. (2024). An annotated introductory reading list for neurodiversity. *eLife*, 13. DOI: 10.7554/eLife.102467