CHAPTER 17

On the Simple Joys of Bouncing: Duoethnography of Neurodivergent Researchers in Academia

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Introduction

We are openly neurodivergent researchers with experiences of autism and attention deficit hyperactivity disorder (ADHD). In this chapter, we use duoethnography—"a collaborative research methodology in which two or more researchers engage in a dialogue on their disparate histories in a given phenomenon" (Sawyer & Norris, 2015, p. 1)—to make meaning from our experiences as individuals at the intersection of being neurodivergent and researching neurodiversity. We are particularly interested in the ways that academia structurally interfaces with neurodiversity and neurodivergent individuals' experiences and expectations of such environments (see also Chapters 16, 18, this volume).

In undertaking this exploration, we represent the experience of one individual who is autistic (Noah) and one who is ADHD (Teddy). In fact, these experiences are not mutually exclusive, with symptomatic and neurobiological overlap between the two (Antshel et al., 2013), and a significant population estimated to be both (Antshel et al., 2013; Rau et al., 2020), to the extent that it is sometimes abbreviated as "AuDHD." Executive function, for instance, covers a cluster of cognitive domains, such as activation, focus, effort, emotion,

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memory, and action (Brown, 2009), that are implicated in both ADHD and autism (Brown, 2009; Demetriou et al., 2018; Pellicano, 2012).

In this chapter, we will briefly start with some definitions, then alternate autoethnographic writing, interacting with each other's perspectives by noting shared and distinct experiences. We will conclude by discussing our experiences engaging in this generative project and what we hope this inspires in future investigative endeavors.

Definition of Neurodiversity

There are currently varied and sometimes conflicting accounts of neurodiversity, perhaps even within this book. We feel it necessary, and important, to define our own and thus the basis on which our discussion rests. Accordingly, we use the following definition; "Within the neurodiversity movement, all embodied diversity (including neurological differences) is accepted as a facet of human nature, whilst the concept of 'impairment' and related purist medical models are commonly denounced as normative" (McWade et al., 2015, p. 306). That is to say, *neurodiversity* expresses the idea that there are many different ways of perceiving the world, none of which are inherently superior or disordered. The term *neurodivergence* then refers to the ways that specific individuals "perceive, experience, and interact with the world" in a way that is distinct from societal norms (Hamilton & Petty, 2023, pp. 1–2; for more discussion of terminology see Adams et al., 2023). In this framework, *neurotypical* is used to describe non-neurodivergent experiences.[1]

INTRODUCING DUOETHNOGRAPHY AS A RESEARCH METHOD IN AUTISM AND ADHD RESEARCH

There is little in the way of duoethnographic writing on the experience of autism or ADHD in academia. However, importantly, there is some precedent to the use of this methodology in duo (or multi)-ethnography in autistic autobiographical writings, though possibly not with this specific intention. Miller's *Women From Another Planet*, for instance, includes two chapters (*Beginnings*, and *Differences*) that put the texts' authors in conversation about being and communicating as an autistic person (2003).

Autoethnographies that explore the intersection of being both autistic and a researcher are somewhat more common. Autoethnographies that explore the academic discourse on this intersection are also increasing. Literature on autistic phenomenologies—i.e., lived experiences, as opposed to external

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[1] In this chapter, we will use "neurotypical normativity" to refer to societal assumptions of neurotypicality which accordingly render such experiences neutral, the invisible default. "Neurotypical privilege" will refer to the experience of not needing to consider one's position in the spectrum of neurodiversity due to having a neurotypical experience for which society has been structured (Bouckley, 2022); others have named it "the educational tyranny of the neurotypicals (Ito, 2018)".

manifestations—is also growing. Raymaker (2017), for example, used evocative autoethnography to articulate and describe her experiences as an autistic, disabled "insider researcher," and so to push back in a way that pushed back against sociocultural narratives that expect autistic individuals to struggle to articulate themselves in speaking for themselves. Williams (2020) also published an amalgam of non-fiction and fictionalized autistic autoethnographies that drew from autistic participants' descriptions of their experiences with communication.

Collective autoethnography about autistic experiences to date includes Jackson-Perry et al. and and's (2020a, 2020b) text on sensory experiences and Bertilsdotter Rosqvist et al.'s (2020) on social spaces and community-building. Murray et al. (2023) engaged in an autistic/allistic discourse about individual life course experiences, as synthesized for common themes (e.g., the need for trust and reliability, the impact of context on regulation of emotion, sociability, and empathy) and divergent themes (e.g., primary sensory experience and social joining). Autoethnography of ADHD experiences, however, remains more limited (e.g., Ing & Mills, 2019; Salty et al., 2022, see also Chapter 12, this volume).

Why Duoethnography

We use duoethnography to articulate the experiences of individuals who are at the intersection of researching and being neurodivergent and to explore the ways in which these positionalities interface with academia. It is a very new methodology (Norris & Sawyer, 2012) which, alone amongst other qualitative methods, focuses on researchers, and the dialogue between them, as sites of information-gathering (Breault, 2016). It is thus an ideal method to use in exploring the divergent experiences of neurodivergent researchers within academia, where little such research exists.

Duoethnography is an extension and evolution of autoethnography, which "is a [qualitative] research method that uses personal experience… to describe and interpret… cultural texts, experiences, beliefs, and practices… [from the belief] that personal experience is infused with political/cultural norms and expectations (Adams et al., 2017, p. 1)." Both duoethnography and autoethnography serve to intimately illustrate concepts by grounding individual experiences within theoretical frameworks and, in doing so, respond to community stakeholders' calls to increase research that pertains to their lived experiences (Bertilsdotter Rosqvist et al., 2019; Fletcher-Watson et al., 2019). Duoethnography, however, takes autoethnography further and multiplies it by providing for a collaboration between two (or more) researchers to "juxtapose… and work in tandem to untangle and disrupt meanings about a particular social phenomenon (Burleigh & Burm, 2022)." While there is a young literature documenting autistic academics' experiences, ADHD experiences in academia remain relatively untouched, as does juxtaposition of neurodivergent experiences. Duoethnography as a methodology allows us to articulate and triangulate a common experience.

DATA COLLECTION

As a duoethnography, our primary data is composed of each researcher's individual experiences of being a neurodivergent individual who also conducts research on neurodiversity (Chang, 2013). We took turns writing two self-contained narratives on this experience, the first on our research process and the second on navigating our identities and roles as neurodivergent researchers. We purposely did not discuss or show each other what we would write before doing so. The narratives themselves were written in one-sitting and in a "free-flowing" manner, in order to best articulate our own internal methods of thinking. After the initial "burst" of writing, we went back and edited our own excerpts, while refraining largely from editing those of each other. Those edits we did make were in the form of suggestions and largely restricted to suggesting where something might be elaborated on. A Google Doc (Mountain View, CA) was used for this, which made co-working on the chapter much easier.

Analysis

As an emerging qualitative method of inquiry, the means of analysis of the data gleaned through duoethnography are not yet standardized (Breault, 2016). We opt here to simply compare and contrast our differing experiences of being neurodivergent individuals who also research neurodiversity; one from the perspective of an ADHD individual and one from an autistic. To do so, we each read and re-read the others' narratives and took notes on the aspects of neurodivergency that seemed shared—or different—between us. We then collaborated to provide a shared analysis of the experience of individuals at the intersection of being and researching neurodiversity. In doing so, we draw out common experiences between our two perspectives and provide the groundwork for more in-depth examinations.

FINDINGS

Here we will present duoethnographic data, beginning with autoethnography about how ADHD impacts TGG's research process, followed by NA discussing how autism influences his research process, then TGG commenting on the experience of reading NA's and vice versa.

Neurodivergent Research Processes

ADHD. As I start to write this, I can't focus: I'm in a rolling office chair at work. It's objectively nice, offers adequate lumbar support. Yet, my legs are straightened in front of me under the desk, bouncing up and down, bumping into the wall periodically. For the past decade, my productivity has relied upon using a yoga ball as a chair. I forget about it until colleagues ask why I'm bouncing on video calls. My resting state is bouncing.

The graveyard of half-finished projects on my computer hard drive rolled over when I agreed to write this chapter. *Your day will come*, I assure them. I'm just waiting for the perfect weekend in which I have no obligations and wake up inspired to write one of those data sets into a paper! When that happens, the draft pours forth in a satisfying frenzy of emphatically loud typing. Unstoppable. Is there any difference between a paper written in eight straight hours based on data that sat untouched for two years and steady and deliberate progress on a project over the same period of time? To the journal reader, no. To the spouse, friend, or coworker witnessing the hyperfocus wormhole, absolutely. What magic! Not a researcher, but a machine! Perhaps coveting dazzling efficiency. To me, guilt covers neglected ideas as green biofilm, thicker and slimier each time I remember having forgotten and still lack the motivation needed to open the file and start. No matter what gets finished, I do not feel prolific or even celebratory—I have poor object permanence. *In press* may as well be in a closed drawer or cabinet: as good as forgotten.

I can't imagine spending a career studying one highly specific topic. I get bored. Or rather, I get distracted—I have variable attention (see Bertilsdotter Rosqvist et al., 2023a, 2023b; Hallowell & Ratey, 2021). What is as tantalizing as a new idea? It can make planning difficult. The proposal flows almost effortlessly. Data gathering is intoxicating—the only true novel information that exists in the world. As I said in middle school: science class was a misnomer—it, too, taught history. But where does one find the motivation to transcribe and code after conducting an interview? To revamp a rejected paper and reformat it for submitting to a new journal? There are so many steps between revelation and dissemination, each one treading through quicksand. My initial interest in research, as in medicine, was wanting to improve lives, but I fell in love with research as an adrenaline junky.

My friends in college and medical school could not understand what got me into the lab at 4:00am. My honest response of "data" was unable to convey my dopaminergic glee at the tantalizing possibility of discovering new information. Translating a few hours of work into bursts of numbers that promised a new understanding of the world was intoxicating. It felt like a slot machine that won more times than not; I learned over the course of five years in a wet lab that I didn't have the patience for techniques that didn't, that required more finesse. The microscopic began to threaten meaninglessness.

I switched to qualitative and mixed-methods research exploring human experiences and developing interventions to meet those expressed needs. Such work feels less dissociated and does not require a patience for repetition without payoff that I inherently lack. The stable nature of interview data is more robust to fits and starts—it is not subject to denaturing, swapped reagents, or mold contamination. It also runs on a different funding scale: there is less for me to manage. The intellectual stimulation to executive functioning self-discipline ratio is infinitely higher, allowing me to find a semblance of home, to imagine a career of success rather than self-sabotage—or, at least, to hope.

Autistic. Teddy has sent me an early draft of this article to look at. It's one long stream of text roughly broken up according to headlines that seem haphazard and temporary. I start by editing the abstract, before I even realize that there is more text. I am fixating and it occurs to me, after creating a wall of red track-changes, that Teddy might find this insulting. I realize that I'm not really getting anywhere, so I zoom out and start to work on the paper outline. Making sure that everything is in its right place, with page breaks, proper APA headings, and the margins just so. This is always a good place for me to start. It makes things feel orderly.

I set up my working environment in the same way. Sitting at a coffee shop on a comfortable couch and with my legs crossed or tucked under me. It always has to be the same, but not always in the same place. Right now, for instance, I'm in Glasgow, but usually I'm at a co-working space near my apartment in Berlin. I usually wear big headphones and recently switched to my first pair of active noise canceling headphones[2] (where have you been all my life!). When walking around I'm almost always listening to a podcast, but right now the words will distract me and only synthwave will do. In fact, at the moment I'm listening to Fleetmac Wood.[3]

The headphones are important because sounds and movements will distract me until they become unignorable and start to make me angry. Sudden high-pitched sounds are the worst. This way I can work without distractions, at least for a bit. Of course there are the distractions in my head. Sometimes it's still like a clear pond up there. I can get lost and hyperfocus on the work I'm doing. But sometimes I'm distracted with one of my special interests or, less charitably, obsessions. I listened to a podcast about UAF Flight 571 (Marshall, 2022) the other day. Now I can't stop my mind from wandering back and worrying at it. Like if I could figure out the logic of selflessness and heroism I could provide the formula to the world.

Concentrate Noah.

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[2] Sony WH-1000XM4 for those who are interested.

[3] Check them out @ http://www.fleetmacwood.com/!

It bothers me that Teddy has filled in some areas and not others, created some headings, but left out expected ones. A section for our autoethnographies, but not data?[4] I attempt to impose some more order on it by placing the autoethnography titles under one subheading (Data) and starting a short section explaining our intent. That's a bit better. But still, where to start? In retrospect it makes sense that they would fill out the pieces that they know and leave the rest to me. This is collaboration or, apparently, duoethnography. And I recognize that I make the same assumptions with regards to my own writing, as we pass this back and forth. Nevertheless, I'm not good with a blank page and even worse with one that seems random. I need a model that I can extrapolate from. I often wonder whether it is possible for me to be creative or original, or if I am just very good, *very practiced*, at building seemingly new things from the bricks that others have left behind. I suppose it doesn't matter. My autoethnography is a good enough place to start. A corner that I can wedge the rest of the paper out of.

I keep bouncing back and forth between Teddy's section and mine. I can't say I speak for all autistics, but much of what others' write seems hauntingly familiar. The hyperfocus that results in writing screeds of information over a relatively short amount of time, followed by months of avoidance. The preference for late night work. I have never been what you might call a morning person. But, unlike Teddy, I love reformatting and editing papers. It's like pulling teeth to get it out, but going over and making it better is easy and what's more, fun. I feel like I'm achieving something and working towards a goal. That it's measurable in some definable way. I have always loved paperwork. Probably for the same reason I love data entry. I'm an excel-spreadsheet junkie. I find the idea of working steadily on a small but incremental contribution to a distant goal that I'm passionate about deeply satisfying. You see that tiny dot there? That's me!

That's an autistic thing too. That hyperfocus and fixation on 'special interests.' I have many special interests of course, but my interests in research methodology, as well as transgender and autistic subjects, probably serve me the best in an academic and research environment. I suppose in many ways this makes me the platonic ideal of a researcher. Diligent, hardworking, and without a good work/life balance. That's fine. But academia is more than that. There are hidden power dynamics and politics and the day-to-day realities of interpersonal communication in research groups and with colleagues. It would be an understatement to say that I am terrible at both. I lumber around like a bull in an emotional china shop. Stumbling into shelves and knocking over interpersonal teacups. People read intention into my misunderstanding or failure to pick up unspoken hints, but more often than not I just haven't noticed. On the occasion where I do, I have learned not to react for fear of assuming the wrong meaning and thus saying or doing the wrong thing. In

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[4] Later when editing I will forget that I wrote this and haphazardly delete a heading that no longer seems adequate to me. I will wonder who put it there.

my calculation it seems better to gamble at people being confused than being sure that we will misunderstand each other. Most often though I don't even notice and so it will get back to me months, or even years later than people have assumed my terseness or lack of emotional response was a judgment of them. All in all, it seems better to just isolate myself from others and limit my interactions to email as much as possible.

Don't get me wrong. I have attempted to bridge this communication gap and explain when I notice that I am miscommunicating. It has been my experience however that neurotypical people tend to view this as 'making excuses' and to overestimate their ability to empathize with what it means for me to be autistic. Milton (2012) identify this as the double empathy problem; where communication breakdown occurs between autistics and allistic (non-autistic) people, but the autistic person is primarily or solely seen as the problem. So, all In all, it seems safer just to agree with them and stop speaking. Unfortunately, this isn't ideal for climbing the academic hierarchy which, admittedly, is something I have little to no interest in anyway. I do worry about my ability to navigate academic politics in hiring and staying employed though.

Navigating Identities and Roles as a Neurodivergent Researcher

ADHD. The main ghost that haunts my racing thoughts in the middle of the night is named "professionalism." An acceptably veiled term used to block access to expert status within medical and research from those of us for whom these fields were not made (e.g., Frye et al., 2020; McCluney et al., 2021). I am more familiar with this explicit phenomenon with regards to my transness, as my ADHD is generally obvious on observation to a trained eye, but is not written on ID badges and email signatures with my they/them pronouns–or stereotypically clocked in my short stature, youthful appearance, and patchy beard. I have a decade of research experience on transgender, non-binary, and/or gender expansive health, including developing the first animal model of gender-affirming hormone therapy as my master's thesis, and yet… I have been invited to speak at conferences with cis colleagues, only to later learn that while they will be reviewing the literature, I (the only speaker who conducted primary research on the topic) am to provide the "color commentary" discussing my personal experiences as a non-binary/trans person. I have swallowed my rage and pride, played the academia game, only to have my personal and professional expertise directly contradicted and undermined by my co-presenters.

With ADHD (as with my chronic illness), I am not tokenized the same way. Though I am open with colleagues about my lived experiences on principle–I refuse to contribute to stigma, to give myself permission to feel shame–those labels do not seem to color their every interaction with me. This is exceedingly ironic as my neurodivergence courses through my every thought and action in a way that my gender does not. Perhaps neurodivergence feels more nebulous to neurotypical brains—or the façade of neurotypical normativity remains particularly impermeable—and accordingly it's easier to consider manifestations as individual traits, or more often eccentricities, even failures.

My core ADHD fear as a doctor and researcher boils down to: *am I interpreted as unprofessional*? This blares in my brain as follows:

Sitting on a yoga ball chair improves my focus, but accentuates my baseline bouncing–in video meetings, should I forgo this aid to mask, try to shake and squirm entirely off-camera?

> Was I seen as too loud, too fast, too much when enthusiastically talking about my research with a potential collaborator or employer?
>
> Was I labeled rude when I was overstimulated by the noise and lights at a networking event and stopped engaging appropriately? Or, as aloof or arrogant when I then tried to hide in a corner alone to re-regulate, unable to suppress the wince on my face?

I have developed so many work-arounds for my profound difficulty holding multiple pieces of information in my awareness simultaneously–like responding to emails immediately, before they disappear from my awareness for good, and setting repetitive phone alarms to remind me of meetings–but sometimes I am interrupted or just too burnt out. How much erratic (dis)engagement can a work relationship tolerate before I am labeled unreliable or flaky? I fear that the times I'm able to meet expectations will be held against me when I fail to do so–evidence that I have chosen to fall short. Meanwhile, neurotypical privilege renders my efforts invisible.

How many typos, half-finished sentences, and formatting errors are acceptable in a paper draft? When writing (and editing), I jump around between sentences and sections, following the dopamine, allowing my thoughts to charge forward and flow out onto the page. Prolific! Yet, I leave fragments in my wake. Forcing myself to go sequentially leads nowhere: I get bored and bail. I feel self-conscious when the time-stamps on tracked changes and comments in word processing documents expose my process. There are currently three finished primary research papers that sit unpublished on my computer hard drive because of my physical inability to reformat them for a new journal's stipulations after our prior rejections. My shame prickles whenever I remember that manuscript graveyard; I have no idea what my co-authors–mentors and collaborators–think.

Navigating academic cultural expectations and values is not a neutral experience. How many times will I sit in a lecture by someone who does not share my lived experience, about my lived experience (and professional expertise), and hear incorrect (even offensive) information spouted as fact? How many times will my heart race, my face flush, my eyes burn, as I decide whether or not I may speak up *again* in that room? How many times does that trauma wreck my productivity for the remainder of the day? I am a scholar who studies my community's experiences, needs, and preferences and I work tirelessly to manifest that better world. Yet, trying to live up to the pressure of being the voice in those rooms, advocating for those who are not, takes a toll.

Autistic. "They say they want you successful, but then they make it stressful/ You start keepin 'up the pace, they start changing up the tempo" (Mos Def in Jackson, 2021).

Much of what Teddy has written above seems similar yet ever so slightly different from my own experiences. I don't, for instance, worry so much about the number of typos in a submission (especially since the almost universal availability of spell check). But I certainly self-police for whether my emotional and reciprocal expression appears correct to others. Was I too loud? Did I speak too much or too little? The rules seem capricious and unreliable.

It's a cliché, but I'm reminded of a scene from Star Trek Generations (Carson, 1994) where Data attempts to emulate a practical joke played on one crewmate by repeating it on another.[5] Logically, this makes sense. Data is simply recreating the joke played on Worf in an attempt to share the experience with his comrades. But it lacks context and, more importantly, the seemingly psychically communicated emotional subtleties that tell his colleagues where 'the line' is. As Teddy states, the person communicating in this way is perhaps seen as rude and unpredictable. The alternative is not to participate at all and thus be viewed as aloof, arrogant, and to be intentionally nonverbally communicating disdain and a lack of interest. It doesn't matter that I haven't said this or even, when asked, specifically refuted this intention. It seems that, no matter what I do, my social behavior is interpreted as unprofessional.

In fact, the very concept of professionalism represents a collection of unspoken and rarely articulated ideas about the 'proper' way to behave at work that are an outgrowth "of the values, actions, and emotions of straight white men (Mann, 2018)." Tami Jackson beautifully articulates how this especially affects black women who are "mentored to mask [their] personhood and humanity into a small, shallow, tight box… designed to suffocate [them] with white norms (2021)." These aren't, per se, challenges of the core values of professionalism, such as respect for patient welfare and a commitment to being on time (Lucey & Souba, 2010). Rather the challenge is to the 'neutral' baseline on which professional appearance and communication is determined.

I have, nevertheless, developed a series of adaptations to manage my own workflow and communication with others. First and foremost, I strongly prefer online communication if possible. This allows me time to consider and frame my responses in a way that neurotypicals can understand. I use an email client to collect and access all my email addresses into a central location and I treat the inbox as a list of things that need to be acted on. Everything else is immediately moved to 'archives.' I am always in search of 'inbox zero,' and achieve it 1–2 times a month. Like Teddy, I have a mountain of unfinished projects. Though, over time, I have become better at picking out and pursuing projects

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[5] I highly recommend Gil Goletski's Bodies with purpose: An exploration of the intersection of autistic and transgender coding in Star Trek (2019).

to completion. Part of this is learning to say no more often and part is knowing that the time for old projects often comes back around again. I've developed a digital filing system for those that get shelved to allow me to easily access them again in the future. I also often offer unfinished projects to others if I see that they are doing something similar. Better that they do something with it than it just sits on my hard drive forever.

Analysis

Teddy's Reflection on Noah

Reading Noah's reaction to getting my chaotic seedling of a document made me laugh out loud. "Haphazard and temporary" is how all of my work starts—I chafe against strict formats, I struggle with being told what to do. I cannot relate to his reflection, "I need a model that I can extrapolate from." Rather than hurt, I was profoundly relieved when Noah reorganized everything. It did not change my writing process at all (I continued to bounce between sections) and saved time and frustration on the back end. Trying to tidy up in that way is exhausting and difficult for me—I couldn't care less and don't even really see it.

Noah's description of needing specific sounds or quiet for different tasks resonates with mine. For my brain, the most taxing cognitive functions require silence, but I have specific playlists that I play while writing if I need a stimulus to prevent me from just zoning out thinking for the next hour. This week my hyperfixation has been Rachel Carson after learning more about her work and life in an audiobook that I was reading. I wonder about the structure of Noah's headphones. I can't handle over-the-ear ones. I bop my head too much and they wiggle and drive me nuts. Also they squish my ears into my glasses. I need soft-tipped earbuds (never the hard plastic!).

Noah's invocation of the bull in the china shop metaphor interests me, because I've often been described as moving that way (impulse to muscle faster than it's possible to notice the person or end table that is already occupying that space. I don't resonate as much with Noah's interpersonal iteration. I sometimes bowl people over with overly direct responses, but navigating social (and really political) dynamics doesn't mystify me the same way that it seems to Noah. I don't like feeling like a cartoon spy playing laser limbo, but with intention I'm usually able to avoid getting burned.

I share Noah's quest for 'inbox zero,' but am eternally out of reach of it. Part of it is that certain messages are not truly crossed off my to-do list. The larger factor is the digital manifestation of object impermanence. The same reason I forget to close kitchen cabinets and leave items lined up on the top of my desk instead of in a drawer—for me, out of sight is out of mind and I don't want to lose things that I think might be important in the future. I have a comprehensive email inbox folder filing system, but it's an archive: I only move messages into storage when I don't think I will actually need them, but keep them for posterity just in case. I wonder if Noah has the same problem or if his filing system feels dynamic, accessible, always within reach. I wonder if he trusts himself to know where he leaves things.

Noah's Reflection on Teddy

As I read through Teddy's reflections on their processes as a neurodivergent researcher I am struck by the similarities to my own experiences. We share a non-linear thinking style, but it is articulated in different ways and with unique dimensions. We are alike in that we have both consciously—and probably unconsciously—adapted to working in and with the neurotypical world. But the ways in which we adapt sometimes differ. Teddy bounces. I burrow into a topic until I can't hear anything around me, preferably while sitting on a weatherbeaten sofa in the corner of a coffee shop. We both worry about the acceptability of our adaptations and the degree to which they are tolerated by our colleagues. I deal with this by avoiding them, but I imagine Teddy doesn't have that luxury.

I am trying hard here, as we agreed, to not read Teddy's response before finishing my own, but I did spy the last line, in which they muse on my own relationship to object permanence. That is, do I so meticulously construct my 'intellectual filing system' because I don't trust myself to know where I put things. The short answer is that I don't. Out of sight, out of mind. I structure things in a consistent and patterned manner so that, even when I forget about the whole, I can find the individual components and trace things from there.

Teddy shares their need to work on new projects in order to maintain interest and enthusiasm. I have certainly had these moments but, overall, I prefer to slowly and methodically work through the intricacies of data, entering things in spreadsheets, and organizing them. And while Teddy mentions difficulty in returning to and revising articles, I thoroughly enjoy it… as long as I can understand and accept the revisions suggested, which is far from guaranteed. I suspect my problem here is more one of stubbornness than attention though.

Both Teddy and I appear to have learned to direct our academic work towards our strengths and away from the areas that we find intolerable or impossible. Though our directions might be different, the goal is the same and often the 'work-arounds' and adaptations we develop are as well. Likewise, we share concern that 'professionalism' is used to disparage the work of researchers who diverge from the mean. Researchers who bounce. It never seems to occur to those defining normality that they are, perhaps, the abnormal ones. Teddy observes that academic cultural expectations and values are not neutral, and I add that they are also invisible to the very people who are centered by them. I am fascinated by their observation that their trans identity is more often the source of academic marginalization and tokenization than their neurodivergence though.

Then there is the shame. The fear of being first noticed as different and then excluded for it, no matter the quality of your work or time spent on it. And the fear that your non-linear style of thinking is bad, or somehow wrong, simply because it is different. And the burn out when we are forced to perform in a personally abnormal manner for too long.

Discussion

The process of creating this duoethnography, our first, was illuminating. The focus of this chapter is on juxtaposing our experiences of neurodivergence *vis a vis* being both neurodivergent individuals and researchers of this subject. This exploration led us, unexpectedly, to find common experience between our respective methods of navigating neurotypical normative academic environments. We both, for instance, have non-linear thinking styles, issues with object permanence, and deploy multiple adaptations—particularly organizational—to integrate into the neurotypical world. Our differing neurodivergencies (ADHD and autism) go some way to explaining the distinctions between how we experience and do these things, but the similarities are, at least to us, surprising.

The key similarity between our experiences appears to be the overall sense of hypervigilance we have over our actions and behaviors, and the ways in which they are perceived by the neurotypical world. Teddy with their bouncing, and Noah with his uncertainty regarding others' expectations. While we focus on moving toward our neurodivergent strengths, this vigilance has a continuous and corroding impact on our sense of self and certainty as individuals and academics. It is a situation aptly described by the double empathy problem, whereby neurodivergent individuals bear the higher burden of rectifying communication breakdowns with neurotypicals (Milton, 2012). But this is also a problem of masking, that is the multiple strategies used by neurodivergent people to hide their diversity, which has been found to have a profoundly negative self-impact (Miller et al., 2021).

Masking, however, is often perceived as necessary to compete in the highly structurally neurotypical world of academia, where neurodivergent behaviors (e.g., rocking, stimming, needing adaptations) may receive harsh criticism and even censure from neurotypical peers. In this context, neurotypical behavior is seen as normative and natural, whereby many neurodivergent ones are perceived, without evidence, as intentional, problematic, and even harmful. Indeed, research suggests that neurotypicals may be much more vulnerable to making snap negative decisions about neurodivergent peers—specifically autistics—based solely on social and non-verbal differences and despite 'functioning' status (Sasson et al., 2017).

In fact, this is an expression of ableism in academia more broadly, where disclosure by and representation of disabled academics continues to lag behind the student population (Brown et al., 2018). Nevertheless "'coming out' and the complex issue of representation for disabled academics is a double-edged sword involving an intricate web of negotiations, rarely with the promise of a positive career outcome (Gillberg, p. 13)."

A recent German study found that the unemployment rate amongst autistics is roughly 5 times the general population (25.2%), that these periods average 23 months, and that "interpersonal problems [are]… the main reason for contract termination (Espelöer et al., 2023, p. 731)." Higher levels of education did not protect against this. This study is typical, with others finding even higher rates of unemployment (Ohl et al., 2017). Whilst information on unemployment of ADHD individuals appears to be scarcer, one study did note that these individuals had a 17% lower income and more days of unemployment per year than neurotypicals (Jangmo et al., 2021). Accordingly, neurotypical bias against neurodivergent individuals' ways of thinking and interacting with the world appears to carry a real potential to negatively impact our career possibilities and outcomes.

One potential answer to these dilemmas may be to support neurodivergent individuals in conducting and leading research on neurodiversity. Doing so would create an opening for neurodivergent researchers in the academy, increase knowledge on our experiences, and provide better access to what can be a very hidden population. At its most basic, doing so would entail acknowledging that neurodivergent individuals can act as competent and objective researchers on subjects that center our own experiences. From a more structural perspective, adaptations to Research Ethics Boards and a greater appreciation for neurodivergent communication styles in the academy, on project teams, and in meetings would be necessary.

Conclusions

Engaging in ADHD/autistic duoethnography about our experiences as neurodivergent scholars was both revelatory and healing. We were able to glean a better understanding of how our own minds worked and plumb the richness of divergent and overlapping experiences that openly naming—and celebrating!—neurodiversity offers. Explicitly articulating our chafing against neurotypical normative social contracts and sharing that with a neurodivergent colleague combatted the shame that we feel for such, usually internalized, struggles; this Google Doc was a space in which we found community. We hope this project underscores the value of collaboration and knowledge exchange between individuals with distinct neurodivergent experiences and inspires future projects utilizing similar methodologies.

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CHAPTER 18

The (In)Accessibility of UK Universities' Ethics Application in Humanities and Social Sciences

Katie Munday

INTRODUCTION

Research ethics frameworks aim to ensure that researchers maintain high ethical standards, integrity, and confidentiality, protecting the researcher and their participants, as well as the reputation of their affiliated university (Bryman, 2012). Ethics policies within UK universities outline that all research and innovation activities undertaken by staff and students require ethical review (this includes undergraduate students who speak to human participants as part of their dissertation). Ethics applications within Humanities and Social Sciences (HSS) in UK universities should be flexible enough to work across different disciplines but precise enough to keep individuals safe and ensure good quality outputs (Federman et al., 2013). Despite the importance of ethics applications and the practices they uphold, the process of obtaining a favourable opinion may contain barriers which disproportionately impact neurodivergent students. In this chapter, I explore the barriers in formal research ethics assessments for neurodivergent individuals in UK universities, as well as the informal researcher ethics around ableism and inaccessibility. I reflect on my own experiences and those shared with me online. From this, I suggest recommendations for UK universities to make the process more accessible and give advice for other Autistic ADHD researchers. The aim of this work is to begin to deconstruct the UK ethical application process to make it

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more accessible to *all* students and researchers. The examples and experiences discussed in this chapter are related to autism and/or ADHD, with a focus on my Autistic and ADHD experiences. It is worth noting that 'neurodivergent' covers a much broader range of neurologies and experiences, with overlapping but non-identical access issues in the ethics application process.

UK University Ethical Standards in the Humanities and Social Sciences

Humanities and social sciences (HSS) research students and faculty in UK universities must abide by a strict ethical code of practice whilst conducting research involving human participants. These ethical standards are based on the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research, 1979), which outlines boundaries between practice and research as well as how to gain informed consent, create risk assessments, and recruit participants. Over 30% of UK universities also follow the ethical guidelines set out by a dedicated research integrity organisation, the UK Research Integrity Office (UKRIO). UKRIO aims to enhance the international reputation of UK research, as well as protect the public by encouraging a strong professional ethos based on integrity, accountability, and continued professional development. Under UKRIO guidance, universities and their researchers (students *and* staff) can reflectively strengthen best practice. UKRIO suggests that universities provide researchers with varied development opportunities to enable them to conduct research to the required ethical standards.

The ethical guidelines used in higher education in the UK are also beholden to national and international law. University-based researchers must show a knowledge of these laws and how they apply to their specific area of study and methodology. A researcher who works with children and young people, for example, would need to recognise the United Nations Conventions of the Rights of the Child (UNICEF, 1989) to protect the interests of young participants. Researchers who collect sensitive data must follow the European guidelines of General Data Protection Regulation ([GDPR], EU, 2016/679) which outline the safe retention, reuse, and destruction of personal information. GDPR, with regard to research, protects raw data, however, when storing personal data (whether anonymised or not) participants can request that their data be destroyed (GDPR, EU, 2016/679). Since the UK left the European Union in 2020, researchers must now follow the guidelines of UK GDPR set out under the Data Protection Act (Department for Digital, Culture, Media & Sport, 2018).

Where relevant, researchers in UK universities must also follow the requirements of professional bodies in their field of research and the professional regulating bodies of which they are members (Universities UK, 2018). All research involving National Health Service (NHS) patients and/or their relatives requires ethical submission to the appropriate NHS Research Ethics Committee (REC). Studies outside of the NHS may need to be reviewed by other external bodies including the National Social Care Ethics Committee; Her Majesty's Prison and Probation Service (for research involving prisoners) and the Ministry of Defence REC (for research relating to military personnel). In these cases, researchers may need to submit an ethics form to their university (as is standard in most UK university-based research) as well as gaining external ethical opinion, which must be shared with their faculty ethics committee. All faculty and students involved in research are accountable to their research volunteers and funders, to their profession, the university, and to society (City University of London, 2021).

Methods

This chapter is a reflection on (in)accessibility, using my own lived experience of applying for ethical approval as a postgraduate researcher in Humanities and Social Sciences in the UK. I also share the views and opinions of other Autistic ADHD individuals within this chapter to better understand the current state of ethics applications in UK universities. Information was gathered from an online Autistic researchers' group as well as Twitter and Facebook; answers to which have been pseudonymised and they/them pronouns have been applied. My Facebook and Twitter posts were posted on 17th April 2023 and read: "Do you have any recommendations for UK universities to make the ethics application process easier for Autistic ADHD individuals? I'm writing a book chapter on this." These reflections are on formal and informal ethical issues which make university-based research more difficult for neurodivergent people.

Autistic ADHD Experiences of UK University Ethics Applications

My undergraduate dissertation project, in the School of Education and Sociology, was literature-based and therefore did not need ethical approval. There was an opportunity to engage in research with human participants, although students were discouraged to do this due to the complexity of researching with young people. In my dissertation, I explored how to support lesbian, gay, bisexual, and transgender Autistic school students. My Master of Research (MRes) dissertation collected the narratives of gender diverse Autistic people and their thoughts on research on our lived experiences (Munday, 2022). All MRes research students needed ethical approval which covered anything from archival and literature-based work to research with children and young people. These applications were complexified by inconsistent COVID-19 restrictions in the UK,[1] which changed the parameters of health and safety within

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[1] COVID-19 restrictions started in the UK in March 2020 and stopped Oct 2022. Restrictions included mandated lockdowns, restriction of movement, mandatory face coverings, and personal space.

participant-based research. Many of my cohort started as full-time campus-based students but, as it became more obvious that COVID-19 would be a long-term issue, many of us changed to part-time and studied from home.

Thankfully, I started my MRes with some knowledge of formal research ethics gleaned from an undergraduate psychology module, in which I collected and analysed data for a short research assignment on verbal fluency. Whilst this gave me some experience of empirical research, I needed a much deeper understanding of formal ethical standards for my MRes. I was not prepared for the formal barriers within ethics assessments, including a plethora of paperwork, unclear expectations, and miscommunication from faculty. Nor did I expect the informal issues which underpin many of these processes including perceived neurodivergent 'bias' and positionality, and the perception of vulnerability and naivety of Autistic participants.

Paperwork, Paperwork, and More Paperwork

My MRes project consisted of interviewing 13 participants who were Autistic, either formally or self-diagnosed, and transgender and/or non-binary (Munday, 2022). I recruited 8 participants for video-conferencing interviews and a further 5 for written interviews. Due to the nature of my study, I needed to create many different forms including consent forms, debrief sheets, and participant information sheets. The creation of these forms ran alongside the formation of interview questions, risk assessments, scripts for oral consent, and a recruitment advert (with plans of where and when to recruit). Many ADHD people (including me) cannot efficiently move between different tasks due to differences in working memory, response, and attention (Bueno et al., 2017). This issue with task-switching means that an ethics application can quickly become overwhelming, especially when being undertaken for the first time. As Sharon, a neurodivergent postgraduate, suggested: "I was expected to magically know the conventions" having never engaged in an ethical application before. Thankfully my university had lots of explanative notes in their one-size-fits-all paperwork, but I remained confused around some of the nomenclature and unexplained acronyms.

When I asked for clarity, I was often told by faculty that all the information I needed was on Moodle[2] and that I simply needed to look for it. However, navigating online systems is difficult for me especially as their design elements make them inaccessible to most students and faculty (Martin, 2020), let alone those of us who communicate differently. When I started my postgraduate in 2020, some accessibility features were added to the university's Moodle site,

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[2] Moodle is an online university portal used throughout the UK—it is an online space where students can check their schedule and information around exams and course work. Usually, lecturers share notes, videos, and other resources there too.

including dark mode,[3] and the ability for screen readers to make sense of the text layout. Around a third of Autistic people have co-occurring disabilities (CDC, 2022), which mean many of us have issues with accessing, processing, and recalling written information. Having an online portal where information was stored haphazardly with little or no thought for accessibility made 'looking' for information incredibly difficult. Even when resources were clearly signposted, I was sent on a magical mystery tour for resources which did not exist.

When I started my course, before COVID-19 lockdowns, I wanted to offer participants face-to-face interviews, for which I needed to write a risk assessment. The links to find the university's risk assessment documents led nowhere and the person in charge of creating the documents could not be contacted. This was exceedingly stressful for me and maybe for other neurodivergent researchers due to our differences in processing speed and time management, and challenges with asking for clarification (Van Hees et al., 2015; White et al., 2016). When I did eventually speak to my supervisor and other faculty members (I emailed a lot of people for clarity), it was assumed that I was 'okay' to carry on face-to-face work without risk assessments.

The ethical responsibility for my work, as well as any risk assessments which I may or may not have needed, was unclear throughout my course. The university's guidelines state: "The supervisors of undergraduate and taught postgraduate students take the responsibility of principal investigator" (University of Portsmouth, 2020) however, my course was not a taught course, so it was unclear who the principal investigator was. I could not ask for clarity from my course liaison tutor, as they left in the first year and were replaced by someone who never got in contact with me. There were just too many occasions on which I needed to ask for help but wasn't sure who to ask or how to ask for it. Consistently having to translate expectations leaves many neurodivergent students to expend significant amounts of energy to organise admin, keep to timelines, and understand who we need to communicate with (Pellicano, 2012). Miscommunication can be an issue for any student/researcher: however, it is more difficult for neurodivergent people due to issues with working memory, response speed, and other areas of executive functioning (Gobbo & Shmulsky, 2014).

Whilst the skillset required for ethics applications is challenging for many in academia, it can be particularly difficult for neurodivergent people as we often have an uneven cognitive profile, in which we have great strengths in certain areas and great challenges in others (Jones et al., 2009). When asking for support with administration, we can be met with incredulity, especially if we are considered to have academic rigour, as it is considered implausible that we can write and present information well but need help with 'simple' paperwork.

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[3] Dark mode is a display setting for user interfaces including smartphones or laptops. The display background is black, with white text. This mode can be helpful for people who are dyslexic, colourblind, or have processing differences.

Not only is this a false representation of Autistic ADHD embodiment,[4] it also undermines the significant amounts of effort which neurodivergent students and researchers put into academic work. As Bella, someone who was unable to access university, shared: “One of the main reasons I never went to uni: I can’t do paperwork without support and support I am sadly without.”

The Luck of the Draw

Students in the UK can apply for support through the Disabled Students Allowance (DSA), if they have a mental health problem, long-term illness, or any other disability (Department for Education and Skills [DfES], 2009). DSA can support Disabled students with specialist equipment, non-medical support (such as a mentor or specialist note taker), travel expenses to university and placements, and other disability-related study support (DfES, 2009). DSA support can only be granted if the applicant has a formal identification for their need, meaning fewer than a third of Disabled students access the funding (Grant et al., 2023; Holmes, 2022). I applied for DSA in the final year of my undergraduate once I had my formal autism identification, up to that point I was unable to access support.

Having access to a mentor for the final part of my undergraduate degree, and throughout my MRes, meant that I could access specific help with regard to ethical application. Thankfully, my mentor had just finished her sociology PhD, so I was able to ask her questions and speak at length about the application process throughout our sessions together. Sam, a participant in Munday (2022), also shared their ‘luck’ in university:

> We [me and the other neurodivergent students] all had a lot of extensions. We all struggled a lot with actually getting the work done on time, and to understand what’s being asked of us. I don’t know whether that’s because of what kind of course we were doing, or it was just really complete luck of the pot of who ended up teaching us and was in the well-being service at the time. Yeah, they did a much better job than I’ve ever experienced in any prior education I’ve ever been in and yeah, I just feel sad at how that wasn’t normal for most people and I’m just like ‘how did I just suddenly get this random jackpot here?’

Sam shared that they felt they had hit the ‘jackpot’ with their faculty and that they felt supported. They reflected that they felt sad that this was not usual for other research students on their course. Many neurodivergent students and faculty researchers cannot access tailored support for their ethics application. It is understandable that some students may feel like Sheila, a neurodivergent postgraduate, who shared: “My ethics application in the UK nearly broke me, it is such an unfriendly process.”

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[4] Autistic ADHD embodiment means how we understand, respond to, and move around in the world as Autistic ADHD people.

Miscommunication

The turnaround for feedback for my ethics application was unclear, which left me in limbo—I could not progress with my time-constrained project due to administrative backlog and faculty miscommunication. These miscommunications can be viewed as an example of the Double Empathy Problem (Milton, 2012) in which the breakdown in reciprocity and mutual understanding between Autistic and non-Autistic people is situated within *both* individuals. Unfortunately, the blame for communication breakdown follows many neurodivergent people across our lives, including in academia. Many academics have limited understanding of Autistic and ADHD embodiments, meaning neurodivergent students and researchers must constantly self-advocate to ensure that our supervisor or colleagues are aware of—and responsive to—our needs (Elias & White, 2018; Jones, 2023). Self-advocacy becomes more complex with regard to disclosure; if you do not disclose you are less likely to get support, if you do disclose you risk ignorance and stigma following you throughout your academic studies and/or career (Jones, 2023).

Even if we do disclose and self-advocate, faculty may remain reluctant to provide explicit instructions for ethics applications—we are expected to find our own way of doing things whilst miraculously following a framework and hierarchy which is never communicated to us (Martin, 2020). The *correct* person and advice to follow is not always made clear, as Samantha, a neurodivergent Graduate, shared:

> The process, when I applied, was very long with lots of different people needing to get back to you without a timeframe. So, the entire process is really overwhelming [and] could prevent people for applying for university in the first place. The process at the time required individuals to keep logging in and checking for updates on their application. This can be really anxiety-provoking.

Samantha explained that a lack of clear communication and expectations made them feel overwhelmed and confused. Having to correspond with different faculty meant that they had the same conversations several times, and lost track of who they needed to speak to about specific issues, and within what timeframe. Similar issues were found in Martin (2020) with one neurodivergent participant sharing: "Administrative barriers are the most immediately stressful. Complex and convoluted online systems and programmes, labyrinthine networks of people that you need to call or email to get things done" (p. 297). The lack of timeframes around feedback on their university's online portal meant Samantha felt the constant need to check their ethics status. Interestingly, Samantha also considered that the application process itself may put off potential students from applying to university altogether.

Neurodivergent 'Bias' and Positionality

Institutional ableism is often exemplified by a culture in which normativity dictates processes, and divergence is not accepted, let alone celebrated (Kattari et al., 2018, see Chapters 7, 8, 9, 13, 17, 25, this volume). Unfortunately, institutional ableism is deeply ingrained in academia, often meaning that neurodivergent students and faculty must do *more* work for the same outcomes as our non-Disabled peers (Botha, 2021; Brown & Leigh, 2018). Neurodivergent researchers are often assumed to be biased when working with members of our own community, we are considered to lack epistemic authority over our own culture, history, and knowledge (Fisher, 2023; Hacking, 2009; Hens et al., 2019). These ideas affected the way I framed my ethics applications as I was made aware that first-hand accounts of Autistic (and otherwise neurodivergent) people are often considered biased and inaccurate simply due to our neurology. Positionality and reflexivity is an important part of *all* research and should not be dependent on the identity of individual researchers (Braun & Clarke, 2019).

Throughout my MRes, I reflected on my own experiences, both professional and personal, as I "did not feign the distanced impartiality of an outside observer: [as] it would erase my own queer Autistic voice to do so!" (Sparrow, 2020, p.164). My lived experience informed *all* aspects of my study including ethical considerations, as I wanted to ensure that participants felt listened to, as well as keeping them safe. From my own experience, I knew that certain subjects could be triggering, so I chose a narrative methodology which allowed participants to share what they wanted to. I also created a robust ethics entry around accessibility of interviews to reduce the stress of participants. Participants were told of my identity upon recruitment, and some commented that they felt more comfortable talking to a researcher who shared parts of their identities (Munday, 2022). My position also influenced how I recruited participants, as I recruited through online gender diverse Autistic groups which I have been a member of for several years. I may have unintentionally sought out participants who reflected my own experiences and views, however, it is essential to remember that no two Autistic experiences are the same (Mendes & Maroney, 2019). I felt there was a greater need for me to reassure the ethics committee that I was underpinning my work with research created by non-Autistic researchers. However, this may reflect my anxiety around being 'taken seriously,' as opposed to explicit instruction from the ethics committee.

Feelings of anxiety and inadequacy can be felt elsewhere in ethical applications: as we must illustrate how we ensure the safety and wellbeing of participants but not whether we are protected from reading deficit-based work (Botha, 2021). When researching within disability studies and autism research, we must often work from diagnostic manuals and theoretical underpinnings which can be traumatising to read. Consistently reading that you are considered to have *disorders, deficits, inflexibility, failures,* and *difficulties* is distressing and yet does not appear to be a consideration for ethics committees in HSS in the UK. Ethics applications are created and upheld by neuronormative systems of academia which do not consider neurodivergent researchers or those we research with.

Perceptions of Autistic Participants

During my ethics application, there were several barriers to working with Autistic adults, due to the assumptions that Autistic people are either incompetent or too vulnerable (Hacking, 2009; Hens et al., 2019). It is important that *all* participants in research are protected. However, harmful stereotypes still appear to affect the ability of researchers to work with Autistic participants. Unfortunately, this perpetuates autism research, which focuses largely on non-Autistic people's experiences of Autistic people. Our teachers, parents, carers, family, and therapists are spoken to more than we are, often leaving our voices unheard (Fisher, 2023; Milton & Bracher, 2013; Roche et al., 2020). Focusing exclusively on the experiences of others ignores the most important part of the autism community: Autistic people. In trying to protect us, ethics processes can unintentionally silence us, especially those of us who are non-speaking, learning disabled, or come from marginalised backgrounds. The stigma which sees all Autistic people as 'too vulnerable' or lacking mental capacity is something we must fight against within and without academia (see Chapter 10, this volume).

Recommendations for UK Universities to Make the Ethics Application More Accessible for Autistic ADHD Researchers

Many of the issues I faced in applying for ethical approval were reflected in the experiences and recommendations of those who shared their experiences online. Recommendations to improve ethical assessment processes specifically include creating comprehensible guidelines, offering individualised support, and allowing researchers access to examples of past ethics applications and forms.

Comprehensible Guidelines

The literature around ethical applications can be unclear, and it can be difficult to understand the expectations of paperwork and practice. Neurodivergent students have reported that they benefit greatly from structure and concrete instructions (Cai & Richdale, 2016; Knott & Taylor, 2014). Universities, and all those they support, would benefit from:

- Virtual meetings in which students (neurodivergent and otherwise) can ask specific questions about their specific application.

- Clearer guidelines on how to tailor the ethics forms to different types of study, e.g. qualitative or quantitative, literature-based or participatory.
- University websites which act as a 'one-stop shop' which would inform students on what they'll need to gain approval, what clearances are needed, a timeframe and contactable person(s) to go to for further clarification. These steps would be based on the information the student/ researcher inputs.

Offering Individualised Support for Those Applying for Ethical Approval

Autistic ADHD individuals often benefit from clear expectations and guidelines, and individualised support. A mentor, specifically someone who is neurodivergent or has experience working alongside neurodivergent people, could support an Autistic ADHD student with all aspects of the application. Support could be in the form of:

- Interpreting feedback.
- Completing revisions.
- Signposting to useful faculty members and resources.
- Keeping the student/researcher to time with gentle reminders.
- Creating a longer timeline together which gives structure but allows for flexibility.

The final point not only supports the executive function of neurodivergent individuals, but it also appreciates that many of us have co-occurring disabilities and chronic illnesses which affect our energy levels and work output. Creating plans for dips in energy and function is an important part of supporting neurodivergent students and researchers.

Allowing Researchers Access to Examples of Past Ethics Applications and Forms

Examples of recent previous successful ethics applications and connected forms (such as participant information sheets and debrief forms) would allow Autistic ADHD individuals to understand the expectations of ethical applications in their university. During my ethical application process, I was given unclear guidelines on word counts or referencing expectations. My ethics proposal was given a favourable opinion with minor revisions, however, there were comments that what I had done was 'too much.' If I had been given more information upfront, including examples, then I could have used this energy elsewhere. Examples and templates would support Autistic ADHD individuals understanding of:

- What information to put under what heading.

- How much information is 'just right' to be successful.
- Understanding phrasing and language expectations.
- Word counts—even if these exist as a general range to aim for.
- How to answer open-ended questions.
- Jargon and acronyms.
- Resources to draw from.

It is important to note that changes which would make HSS ethics applications in the UK more accessible for neurodivergent individuals would make things easier for *all* students and researchers.

Advice for Autistic ADHD Individuals Undergoing Ethics Application in UK Universities

Undertaking Higher Education can be difficult for those of us who are underrepresented in the formulation of curriculum, including those of us who are multiply neurodivergent. I was formally diagnosed as Autistic in the final year of my undergraduate degree which meant I was unsupported during most of my undergraduate degree. Even with support, there is an often-chaotic relationship between my Autistic and ADHD embodiment. Ideas which would support my Autistic sensibilities—lists, organisation, clear communication, and asking lots of questions—would not necessarily suit my more impulsive eleventh-hour ADHD tendencies! There was a constant need for me to re-evaluate how I was working, as it would have been easy to become overwhelmed. Things which may help other Autistic ADHD students/researchers include looking to others for support, giving yourself plenty of time to apply, and asking for examples of previous applications.

Ask for Support

It sounds like obvious advice, however, experiencing consistent invalidation and ignorance can leave many of us doubting our skills of self-advocacy. This is your research so *take up space*, this is your time to ask questions, and look for support. Things which may help:

- Ask as many questions as you need until it becomes clear—do not be afraid to ask more than once or to ask several faculty members (they are contacted by many people, so almost certainly won't speak to each other about it).
- Make sure you have support around you within and outside of the university. Faculty can help with research specific issues, family and friends can help with emotional and physical support (support with other elements of your life can leave the executive function for the ethics application process).

- Your supervisors or research lead are there to support you—ask them questions and get their advice.
- If your supervisor is not responding to your attempts to contact them, contact the person in charge of dissertations in your department, or 'postgraduate research' if you are a research student.
- Create or join a neurodivergent research group, either face-to-face or online. Connecting with peers means that you can find answers together rather than struggle independently. These groups can also help with body-doubling, where you keep each other accountable whilst studying together or regularly checking in with one another.

The ethics process in HSS in the UK can be overwhelming, however, there are people who can help—disability and academic skills services, your tutor, supervisor or research lead, and your colleagues. Your ideas and your work are worth other people putting their time and effort into.

Give Yourself Plenty of Time

Again, this sounds obvious, but this is not something which comes naturally to many of us. The following ideas may help with time management:

- Look up timeframes in advance.
- Make a list of all the forms you need at the start, download them, and work through them with plenty of time (more than you think you will need). The application process can be easier to contend with when it is broken down into steps. These steps give the opportunity for many 'jumping in' points or the ability to do everything all at once, depending on your study style.
- Complete the ethics application as soon as possible—this allows your supervisor or research lead to support you if needed. Peer-review can also take time, so starting early helps.
- Make a note of when the ethics committee closes (some close over the summer in the UK). It can take up to three months to get feedback from ethics applications, so ensure to factor in closures and feedback time.
- Look at the steps at the beginning of a course as they can take time, for example, if you need a DBS (disclosure and barring service) check to work with children or vulnerable adults, this can take several months and is worth doing early.

Plans can be created alongside your supervisor or research lead, with whom you can have 'check in' sessions or emails to check on your progress. Having someone to keep you accountable can be helpful. It can feel overwhelming looking at everything which needs to be submitted, breaking this down into chunks makes it easier to process and ticking things off your list can be satisfying. Remind yourself as often as you need to about the timelines. For me, this looked like a wall planner with a sticker system, which clearly showed my progress (I went for cute glittery stickers, but plain ones work just as well!).

Ask for Examples

Examples can give a clear indication of expectations, including word counts, use of language, and referencing. Fortunately, the ethics application at my university gave maximum word counts and had clarifying points for each question. This allowed me to get on with most of the work by myself. However, this is not a practice used by all UK universities in HSS. I emailed several researchers from other universities about their ethical and methodological approaches and was pleasantly surprised by their response. There is nothing quite like connecting with people who share your academic interests. I was worried about reaching out but kept reminding myself that the worse thing people could say to me was ‘no’ or simply skip over my email.

There are many places where you can find examples to help you create a more robust application. Your supervisor or research lead should be able to help you find previous successful ethics applications and may even share those from their own work. You can reach out to researchers who have done similar work to yours, just be aware that some of the information they share may be country or institution specific. Combining approaches from examples and advice from researchers in similar areas, as well as your own contributions, will help create a strong ethics application. If your application goes through the first time, or comes back with a small amount of feedback, then you have more time to give to your research project. Also, many of the parts you use in your ethics application may be used in your final research thesis, so time spent on the application will benefit you when you come to write your final thesis.

Conclusion

Ethical frameworks aim to ensure that researchers maintain high ethical standards to protect the researcher, participants, and the affiliated university. To gain ethical approval, all researchers must create and organise multiple pieces of paperwork, usually in a short timeframe. For neurodivergent researchers, little individualised support may be available around translating nomenclature. Breakdowns in communication between neurodivergent and neuronormative individuals, mixed with the power dynamics of university hierarchies, mean that neurodivergent researchers are often blamed for misunderstandings (Milton, 2012). Self-advocacy becomes more difficult when our support needs are questioned, or universities simply do not believe we exist in their institutions (Martin, 2020). This stigma puts undue pressure on neurodivergent researchers to consistently adapt to neuronormativity. Even when support is in place, it is not always appropriate due to the misunderstanding of support needs in UK universities (Cage & Howes, 2020).

This chapter has identified some ideas which may help neurodivergent people when applying for ethics in HSS in UK universities including looking to others for support, giving yourself plenty of time to apply, and asking for examples of previous applications. Universities should also improve their accessibility within ethics by creating comprehensible guidelines, offering individualised support to those applying for ethical approval, and allowing researchers access to examples of past ethics applications and forms. Many of these recommendations for university ethics applications processes would improve outcomes for *all* students—a university degree should be evidence of knowledge, *not* a test of resilience.

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CHAPTER 19

Meaningful Engagement with Neurodivergent Public Work

Alyssa Hillary Zisk

INTRODUCTION

Some researchers have connections within the communities we research. Others may not have these personal connections, but still want to use publicly available work (e.g., blogs, videos, or podcasts) in their research. This engagement can be an important way of including the experiences, theories, and work of community members who work outside of academia within academic conversations. It can also be extractive, taking community knowledge and independent scholars' work and erasing its source. This chapter will explore and illustrate ways of engaging with neurodivergent work beyond academia. I hope this chapter can serve as a precedent, a sort of citational seed (Liborion et al., 2022), to be an academically published reference that neurodiversity researchers who want to cite blogs can use to justify doing so.

The first thing to recognize is that attempting to meaningfully engage with neurodivergent work beyond academia is working against current norms. Doing so isn't necessarily against any *rules*—I have never been called on citing blogs, videos, or fanfiction—but it is against the grain of how academic research is typically done, and that means it takes *work* to meaningfully achieve (Hawkins et al., 2021).

It is, generally speaking, easier to follow an existing model (or to take pieces from a few different models) than to do something without a model. Even

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when we, personally, do not know about any of the potential models, what we're trying to do probably isn't totally new. Claiming newness or firstness often requires stringent limitations on what we count as knowledge or as relevant, which perpetuates the kind of exclusion we want to avoid while making that exclusion harder to perceive (Liborion & Li, 2022).

Existing Forms of Engagement

Neurodivergent Researchers Doing Neurodiversity Research

There is considerable community favor for autistic autism researchers and neurodivergent neurodiversity researchers in general (Eb, 2015; theoriesofminds, 2015, 2017). There are now more examples of this than I can reasonably put in a chapter that is mostly Not About This, but Michelle Dawson's body of work (e.g., Dawson & Fletcher-Watson, 2022) is an historically important one.

Neurodivergent researchers doing neurodiversity research get neurodivergent ways of thinking about neurodivergence into the academic record. At best, rather than taking a seat at a table still run by neurotypical professionals and academics, this can lead to at least a small table of our own—if we get support for our research programs, or when we sit on the editorial boards of journals (Nicolaidis, n.d.; *Ought*, 2019–2023).

I am not aware of formal studies examining this, but in my experience, openly neurodivergent neurodiversity researchers seem to be at least somewhat more likely to engage in the other practices described below. When we do this, we need to make sure to maintain proper ethical and research standards–while academic establishments may view our work with greater suspicion due to our disclosed neurotypes, we are often operating from a position of more trust *within* our communities due to our identities.

Reprinting and Sometimes Expanding Work From Outside Academia in Academic Journals

Reprinting neurodivergent work from outside academia gets that work into the academic record. This is useful, but most relevant to people who, for whatever reason, are either unable or unwilling to cite work from beyond academia. Also, blog preservation is an Actual Issue (Peoples, 2010). Autistics.org, for example, is now only available through the internet archive. Reprinting in an academic journal with permission from the blog author is one way of preserving at least a few key blog posts that are considered foundational documents.

This is also a patchwork, band-aid style solution. It's typically applied to blog posts that have already attracted significant attention, and the academic journals that *do* this are fairly low in number, with limited capacity. *Autonomy*, which did this (Arnold, 2019), now seems to *also* only be available through the internet archive (Autonomy, n.d.).

The article in *Disability Studies Quarterly* (Yergeau, 2013) that I know comes significantly from a blog post (Yergeau, 2011) is important, one I regularly refer to: however, Yergeau is also an academic.

Bibliographies and Other Lists

One of the challenges of meaningfully including and engaging with neurodivergent work is in finding it. This can be true even when we have community connections. For example, at different times, I primarily engaged in blogging (Blogspot and Tumblr), on the site formerly known as Twitter, and in certain Facebook groups. Each of these communities had its own norms and its own overlapping but non-identical participants. I am, by and large, not aware of the people who are currently theorizing on TikTok or other audiovisual-heavy platforms. When I am aware of people who are primarily active in modalities other than text, it is usually because I have been directed to that work by other people who are active in both those communities and at least one of mine.

Direct person to person recommendations of work can be the most personalized. We can (and often do) share links with each other based on known interests. But there are also times when we organize lists which can help support engagement with particular kinds of knowledge.

This can include broad lists, aiming to help people find a wide variety of work from members of a particular group or addressing a particular topic. Broad lists of autistic work include Bagg's list of books by autistic authors (2006). There is also now an Autism Books by Autistic Authors Project (n.d.) containing over 1000 books ranging from new 2024 releases to out of print books referenced in Bagg's list. On a similar note, there are several listings of autistic bloggers, YouTubers, or pages (Bristol Autism Support, 2021; Judy, n.d.; Neuroclastic, n.d.), as well as a listing of autistic researchers (Thom-Jones, n.d.). These blog listings are particularly useful to people who either are not familiar with existing Autistic blogger communities or are aiming to look at a wider variety of blogs, as searching for autistic blogs can in many cases lead to *autism* blogs which are written by family members, researchers, or professionals who are not themselves autistic. Similar issues are apparent in searches for ADHD blogs and are likely present for a variety of neurodivergences.

These broad lists, however, are often very long, and shorter guided lists also have their place. A shorter guided list does not aim to cover a topic or category thoroughly. Instead, it is usually an introduction to one topic or a few related topics, with explanations for why each piece in it fits the list. The Framework for Open and Reproducible Research Training (FORRT) has a Team Neurodiversity (n.d.) with one such annotated reading list as a project in early stages. I also published an annotated list of sources from beyond academia which are relevant to critical autism or neurodiversity studies (Zisk, 2023). My list aimed to highlight key pieces from diverse creators whose other work may also be worth considering when seeking to engage with neurodivergent neurodiversity work, as well as to capture items which may not be as widely known (e.g., no 'Don't Mourn for Us', despite its definite importance; Sinclair, 1993) and some prior archival efforts.

Community-Based Participatory Research

Community-based participatory research (CBPR) is one way to ensure people can be involved in directing research whether or not going through all the formal education currently needed to lead it is a practical possibility. The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) is a community-based participatory research partnership born of the need for autistic-led research (Raymaker, 2020, see also Chapters 4, 25, this volume). That is, AASPIRE comes from the same needs for autistic-led research community members described in #AutChat conversations (e star, 2022; Eb, 2015; theoriesofminds, 2015, 2017). AASPIRE is, to the best of their knowledge (Raymaker, 2020) and mine, the first use of CBPR with autistic people. More have followed, including additional partnerships involving members with multiple roles: AASPIRE is co-directed by an autistic academic and a parent-academic (Raymaker, 2020), and I serve as both an Additional Collaborating Academic and a community partner working with Dr. Amy Donaldson (Donaldson et al., 2023). Some autistic people have suggested using research to verify community knowledge (Eb, 2015; see also Chapter 24, this volume). This requires finding out what the community's knowledge is. Qualitative CBPR studies are an option here (e.g., Donaldson et al., 2021).

Neurodivergent Review

At varying stages of research projects, it is possible to ensure that members of relevant groups review the work (see also Chapters 4, 10, this volume). Sometimes, this is done on an individual level, analogous to authors of fiction seeking beta readers. This can overlap with CBPR, though any consultants who are checking over the work and making suggestions at set points rather than throughout the research may more accurately be considered neurodivergent reviewers than community members of a research team. The same project can have both community representatives on the team *and* review from external neurodivergent people. One reason a research team might choose to do this is if a particular person who wants to be a community representative doesn't have the time to dedicate to that role—someone else could fill that role, and the original person could be a reviewer or consultant with a smaller time commitment at certain set points.

Neurodivergent review is possible at any point where review occurs, including grants, requests for proposals, and journal articles. However, the examples of systematic neurodivergent review that I am aware of are both for autism journals. *Autism in Adulthood* and *Ought: The Journal of Autistic Culture* both systematically ensure autistic people review papers. AASPIRE is part of how and why *Autism in Adulthood* exists to have this policy (Raymaker, 2020). There may be other journals that do so. This is a good thing! I have served as a reviewer for both of these journals in the past, and if I am asked I will likely do so again. I have also served as an aphantasiac reviewer of a paper about aphantasia, though I (1) cannot tell you what paper this was, and (2) have no idea if this was intentional on the part of the editors.

There are multiple advantages of autistic peer reviewers for autism research, and similarly of other neurodivergent people for the research relevant to their neurotypes. One is that we can often catch the most obvious neurotypical (mis)interpretations that come from people interpreting behavior as if they were the ones who took the action, rather than in the reality that someone significantly different from them took the action (Hillary, 2020; Milton et al., 2022). Getting autistic reviewer perspectives while there's still time to edit or reject a paper helps reduce these misinterpretations before publication (Raymaker, 2020). One illustration of the need for autistic review comes via an observation of what happens without it. Some autistic people have noted that they prefer reading autistic perspectives and summaries of existing research to reading academic publications directly due to the pathologizing misinterpretations common in the academic literature (Eb, 2015).

Another advantage of autistic reviewers for autism research (and similar policies for other neurotypes) is that authors submitting to a journal known to have this sort of policy are at least intellectually aware that members of the group they're studying will read their work and comment on it. It's a reminder that we are, in fact, in the audience.

Blog-like Work as a Data Set

Sometimes, people use blogs, YouTube videos, Facebook pages, or similar types of neurodivergent work as data sets to address a variety of research questions. Examples include Angulo et al. (2019) study of autistic perspectives on neurotypicality, Coles-White, Jones, and Saka's (2023) study of perspectives on camouflage from Black Autistic women, Guberman's (2023) study of epistemic resistance on Twitter, Harmens, Sedgwick, and Hobson's (2022) work on women's experiences during identification and diagnosis, and Seidmann's (2021) on blogging, bloggers, and autistic space itself. Most of this research is similar to interview-based qualitative research, and researchers may in some cases (e.g., Seidmann, 2021) conduct qualitative analysis on both the blog data *and* on interviews with some or all creators behind the analyzed blogs. An advantage of analyzing blog data rather than (or in addition to) interview data is that it does not require bloggers to repeat what they have already written, reducing the work they have to do.

The Work of Ethical *Engagement*

Researchers in general are expected to conduct ethical research. For work with human participants, this generally means alignment with certain principles and may also mean following guidelines set by laws, supervisors, and/or review boards. For example, authors may be required to declare that their work followed the principles of the Declaration of Helsinki (World Medical Association [WMA], 2013), or to have a committee review the ethics of their proposed research before conducting it. Whether or not formal review is required, researchers have an obligation to consider the ethics of our work, both in how we do it and in the effects it may have. Community membership may engender more trust from fellow community members, but it does not automatically make our work ethical—we still need to think about ethics and make sure our work is ethical.

Ethics Review and Vulnerability

Some forms of engagement with neurodivergent people and neurodivergent work may require formal review. In principle, this review is a good thing. However, neurodivergent academics have encountered reviewer comments suggesting that all autistic people be categorically considered decisionally impaired or that 'there is not adequate evidence that the self-reports of individuals on the autism spectrum are valid or reliable' (Anonymous qtd. in Raymaker, 2020, see also Chapters 10, 18, this volume). In these cases, ethical review becomes a discriminatory and exclusionary barrier to meaningful engagement with neurodivergent people. Research ethics require additional protections for vulnerable participants, but it is important to consider situational vulnerability, rather than beginning and ending with the idea that certain categories of people are always vulnerable (Gordon, 2020). Disabled people are vulnerable to exploitation in a variety of ways, and our presence in research often triggers additional scrutiny in ethics assessments (Scully, 2014). However, a great many disability-related vulnerabilities are at least somewhat situational, rather than categorical, particularly under a social or relational model of disability. We therefore must be careful not to increase situational vulnerability to certain forms of harm or exploitation in the name of mitigating inherent categorical vulnerability. Otherwise, categorical vulnerability may be used to justify paternalistic research and interventions (Mackenzie, 2014). Instead, responses to and protections for vulnerability should ideally support autonomy (Mackenzie, 2014).

One way that protections for categorical vulnerability can aggravate situational vulnerability is when ethics boards treat community partners in research as identical to research subjects—while ethical engagement and compensation for community partners is important, these are not in fact identical situations requiring identical protections. Community partners are ideally in a position to determine research questions and procedures, meaning that they are *necessarily* involved before a particular research procedure is submitted for ethical approval. Requiring ethics approval for the involvement of community partners then leads to either the need for an additional submission about forming the community-based participatory research team (likely the best solution for a research team facing this challenge) or a situation in which research questions and procedures are significantly determined before partners can be involved (limiting the truthfulness and effectiveness of the claim to community-based research).

Another way that protections and autonomy can be in tension is when work with blog data is considered to be a form of human subjects research, thereby requiring confidentiality. The best ways to handle blog and social media work in research are situational and subject to significant discussion—there are times for anonymity and heavy disguise of work (Bruckman, 2002), but there are also times when anything except credit and citation would constitute theft and erasure of disabled people's work (e.g., Jackson et al., 2022).

Tensions of Credit, Confidentiality, and Erasure

When working with blog or social media data, community opinion seems to tend toward the idea that researchers should engage with autistic writing on social media and blogs—but also that they should ask permission, and that people should have choices about non-use, anonymity, pseudonymity, and citation (Solveig et al., 2022; Williams, 2019). That is, rather than a default of taking the names off public writing but leaving quotes intact, which leaves people identifiable but not credited—the worst of both worlds, but approved by some ethics boards (e.g., Harmens, Sedgwick, & Hobson, 2022). It is best to ask the people whose work you are considering using. A listing of public neurodivergent work may be a place to *find* the work, but researchers would in this case still be responsible for seeking consent and for respecting people's choices around credit versus confidentiality.

Tensions of credit, confidentiality, and erasure overlap with citational politics. Citational politics is the politics of how sources get cited in academic work (Hawkins et al., 2021). Citational politics looks at how citational practices make disciplines seem whiter, more male, more cisgender, more global north (Ahmed, 2013, 2020; Liborion & Li, 2022, see Chapter 22, this volume)—and more neurotypical. Different disciplines have different patterns of what gets counted as a source and about what should be cited, but there are some patterns that are common across many disciplines. Reading lists and reference sections are full of white men (Ahmed, 2013, 2017), for example.

These 'standard' citational tendencies are present—and a problem—in neurodiversity work[1]. Neurodiversity work is too large for any one discussion to cover it, so choosing a focus and then specific things to engage with within

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[1] Neurodiversity work is distinct from neurodivergent work, in that neurodiversity work addresses the topic of the work, whereas neurodivergent work is about its authorship. The terms can and often do apply to the same work, but the emphasis differs and each term can apply even when the other does not.

(or related to) that focus is a practical requirement. It's also a political decision, and in practice, discussions of neurodiversity often leave people behind (e.g., described in Baggs, 2014). Academic discussions of neurodiversity are no more immune to this than neurodiversity work beyond academia. In addition, academic discussions tend to prioritize other 'traditionally academic' work as sources to cite, whether by not engaging with broader work or by engaging but *failing to cite it* (Jackson et al., 2022; Liborion & Li, 2022).

These tendencies lead to a wide variety of community knowledge either being ignored or being taken with incorrect or missing credit—so, this is not only a philosophical ethical issue, but a very practical one. They are compounded when multiply marginalized figures in neurodiversity movements are also not academics and write primarily in non-academic spaces, as in Kassiane Asasumasu's coining of 'neurodivergent' on About.com (Asasumasu, 2015a), not in an academic paper, and her explicit intentions in coining the term (Asasumasu, 2015b). Singer has been mistakenly attributed with coining 'neurodivergent' on the basis of her early use of 'neurodiversity' (Botha et al., 2024). Looking for academic sources, rather than references to the blogs, social media posts, and email lists where neurodiversity work has often actually happened makes it much harder to follow who actually said what, when, where, and why.

Citations of blogs may not be typical—but typical ways of doing things lead people to repeat those same ways, or one way of study being dominant can lead people to think it's the only way—the published literature is its own domain of im/perceptibility (Liborion et al., 2022). Besides, the common reference formats support blog citation, and I've yet to be challenged when I simply *do* it.

Patterns of exclusion in citation can be present even when researchers theoretically want to do otherwise, because doing otherwise takes Significant Effort. It also tends to require significantly atypical choices about citation—seeking out non-academic sources to cite is one example of an atypical choice that can lead to crediting a wider range of creators. However, with effort, it can be done. This chapter, for example, currently cites 52 sources—of which 25 are not from books, academic journals, or the World Medical Association. Similarly, while describing the authorship of a source such as an *entire journal* is complicated, about half the academic sources where it makes sense to describe the authorship include openly neurodivergent authors.

Additional Labor and Who Is Asked to Do It

People who blog and make public posts have already done the work of putting together whatever they have shared. They have already self-published, with both the speed and the control over their own content that provides (Nelson, 2022). Asking them to put it together again in a formal research study is, in fact, asking them to do more work even if they retain the same level of control over what they say, write, or share. Depending on the extent to which existing works directly or tangentially address a specific research question, asking for this labor may be warranted. However, we need to be clear that it is a request for additional labor.

A preference for anonymity may also be a reason to consider this labor. However, depending on how well known a person's blog and social media work may be, this rephrasing or recreation may not even prevent them from being identifiable to other community members (e.g., Donaldson et al., 2021). If confidentiality isn't going to be maintained effectively with any disguise strategy that leaves quotes intact (Bruckman, 2002), then we need to seriously consider whether or not there's any advantage to a new qualitative study worth requiring participant time and effort over citing existing public writing.

Seeking consent from creators ahead of using their work is labor for researchers. However, the extent to which it is truly *additional* labor is questionable. Similar alternatives include conducting an entire qualitative study, which also requires the work of seeking consent. Disguise methods also require labor to implement, and every creator who chooses citation and credit is a creator whose work the researchers do not need to disguise.

Compensation

Researchers typically get some sort of compensation for our work. The exact nature may still be exploitative, but if research is part of our job, then there is generally some incentive or compensation around the fact that we are Doing Research (c.f. Chapters 4, 5, 6 this volume). For research participants, compensation is an option but not generally a requirement, and incentives that would constitute full payment for their time may in some cases be criticized as undue influence (Largent & Lynch, 2017), particularly with groups who are considered categorically vulnerable (whether or not that is an accurate consideration).

For other activities associated with research, compensation may not typically be considered or available—but when including non-academic community members for whom these activities are *not* part of their regular jobs, it should be. For people with certain kinds of academic and academic-adjacent jobs, peer review is part of the job, and expectations about productivity may even recognize this reality. For everyone else, peer review is just extra unpaid labor, which it is still not fair or reasonable to expect of disabled people. Autism in Adulthood recognizes the problem—they're looking into ways to compensate this labor for autistic reviewers—but they do not currently do so (Nicolaidis, n.d.). The Community Against Prejudice Towards Autistic People (CAPTAP) also notes the importance of compensating autistic reviewers in their draft guidelines (Botha et al., n.d). I am not aware of other journals which are looking into this issue for reviewers.

When compensation is offered in consultation or advisory roles, underpayment is an issue (Wells, 2023), just as it is when considering compensation for research participants. Payment which is not on par with the pay for people with academic or clinical credentials is an equity issue for neurodivergent reviewers, consultants, and community partners.

Recommendations

There is value to engaging with neurodivergent work beyond the academy. There are existing frameworks for how this can be done, from which we can borrow the pieces that work well. There are also challenges in ensuring that the engagement is both meaningful and ethical. Overall, I suggest the following:

- Consider neurodivergent work from beyond academia (such as blogs, videos, or podcast) as sources of theory and in some cases as primary sources, not only as sources of data.
- Actively look for these sources; when relevant consider seeking them out *before* looking for (neurotypical-authored) academic sources that repeat community knowledge.
- Ask neurodivergent creators if they would like their work to be used in research, and if so whether they prefer credit and citation, anonymity, or pseudonymity[2]. Note that in many cases, blogs or other work may already be written under a pseudonym (e.g., Chavisory, n.d.), and that pseudonymity and citation may not be mutually exclusive.
    - Allow sufficient time for creators to think about this question and respond ahead of any deadlines.
    - You may need to come to an agreement with a supervisor or review board about the inclusion and/or level of disguise used for creators who do not or cannot respond.
    - Ideally, neurodivergent participants would not *need* to initiate the conversation about asking to be cited rather than anonymized, and the option would be given from the beginning. However, if the option is for whatever reason *not* initially available (e.g., concerns from an ethics committee, or joining a research project after its initial approval), then a request for credit from a neurodivergent creator should lead to returning to the ethics committee to support the request.
    - Look into funding mechanisms to appropriately and equitably compensate neurodivergent collaborators for whom any research work is not part of their jobs.

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[2] For this chapter, I did ask living people whose non-academic blog posts or Twitter threads I cited if it was acceptable to do so. I also asked some but not all creators of academic or academia-adjacent blogs.

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CHAPTER 20

Participatory Methods: Researching Autistic Sexuality, Intimacy, and Authenticity

David Jackson-Perry

INTRODUCTION

The past decade has seen increasing interest in participatory frameworks within autism research, alongside a certain pressure to integrate participation and collaboration with autistic people into research processes (Bertilsdotter Rosqvist et al., 2019; Crane et al., 2018; Woods & Waltz, 2019; Hobson et al., 2023; for discussion, see also Chapter 22, this volume). However, while early-career researchers may be enthusiastic about using participatory approaches, few resources give detailed descriptions as to how participatory methods have been implemented in research (Fletcher-Watson et al., 2018; Pickard et al., 2021).

To address this gap, I draw extensively on my doctoral research for this chapter. (Jackson-Perry, 2023). However, at the time I identified (to myself and to participants) as a neurotypical researcher: I have since received a diagnosis of ADHD and reflect on this where it seems relevant for what follows. I start with a brief overview of the study and its aims before giving a detailed account of the participatory process employed during the doctoral study on which this chapter draws. I describe the five principal steps I undertook: formal and informal community engagement; the creation of a research website; the recruitment and involvement of the Research Advisory Group; an online survey, and finally written interviews. The emphasis here is on practical,

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methodological questions of the early and middle parts of the research process, up to and including data collection: findings have been published elsewhere (Jackson-Perry, 2024; see also Chapter 22, this volume).

STUDY OVERVIEW

The doctoral research from which this chapter has been adapted explored the barriers and opportunities experienced by autistic people in their intimate and sexual lives. It used a critical autism studies (CAS) framework and drew on constructivist grounded theory for data analysis. The research questions were:

1. What are the challenges and opportunities faced by autistic people as they develop their sexual and intimate lives?
2. What are the processes by which they overcome those challenges and maximize those opportunities?

The 16 autistic participants, aged between 22 and 54 years old, and with a wide range of gender and sexual/affective orientations, took part in a total of 24 semi-directive, mostly written qualitative interviews.

I had retained four principles as being central to this research process, which I based on readings within critical autism studies and critical disability studies more broadly:

> Consultation and engagement: both formal and informal, with autistic individuals and communities throughout the research process.
> Relevance: questions investigated, and the results and reflections to which they lead hold the potential to contribute to positive impact for the people concerned, within academic autism discourse and/or in practice.
> Accessibility: both the research process and its results are to be as accessible as possible for participants and autistic individuals and communities more broadly.
> Empowerment: a move "to increase the influence of relatively powerless sectors of society" (Hahn, 2002, p. 181) is "not in the gift of the researcher" (Mercer, 2002, p. 237). However, by rejecting medical or deficit readings of participants' accounts, and respecting the points above, I sought to "facilitate this process" (Oliver, 1992, p. 111) as far as possible.

These principles were all the more important to me as I am not autistic. At the time I thought of myself as a neurotypical researcher. This may—or not—be pertinent as I now realize that I was groping, as far as was possible to me at the time, toward a form of what Raymaker (2020, p.138) calls "scientific activism," defined as work seeking:

- To encourage the inclusion of people on the autism spectrum in matters which directly affect them.
- To include people on the autism spectrum as equal partners in research about the autism spectrum.
- To answer research questions that are considered relevant by the autistic community.
- To use research findings to effect positive change for people on the spectrum.

Formal and Informal Community Engagement

Fletcher-Watson and colleagues (2018, p. 944) note that "engagement with the community in general (e.g., via social media) and consultation with relevant individuals or community organizations" is one of various "manifestations of participatory research." Indeed, consulting one or more autistic people does not, as Fetcher-Watson and colleagues (2018, p. 950) make clear, give "non-autistic researchers access to a consistent 'community view.'" I therefore found it important, as Milton and Green (2024, p.3) have since advised, to "(E)ngage with the autistic community at an early stage of the research process, as not doing so may lead to some costly regrets" (see also Chapters 4,10, 19, this volume). The need for building bridges between autistic communities more broadly and researchers is also noted in a review of researchers' views and experiences of participatory research processes (Pickard et al., 2021).

Previously, the only autistic people with whom I had had any sustained contact (to my knowledge) were the children and adolescents I supported—largely concerning sexuality—in their homes or schools. Of the 140 references in my 2016 master's dissertation, only three (apart from the posts from the website I was analyzing) came from sources I knew to represent autistic people or organizations. This reflected both the reading list for the master's program in 'autism spectrum disorders', which drew mainly on non-autistic third-party, professional, and caregiver accounts, and my ignorance at that point of other, more critical bodies of literature.

I then became aware of CAS, first through reading Worlds of Autism (Davidson & Orsini, 2013), and of autistic academics and activists who have been debating various aspects of autism, including knowledge creation (Arnold, 2012; Bertilsdotter Rosqvist, 2014; Chown et al., 2017; Milton, 2014; Milton & Bracher, 2013; Murray et al., 2005; Yergeau, 2013). I engaged with lay and academic autistic communities, online and through attending conferences. This positively impacted the research process in various ways. It led to possibilities for collaboration, facilitated calls for participation as I was familiar to a number of people who were interested, and brought a level of transparency that I hoped might mitigate some of the "distrust from autistic persons toward researchers" (Woods and Waltz, 2019, p. 2). Finally, observing and engaging with exchanges of ideas within autistic communities sensitized me to questions of importance to them, perhaps mitigating the risk of finding myself in an academic silo, only addressing questions that were considered to be of interest in research in my own discipline (Arnold, 2012).

I also joined the Critical Autism Network (CAN, 2020) and the Participatory Autism Research Collective (PARC, 2020, no page), attending—and presenting at one of—their conferences. PARC aims "to bring autistic people, including scholars and activists, together with early-career researchers and practitioners who work with autistic people." My engagement evolved and snowballed, deepening organically. With some of the people I met in those contexts, we organized *Intimate Lives?* the first conference in the UK specifically exploring the intersection of autism, sexuality, and gender. With a group of mostly autistic academics, activists, and lay-people, we initiated a loosely formed writing collective that went on to produce several publications (Bertilsdotter Rosqvist & Jackson-Perry, 2020; Bertilsdotter Rosqvist et al., 2019; Jackson-Perry et al., 2020). This form of 'reflexive cross-neurotype' collective writing is seeing an increasing interest within Neurodiversity Studies (see Chapters 7, 8, 9, 14 this volume).

While I have only briefly described my community engagement here, it was an intense part of my life for three years. While not a simple undertaking, from which I felt the need to take a distance as I wrote up my thesis, the stimulation, critical insight, support, and friendship that community engagement brought has been essential to my development in the field, as a researcher, and as a human being.

The Research Website

Another important early step was setting up a research website[1] in 2018. The rationale behind the website was as follows:

1. Transparency: the "history of distrusting researchers among 'minority communities" (Raymaker & Nicolaidis, 2013, p. 169) had been confirmed by many of the autistic people I met. It was important to me that anyone interested in being involved in this study, as advisors or as participants, could easily access information about me and the research. Through the site, potential participants could learn about the study-and the person and intentions behind it—without needing to contact me directly, deepening the notion of informed consent.
2. Accessibility: "what happens to the products of research" (Zarb, 1992, p. 128) is an important question. Too often, communities and individuals cannot access research results, either 'consumptively' (the physical ability to access research results that are often unavailable without academic affiliation) or 'transformatively' (that results, once accessed, are *useful*

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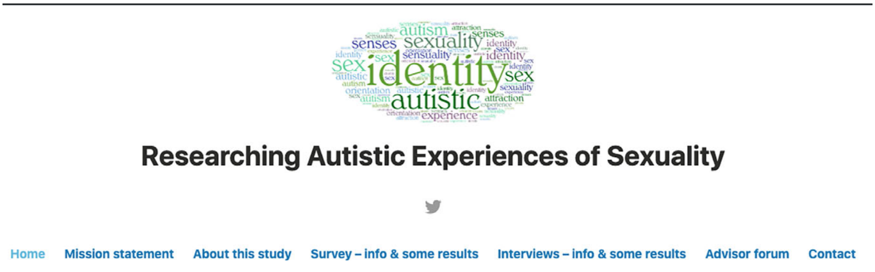
[1] Autismsexualityresearch.com.

and *usable* to those who need them) (Brewer et al., 2014). With the website, I sought to make results accessible to whoever might be interested, whether or not they were part of the study.

3. Impact: extending the previous point, by impact here I mean encouraging other novice researchers to consider using participatory methods in their work. Doctoral students interested in participatory methods may wonder how to create "an active engagement with autistic communities" (Fletcher-Watson et al., 2018, p. 950), and those methods may be perceived as overly complex, risky, or too resource-costly to undertake (Pellicano et al., 2014). I hoped that having a window onto my process via the website might contribute to others considering participatory methods, whether to borrow from, build on, or reject the way I proceeded (Fig. 20.1).

Site content evolved as the research process unfolded. Initially, it contained some information about myself and the study, a statement clarifying some of the principles of my approach, and a link to my academic profile page, which also gives access to publications or conferences I have been involved in. As I looked for members for the Research Advisory Group (RAG—see below) I added the call for advisors and linked to the site from various online media. Once the RAG was in place, and in response to RAG members' suggestions that communicating synchronously across three time zones would be complicated, I added a private forum to the site to facilitate communication between members of the advisory group and myself: this provided a way for advisors to 'meet' that would have otherwise have been impossible in such a large group from different countries and regions. Calls for participants for the survey and in-depth interviews were also linked to the site, and sections provided information about them. These sections were later used to give provisional results, and I informed participants and advisors as they were updated.

Several early-career researchers also contacted me, with various questions about the site and the research process more generally. This suggests that the potential for impact within academia is indeed there, as I had hoped. It also perhaps confirms that despite the arguments made for participatory research



Researching Autistic Experiences of Sexuality

Fig. 20.1 The header for the research website methods, there remains a need for more detailed guidance as to how exactly to go about them, beyond relatively vague statements of intent.

If I were to do it again, I would give the site a far more central role in the research process, even if it meant cutting out other research steps. To have been able to produce, for example, video presentations of results in lay language would have further increased the impact and accessibility of this study. The relatively high time investment could have been amortized by using the site for potential participants to access consent forms and information packs, reducing administrative burden elsewhere.

The Research Advisory Group

One of my earliest decisions was to seek input from a research advisory group (RAG) of autistic people, and I set out to recruit them with a call on Twitter (now known as X). The RAG's role was to be largely decided by the group itself, although their provisional remit was "to guide the research process, and to ensure that this study is respectful, accessible, and relevant to autistic individuals and communities." (see also Chapters 10, 19, this volume) (Fig. 20.2).

The inspiration for the RAG was Martin (2015), who worked with three "adults with Asperger's Syndrome" in research seeking to determine the support requirements of others. Martin initially contacted her members of her group through a regional Asperger's support group, and they met face-to-face at key points during her research project. Following Martin, my initial call sought advisors in the UK for four to five physical meetings during the year.

I very quickly received community feedback on this. Some people told me that the imposition of a face-to-face format was inaccessible either for reasons of mobility or the social challenge of meeting as a group. I also received

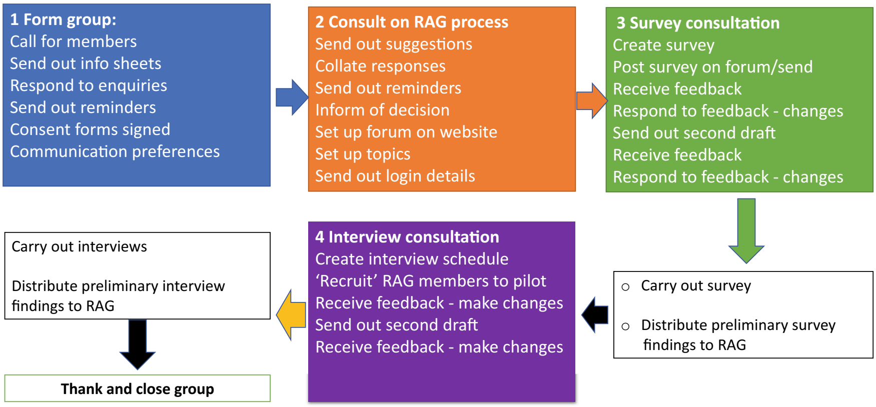


Fig. 20.2 RAG process

emails questioning the logic behind an exclusively UK-based group. Therefore—despite considerable logistical misgivings–I opened the possibility of participation to an international audience and indicated that the format would be decided by the group once it was formed. The resulting RAG was made up of nine autistic adults from the UK, Germany, and North America.

The early days of my Ph.D. were characterized by an often-paralyzing sense of illegitimacy as the neurotypical researcher that I still considered myself to be, and that I presented myself as being in all my interactions with participants and RAG members. Now that I have a formal diagnosis of ADHD, I wonder if having been able to present myself as 'neurodivergent but not autistic' might to some extent have mitigated this. As an ADHDer, I am of course no closer to having insight into autistic subjectivity (and indeed, I now realize that it conceivably worked against me regarding accessibility, as I describe below). However, from a neurodiversity perspective, being in some ways a "cousin" (Kathy Grant, in Sinclair, 2005, no page) may have mitigated the discomfort I often felt, although I cannot be sure. However, when I set up the RAG, I had neither received a diagnosis nor self-identified, and whether for this or any other reason I did not feel confident enough to ask potential members for information about themselves: even hitting 'send' on an email to RAG members sometimes came with much angst, and the concern that I was imposing on them. Therefore, the only information on individual members of the RAG is that which they spontaneously provided.

With a large, international group, face-to-face meetings were not possible. After discussion, some advisors decided to communicate individually with me, others through the advisors' forum on the website, and the rest with a combination of these options. Setting up a forum on the website again required a higher time investment on my part than I had expected: time management difficulties were a signature of this part of the research process. This was largely due to my own inexperience, to having to find solutions to problems that I had not expected, and that are well outside my comfort zone, such as managing a website.

Indeed, the creation and management of the RAG was complex, time-consuming, and often emotionally draining. Each individual item in Table 20.1 represented hours of administrative work, all in parallel to data collection and analysis: to avoid tokenism, an advisory group cannot be a discrete element, but runs parallel to, interacts with, and impacts other steps.

I had set no criteria as to how I would include RAG members: all those who completed the process of receiving information and giving consent were included. While my thesis supervisors had approved this, they also warned me that it would come with drawbacks, which was the case. Initially intending to recruit two to six advisors in the UK, I ended up with nine people in different time zones, making it necessary for me to think about ways to communicate that would take this into account. In hindsight, limiting membership to one geographical location and fewer members, like Martin (2015), would

Table 20.1 RAG members

	Location	*Age*	*Diagnosis*	*Education/ work*	*Preferred communication*	*Other information (as given by members*
Advisor 1	USA	47	As adult	Ph.D.	Email & forum	Male. Has a son with diagnosis of autism
Advisor 2	UK	26	Yes (age unknown)		Email & forum	Female. Identifies as queer/bisexual
Advisor 3	UK	25	As adult		Email	Female. Married to asexual-identified autistic man
Advisor 4	USA		As adult	Ph.D.	Email & forum	Female
Advisor 5	UK	29	Asperger's	Researcher Ph.D. candidate	Totally flexible	Female
Advisor 6	Germany		Self-identified	Medical statistician	Email & forum	Female
Advisor 7	UK	30's	Yes (age unknown)	Computer programmer	Forum	Bi/pan-sexual, non-binary
Advisor 8	UK	30's	Yes (age unknown)	Ph.D. candidate	Email & forum	Female
Advisor 9	UK		Yes (age unknown)	MSc	Email & forum	Male

have been more manageable within the constraints of a doctoral thesis, if less diverse.

Nicolaidis and colleagues (2019, p. 12) note that "community partners often feel that instruments developed for general populations are not accessible, usually due to confusing or imprecise language or ableist assumptions." This was indeed a major area of input from the RAG, both for the survey (see below) and the interview (adapted from McAdams, 2008; see below). I will give one particularly representative example of each here. My original question in the survey (to explore which areas related to.

sexuality respondents would like to see explored) was initially:

- **A** - Please outline one question/area you would like to see researched about sexuality **(Open answer)**
- **B** - Please outline a second question you would like to see researched about sexuality **(Open answer)**

I had wanted to avoid being directive but received several comments on this from advisors. One said:

> It's rather daunting to have a "go for it" section without an easy out. I'm guessing there are some established areas that might be worth putting down for those who could be overwhelmed by a blank canvas… I personally don't know what areas are being studied.

Another, more specifically, suggested:

> It might be worth re-formatting this question to include areas of research as examples, I have no clue what I would answer for this and there is too much choice. If I was writing this question myself, I would give 5-10 examples of research areas and ask people to number 1-3 their most important, with a comment box below if they feel you've missed anything.

The final wording provided six possible areas to be numbered from one to six in order of importance for respondents, with a free response question at the survey's end.

In the written interviews I had phrased a question on sensory experience as follows:

> A sensory experience. Please describe an experience that sticks out in your mind that was in some way connected to your sensory desires or needs. Was it pleasurable, painful, exciting, difficult, comforting? Were you alone or with someone else? How did you feel during and after this experience?

One advisor found the interview "very interesting to complete and quite therapeutic." noting that she could "see the aim is to encourage people to explore their experiences quite freely." However, she went on to say that "information overload," for her, made "questions with a long preamble or a series of questions within a question…disorienting." Her proposition was this:

A sensory experience: Please describe an experience that sticks out in your mind that was in some way connected to your sensory desires or needs. Think about:

- How it felt (for example: pleasurable, painful, exciting, difficult, comforting).
- Whether you were alone or with someone else.
- How you felt during this experience.
- How you felt after the experience.

The final wording of this question was very close to her suggestion. Both my original questions and advisors' comments highlight the tension between wanting to leave respondents as much room as possible to respond in their own way, and the inaccessibility that this might bring by being over-broad in my questions, confirming the importance of "providing enough specificity, even with open-ended questions; and ensuring questions are sufficiently concrete" (Nicolaidis et al., 2019, p. 11). This feedback, along with the relatively short responses given by both advisors who piloted the interview, also led me to add a 'warning' to the interview information sheet: "some of the questions are quite 'broad' and open-ended. This is so that you can talk about subjects that are important to **you**, and not to limit you to what **I** think might be important."

I continued to work in parallel with my Ph.D., and this, combined with my inexperience, meant that I found it difficult to predict and manage the duration of each step. Data collection and analysis—which I had expected to take nine months—lasted almost two years. This seemed too long a period to expect advisors to remain engaged. I was feeling increasingly uncomfortable with communicating with them and felt guilty that I was asking too much of them. I sent a final email to advisors thanking them, stating that I would no longer be contacting them but inviting them to contact me if they had any comments, and directing them to the research website for updates.

The question of time management was a prickly one throughout. From the word go, some members were highly responsive, contributing a great deal of input. However, others were not, and I found myself caught between the need to send reminders to people and the risk of overwhelming or harassing them. This concern was compounded by some advisors having physical and mental health difficulties at various points during the process. In retrospect I would make this part of initial discussions regarding the RAG functioning—how frequently would people like to be reminded, at what point do I stop sending reminders and take silence as a definitive though implicit 'no more please'. I was encouraged to continue contacting advisors with updates when they did not respond by several messages similar to the one below, when an advisor said that they were having health difficulties and were unsure about being able to participate further, but added:

> Thank you so much for checking back in, I was so caught up in my own world due to the recent (mental health) flare that I didn't even have it on my radar anymore. I hope that I can still help with the project in the near future, but right now there's a lot of personal stuff that will be taking priority. Please don't stop keeping me updated / checking in, though. I really appreciate it!

My concern about the level of participation I could reasonably expect from advisors was aggravated by several structural difficulties. One was that I was not able to pay RAG members for their time. While there is "an ethical issue in asking that participants give their time without compensation" (MacLeod et al., 2014, p. 415), I was also advised that an ethical issue of another kind—potentially inducing people to participate if they were paid—was problematic for my ethics committee (see Chapters 10 and 18, this volume for more about ethics applications). I contacted Autistica, an autism research charity in the

UK, which supported the formation of autistic research advisory groups. Far from presenting an ethical difficulty, for Autistica, payment of advisors was a *condition* of their support (which, incidentally, reflected my own view). However, no funding mechanism being in place at that time via Autistica for doctoral research, I was in a catch-22 in this regard.

I was also advised by my supervisors that *too much* input from advisors (particularly co-analysis of data and publications) would bring into question whether the thesis could be considered my own work, a condition for Ph.D. theses in the UK. At the time I was frustrated with this comment. However, with hindsight I am grateful: involving third parties in analysis and publication would have added yet another element to a process which was already, I now see, overly ambitious within the time, resource, and requirement constraints of a Ph.D.

The Survey

There was no information available at the time I was writing concerning which areas of sexuality constituted research priorities for autistic people. I therefore carried out a survey, in which I stated that I sought to understand:

> what aspects of sexuality people (responding to online research) would like to see explored, and the most accessible way to do this. The results of this survey will guide the next stage of my research, the questions I explore, and the way I explore them.

I recruited respondents through snowballing via research advisors and acquaintances; direct emailing to national, local, and student organizations active in autism advocacy and services; publication on Twitter; a link to the Facebook page of the Critical Autism Studies network and on a Facebook page created for the purpose of distributing the survey, and via link to the survey on the research study website. The call used four different color schemes, as suggested by a RAG member. The survey had 12 questions, and I had responses from 567 people from 27 countries in two weeks. I then published a last post, thanking those that had participated and directing anyone interested to the research website for preliminary results (Fig. 20.3).

The results relevant here are, firstly, the research areas of most interest to respondents (Table 20.2).

Based on responses to the survey, I had expected my interviews to be concerned largely with sensory experience. However, this was not the reality of interview participants' responses (see below for discussion).

The second result of interest here was that most respondents preferred a guided interview format, and to respond to questions in writing and in their own time. This is supported elsewhere, with Howard and Sedgewick (2021), finding that particularly when communicating with unfamiliar people, written communication was the preferred option for most of the autistic people

WHAT? A short, anonymous survey – should take 5 – 10 minutes

WHO? Autistic adults (with diagnosis and/or self-identified/diagnosed)

WHY? Tell me what YOU want to be explored in a PhD research study about autistic experiences of sexuality, and how YOU think that research should be done

MORE INFO? https://autismsexualityresearch.com/

TAKE THE SURVEY?
https://www.surveymonkey.com/r/autismsexualityresearch

Fig. 20.3 The call for survey participants on Twitter and Facebook

Table 20.2 Research priorities (as a percentage of respondents selecting each option as either their 1st or 2nd choices)

Sexuality and sensory experience	*44.7%*
Intimate relationships'	39.4%
Social barriers to sexuality	35.5%
Sexual education	30.6%
Sexuality and gender roles	26.2%
Constructing sexual identity	24.9%

solicited. I therefore proposed this as one amongst other possible formats for the in-depth interviews, and written responses were indeed the most popular format for interview participants.

In retrospect, if I had to do it all again, I would not carry out a survey, for several reasons. Firstly, my aim with this thesis was to gather as much depth and complexity as possible in responding to my research questions: clearly, a survey is not an appropriate tool in this case. Secondly, I realize that carrying out a survey to understand areas of research that are important to people, and then interviewing a different set of people, is not a good fit with inductive analysis in general or grounded theory in particular, in which areas to be studied are led (here) by interview data. Finally, the information regarding preferred forms of participation was already available (see, for example, Howard & Sedgewick, 2021; Benford & Standen, 2011).

The Interviews

In-depth interviews produced the majority of data here. Fifty-one people responded to the call on Twitter, and 16 completed the pre-interview process (reading the detailed information sheet and signing the consent form) and went on to be interviewed (Fig. 20.4 and Table 20.3).

This resulted in 24 interviews: seven participants responded to a second follow-up interview, and one completed a third, allowing me to revisit certain themes and check my understanding of previous responses. For the first interviews, 13 participants chose an asynchronous written interview, two a Skype interview, and one instant messaging. People choosing Skype/instant messaging were sent questions in advance. For the second interviews, one person (who had previously chosen written questions) chose a Skype interview, and the others (including one who had previously chosen Skype) chose written questions. The only person to do a third interview did so in writing,

Why ask autistic people about sexuality, intimacy, and sensory experience?

- There is very little research about sexuality and intimacy from an autistic perspective.
- In a survey of 567 autistic adults, sensory experience was the most popular choice for future research about sexuality and intimacy.

Who can take part?

- Autistic adults interested in answering questions about sexuality, intimacy, and sensory experience.

What can you expect?

- To answer some questions about your sexual, sensory, and intimate experiences. This can be done via Skype or I can send you a list of questions to answer in writing, as you prefer. This first phase will probably take 1 – 2 hours.
- To take part in a second, follow-up interview probably lasting about half an hour.
- As a ‘thank you’ you will receive a £25 voucher of your choice for each interview.

More information?

Here: www.autismsexualityresearch.com
Or email me: djacksonperry01@qub.ac.uk
Or DM me on twitter @IntersectQUB

Fig. 20.4 The call for interview participants on Twitter

Table 20.3 Country of origin, age, diagnostic status, sexual and gender identity (as given by participants: pseudonyms were chosen by participants if they so wished)

Name	*Country*	*Age*	*Diagnosis/ self-ID*	*Diagnosis/ID age*	*Sexual identification*	*Gender identification*
Charlotte	UK	32	DX	32	Queer	Cis woman
John	UK	32	DX	4	Neuro-queer/ Grey	Cis male
Sara	UK	36	DX	33	Bisexual/ Polyamorous	Gender-queer
Charles	USA	42	DX	22	Hetero/ Demi-ace	Cis male
Finn	Australia	22	DX	19	Bisexual	Neutrois, AFAB
A	UK	23	DX	19	Asexual	Non-binary
Beatrice	UK	25	DX	23	Bisexual	Cis female
Julie	UK	30	DX	28	Lesbian	Woman
Mia	UK	40	Self-ID	40	Bisexual	Cis female
Hazel	UK	23	DX	18	Heterosexual	Cis female
Mike	Canada	54	DX	54	Hetero (?)	Male
James	UK	20	DX	14	Bisexual	Man
Gillian	UK	41	DX	38	Heterosexual	Female
Oliver	UK	27	DX	5	Pansexual	Cis male
Karen	UK	47	DX	44	Lesbian	Non-binary
Susan	UK	22	DX	14	Pansexual	Female

as they had for the two other interviews. All non-written interviews were transcribed prior to analysis. The average length of written interviews was 2602 words. Two Skype interviews ran two hours and ten minutes and the third just under 45 minutes; the instant messaging interview lasted approximately 30 minutes. In July 2019, I sent an email to participants with some preliminary results, and in April 2020, I sent a final email thanking participants and directing them to the research website for further information.

The interview schedule was adapted from a life story interview schedule, initially used in personality psychology, and shared with me by Marianthi Kourti, a Ph.D. colleague with whom I have worked on several writing projects. While I wasn't seeking to analyze my participants' personalities, McAdams' (2007, p.1) interview schedule aimed "to understand the different ways in which people in our society live their lives and the different ways in which they understand who they are." This ambition intersected with my research questions and with my understanding of the importance not just of events themselves, but of the 'meanings given to events and the actions/ interactions/emotions expressed in response, along with the context in which those response and events occur' (Corbin, 2009, p. 38). After piloting the interview schedule with members of the RAG, I made further adaptations (some of which I described above) before sending interviews out.

I conclude this section on the interviews I carried out with a brief reflection regarding the balancing act between accessibility and the gathering of rich data. Firstly, most participants chose written interviews as being the most accessible for them (c.f. Chapter 21, this volume). I kept many of the questions as open as possible (to allow participants to explore avenues that *they* felt to be important, rather than that I had decided were important), while still giving enough guidance to make responding accessible. This meant that sometimes important elements 'emerged', such as when one participant said "*There were two times I can think of when I was raped*" without giving any further information or context. Had this been in a face-to-face format, I feel I would have been able to infer whether this could have been safely developed, as well as to whether support should be offered. However, to do this in a written follow-up seemed intrusive and perhaps risky. There was clearly a tension between gathering deep, rich data, and making it possible for people to safely participate at all.

Secondly, while I had thought a great deal about how I could be as accessible as possible for participants, it had not occurred to me to worry about my *own* potential difficulties: what is accessible for participants is not necessarily accessible for the researcher (c.f. Chapter 13, this volume). Susan chose to be interviewed using instant messaging, and so we exchanged in short sentences in real time, similar to using WhatsApp. For her, this was the only format that would have made the interview accessible. I found it frustrating, overwhelming, and exhausting. Susan was used to typing very rapidly and replied to my questions immediately and incisively. However, I couldn't process her responses rapidly enough to reply, either to prompt or to ask further questions, to the extent that at one point she wrote "*what is the problem??*" I ended up cutting the interview relatively short with a sense of defeat.

In our interaction, what was accessible for Susan was inaccessible for me. Since carrying out this research, I have received a diagnosis of ADHD, which perhaps goes some ways to explain the incompatibility that Susan and I experienced. Hume (Chapter 13, this volume) notes that it is important to proactively propose accommodations to all participants rather than wait for them to ask for them. In this case, I had done this. However, what I had not seen coming was my own incapacity to use a 'quick-fire', single-sentence format, either from a motricity point of view (of not being able to type fast enough), or from a processing perspective.

That access for one person might be 'access denied' for another was explored briefly in the authors' reflections on the process behind a prior publication (Jackson-Perry et al., 2020). While it is theoretically satisfying to find support for the importance of context when considering accessibility, as a research experience, it was extremely disagreeable. Obviously, the burden of finding an accessible mode of communication for participants is squarely on the researcher's shoulders, which in this case I was able to do only to a limited extent. However, this situation gave me the uncomfortable but useful opportunity to find myself in the shoes of those who are excluded from research participation for questions of access.

LIMITATIONS AND STRENGTHS

Principal limitations throughout are, firstly, that some participants were likely to be part of my social media network, and secondly that we cannot be sure that all respondents meet the diagnostic criteria for autism. My Twitter profile at the time read: *Queer-hood | Researching autistic accounts of sexuality—intimacy | Critical Autism Studies | Sexual health | HIV @CHUVLausanne | He/him* which is likely to bias the profiles of those who follow me. I have no way of knowing how people accessed the call for participants. However, it is possible that responses may have come from a broader section of the autistic population than if I had recruited via existing 'gatekeepers' such as clinics, a point also noted in the few studies that used a similar methodology (see, for example, Byers et al., 2013).

A further limitation throughout this study is a lack of inclusion of those who might be, for example, learning disabled: this limitation is often stated by researchers within autism studies, but is one in which little progress has been made (Fletcher-Watson et al., 2019; see Chapter 15, this volume, for an exception). Indeed, RAG members here had high education levels, which may be itself be a limitation. Further, as I described above, I did not feel legitimate at the time to ask many direct demographic questions of either RAG members or interview participants, and so have no data concerning the ethnic diversity—or otherwise—of these people.

CONCLUSION

The process I have described here was not the simplest or the quickest way of carrying out participatory research. I discussed above the 'casual engagement' with autistic community members that I experienced early in the research process: one of these was a meeting with Dr. Damian Milton in 2017 at the 3rd International Disability Conference in Amsterdam at which we were both giving presentations. His advice to me, given the constraints of a Ph.D., was something like this: "even if you only do one small thing that is participatory during your study, and you do it well, this is already more than most people are doing and is better than nothing." This was the most useful advice that I could have received at that time, and certainly one I would pass on to anyone else doing a Ph.D.. Unfortunately, it was advice that I did not have the confidence to follow at that time: I felt so unsure of myself that I was always looking at how to do *more*, rather than how to do less, but better. Despite having no regrets as to the route I took, as I read this back, I realize that my experience highlights the need to consider how to meet one's participatory ambitions to a degree that respects the central tenets of the framework without putting undue burden on advisors, participants, or researchers. Further, at the time, my sense of discomfort was so intense that, beyond the ‘paralysis’ I mentioned above, I frequently questioned whether I should be working in this field at all. Today I understand that far from being a barrier, my discomfort became a motor, a ‘methodological tool’ even, pushing me beyond what I had been taught (see Chapter 22, this volume). Would I do it the same way if I did it all again? No. Do I regret having done it this way? No: without this—uncomfortable and overwhelming and unwieldy as it often was—my Ph.D. journey would have been lonelier, my thinking more limited, and the result, for what it is worth, poorer.

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CHAPTER 21

Using Email Interviews to Understand Autistic Experiences

Claire M. Chapman

INTRODUCTION

This chapter draws on insights from postgraduate criminological fieldwork (Chapman, 2022) to discuss an email interview method that was purposefully used to create an inclusive research experience with autistic women. Digital environments have increasingly become a place of social engagement and interaction on a larger and more dispersed scale, almost entirely negating both time and space (Gibson, 2017; Hawkins, 2018). With this, there has been an interest from qualitative researchers in the social sciences to explore how the internet can best be used for undertaking research with people and generating rich data (Dahlin, 2021; Gibson, 2017; Hawkins, 2018; James, 2007).

In recent years, autism research has become a more prevalent field of study, with growing interest in understanding more about who autistic people are and how they experience the world (Poulsen et al., 2022; Rice & Lee, 2017). However, a vast amount of autism research is still focused on being about autistic people without necessarily doing research *with* them (Chown et al., 2017), and it is important that research intentionally involves them. Moreover, autism research as a whole also lacks the representation and perspectives of autistic women (Cascio et al., 2021), particularly from a qualitative standpoint (Sohn, 2019).

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In the postgraduate study (Chapman, 2022), email interviews were used to try and improve the experiences of autistic women in research, giving them the agency and environment to participate more meaningfully. The method sought to recognise the individuality and uniqueness of all participants and the researcher, and their communication preferences. Guided by Chown et al. (2017) and their draft framework for inclusive autism research, this research was led by an autistic researcher, had the social model of disability (Oliver, 1990) at the core, and the outcomes of the research aimed to better the lives of autistic people. It aimed to challenge mainstream assumptions and stereotypes and reclaim dismissed or misrepresented stories intersecting disability and gender (Garland-Thomson, 2005) whilst addressing the paucity of qualitative research in understanding autistic women, and the gap in perspectives within criminological research. It also sought to directly address key research priorities identified by the autistic community in Scotland, notably: support services; issues impacting autistic women; and victimisation (Cage et al., 2022) (See also Chapters 4, 10, 13,14, 20, 22, this volume).

This chapter will present an overview of the research, reflecting on the email interview method and how it might contribute to autism research or research involving sensitive subjects. Firstly, it will provide a background to the research in question, describe the method, and provide the justifications behind it. Secondly, it will present an overview of how the email interviews were conducted in practice. Lastly, it will provide methodological reflections of the fieldwork, relating to time and control, depth and authenticity, and suggestions to help inform future research practice.

Overview of the Research

The postgraduate study discussed in this chapter (Chapman, 2022) aimed to address key gaps in academic literature in relation to autistic women, victimology, and associated support services. The initial, in-depth literature review of the study found that as a group, autistic women are underrepresented in research (Cascio et al., 2021; Saxe, 2017; Sohn, 2019). With this deficit in representation, an area of questioning has opened up of how they differ and how their experiences are distinct, with increased interest in engaging with them to answer these questions (Milner et al., 2019; Sohn, 2019).

The research available suggests that autistic women encounter barriers in the social world based on their gender and perceived differences (Bargiela et al., 2016; Saxe, 2017). As women, they have marked differences in both their autism and their position in society, often facing unfair and differential treatment in a world that is inaccessible to them (Davidson, 2007; Hull et al., 2020). The literature review found that disabled women are disproportionately victimised (Ballan & Freyer, 2012). More specifically, autistic women can be at risk of greater and repeat victimisation, especially interpersonal violence or sexual abuse (Cazalis et al., 2022; Gibbs & Pellicano, 2023; Gibbs et al., 2023; Hull et al., 2020; Paul et al., 2018; Pecora et al., 2020). Despite this, there has been little research within feminist criminology exploring the significance of disability[1] and the experiences of those who have been victimised (Macdonald et al., 2023; Shaw et al., 2012).

Autistic women deal with diverse and complex challenges such as masking[2] and internalising emotion (Baldwin & Costley, 2016; Bargiela et al., 2016; Greenlee et al., 2020), and in response to victimisation, there is a greater need for both practical and emotional support services that are substantial, suitable, and tailored to these experiences (Babb et al., 2021; Ballan & Freyer, 2012). This begged the question of what their experiences were of accessing support services following victimisation and how these could be improved. Therefore, the aim of my research was to understand the experiences of accessing support for autistic women who have been victims of crime.[3] This involved exploring participants' perspectives of what good practice looked like, as well as the barriers to support provision and where the needs of autistic women were not being met. Specifically, the research looked to answer the following questions:

1. What barriers do autistic women who have been victims of crime face in accessing support?
2. To what extent are the needs of autistic women being met in this support provision and what does good practice look like for them?
3. How could support provision for autistic women who have been victims of crime be improved?

The research design was rooted in a constructivist approach to grounded theory, adopting a focus on flexibility, reflexivity, and a ground-up, iterative approach to inquiry (Charmaz, 2007). Therefore, to address the aims and objectives of this research, I used qualitative email interviewing to give an alternative platform within research for the voices of autistic women and develop a deeper understanding of their engagement with support services (Bryce et al., 2016). The objective of this was to gather insight into their experiences and formulate recommendations that could be practically implemented, as well as provide theoretical contributions to build upon existing academic work. This emphasised the importance of autistic women's own experiences as individuals set within their subjective realities and contexts, and in doing so aimed to offer email interviewing for them to share their personal stories. Overall, the fieldwork lasted six months (April–September 2022), with 11 email interviews undertaken with autistic women during this time.

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[1] It is worth noting that there is more than one school of thought regarding the construction of autism as a disability; this research allowed participants to take the lead in their self-identification.

[2] Masking: Concealing traits, emotions, or true responses to meet perceived expectations in social situations and appear 'less' autistic (Bargiela et al., 2016; Hull et al., 2020).

[3] To minimise exclusions, the type of victimisation/crime was not specified and is open to the personal interpretation of each participant.

Email Interviewing

Qualitative research can provide in-depth, rich data, adding value and meaning in ways that cannot be obtained from quantitative research alone (Lichtman, 2014; Silverman, 2016). As a key qualitative research method, interviewing is 'one of the most powerful tools available to the qualitative researcher' (Lichtman, 2014, p. 241). Interviews were the primary method of generating data in my research and were used to explore the experiences of autistic women in relation to support services by emphasising the realities and contexts of their personal experiences, offering a space for me to listen, understand, and interpret these. Specifically, I used semi-structured interviews via email as a central component in promoting inclusivity, aiming to ensure that the views of my participants were heard.

Email interviews are a form of asynchronous communication between a researcher and participant where text-based information is repeatedly exchanged out with strict temporal and spatial limitations (Gibson, 2017; James & Busher, 2006; Ratislavová & Ratislav, 2014). All communication is undertaken through email which allows participants to respond in their own time, and interview questions can be sent one or several at a time (Gibson, 2017). The use of email interviewing in qualitative research has been increasing (Meho, 2006), although the method is still somewhat underused, possibly due to the lack of awareness and understanding of it (Hawkins, 2018). Email interviews can remove some of the limitations of traditional interview methods, such as time, cost, and accessing participants, and have been found to be a reliable method, offering a positive experience for both participant and researcher and generating a wealth of rich data (Benford & Standen, 2011; Dahlin, 2021; Fritz & Vandermause, 2018; Gibson, 2017; Hawkins, 2018; Meho, 2006). In a practical sense, email interviewing can break down barriers to engaging in research and facilitate involvement for those who may otherwise have been unable to take part (Benford & Standen, 2011; Hawkins, 2018; McCoyd & Kerson, 2006; Meho, 2006; Ratislavová & Ratislav, 2014). It does this by removing space, time, and financial constraints; addressing challenges with language and communication differences; and has been considered a particularly useful method to engage with isolated or stigmatised groups who may get overlooked in research, such as disabled people, or those who may better express themselves in writing (Benford & Standen, 2011; Bowker & Tuffin, 2004; Hawkins, 2018; McCoyd & Kerson, 2006; Meho, 2006; Ratislavová & Ratislav, 2014).

Why this Method?

Studies that have previously used email interviews have done so due to the potential of the method to be more inclusive, particularly when working with sensitive topics or 'vulnerable' participants. For example, Ratislavová and Ratislav (2014), McCoyd and Kerson (2006) and Beck (2005) all used this method when doing sensitive research with women who had dealt with birth trauma or bereavement, and Egan et al. (2006) used it with traumatic brain injury survivors. When given the choice in these studies, participants overwhelmingly chose email as they felt they could communicate more effectively. The method gave them agency over how they participated in research and allowed them to share their experiences more confidently in a safe, private and comfortable manner (Egan et al., 2006; McCoyd & Kerson, 2006; Ratislavová & Ratislav, 2014). As Gibson (2017) commented, the method is especially suitable for topics dealing with past experiences, memories, and recollections, particularly where the focus is on perceptions of these, or of a sensitive nature.

In line with my research, email interviews have also been used to engage with disabled people (Bowker & Tuffin, 2004) as well as autistic people (Benford & Standen, 2011, see also Chapter 20, this volume). Every person will have their own preference for communicating, but Howard and Sedgewick (2021, p. 2265) found that the type of communication mode used can be either 'enabling or disabling for autistic people'. Their research surveying 245 autistic adults found that written communication was consistently preferred; their participants reported that compared to face-to-face or phone calls, it gave them time to think, provided structure and predictability, and reduced both feelings of anxiety and negative sensory experiences, and this was especially true for participating in research (Howard & Sedgewick, 2021). Moreover, Davidson (2008) and Parsons et al. (2020) discuss how online spaces have become invaluable to autistic people, creating opportunities for inclusive and social engagement in ways that may not be as easy in person. Stepping away from the dominant and neurotypical forms of communication, written text can help autistic people feel safe and empowered as they relay information, valuing the time to think without pressure to respond in haste (Davidson, 2008). Extending this, Cascio et al. (2021) touch on how the internet can facilitate inclusion for autistic people, especially those unable to communicate verbally (although they do note concerns about the total inclusivity of written communication for *all* autistic people).

My research acknowledged the importance of autism researchers using tools to study autism that make sense to autistic people for learning about their experiences (Jones, 2022). Email interviews could open up a space for autistic women to discuss sensitive topics and provide deeper reflective written accounts facilitated by the level of anonymity, comfort, and control for participants that may suit many autistic people (Benford & Standen, 2011; James & Busher, 2006; Ratislavová & Ratislav, 2014; Saarijärvi & Bratt, 2021). They could be conducted in a low-pressure environment at a suitable time for the participants, where they feel comfortable and able to use their 'voice'. Additionally, much like traditional interview methods, they are still said to generate rich, high-quality data capturing participant's constructions of reality, their experiences, and the meaning within these (James & Busher, 2006).

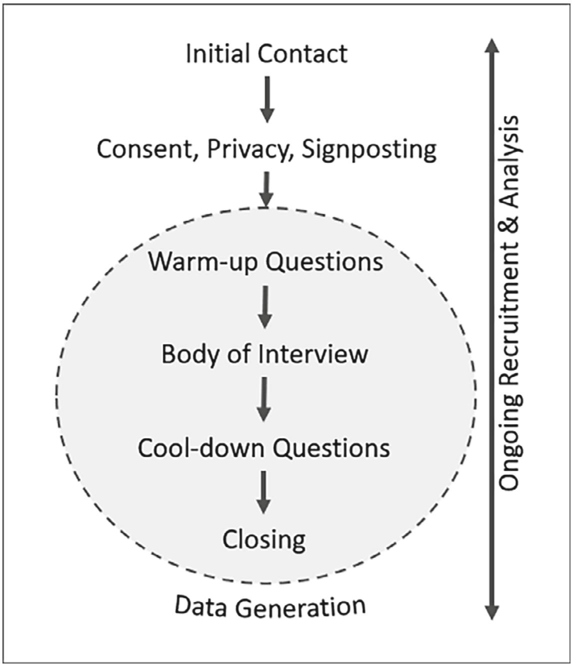


Fig. 21.1 Email interview stages

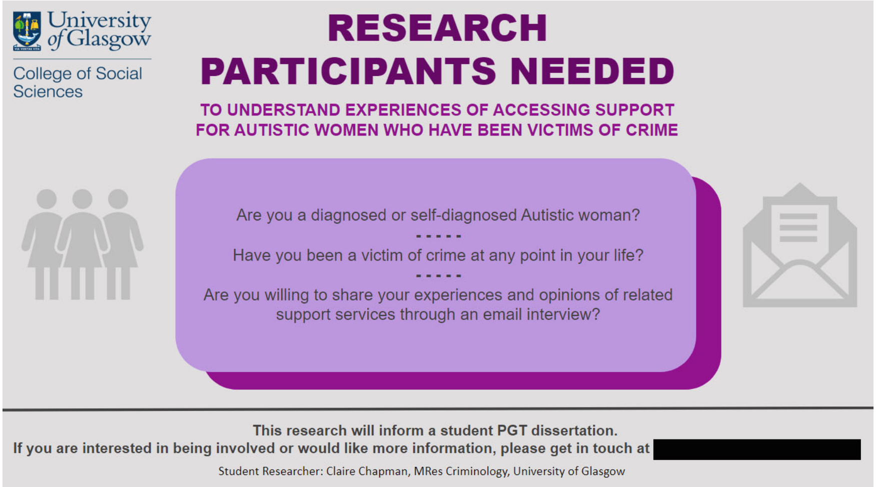
Fieldwork in Action

Through email, I interviewed adults living in Scotland who identified as autistic women and were currently accessing or had previously accessed support services after being victimised. This aligned with constructivist grounded theory principles with co-occurring recruitment, data generation, and analysis—Fig. 21.1 below shows the key stages and how they interacted.

Recruitment and Initial Contact

In recruiting participants, I identified and contacted gatekeeper organisations and online support groups that represented autistic people and/or victims, including those aimed specifically at women. I reached out through email to see if they were willing and able to support the research by sharing a recruitment request (see Fig. 21.2) via their own networks to encourage people to take part in the research. The recruitment request was shared through seven support networks in total.

Potential participants would contact me via email to notify their interest in the research, at which point I would share the information sheet, privacy notice, and consent form for them to read and complete as they felt fit. I also gave them a directory that signposted them to relevant support services and reminded them that their wellbeing was important, and that the interview



University of Glasgow

College of Social Sciences

RESEARCH PARTICIPANTS NEEDED

TO UNDERSTAND EXPERIENCES OF ACCESSING SUPPORT FOR AUTISTIC WOMEN WHO HAVE BEEN VICTIMS OF CRIME

Are you a diagnosed or self-diagnosed Autistic woman?

- - - - -

Have you been a victim of crime at any point in your life?

- - - - -

Are you willing to share your experiences and opinions of related support services through an email interview?

This research will inform a student PGT dissertation.

If you are interested in being involved or would like more information, please get in touch at [redacted]

Student Researcher: Claire Chapman, MRes Criminology, University of Glasgow

Fig. 21.2 Recruitment request infographic for online dissemination

should work around them (c.f. Chapters 11, 13, 20, this volume). This was also an opportunity for them to ask any initial questions before beginning to alleviate any doubts and provide clarity. Overall, I received interest from 24 individuals, ultimately undertaking interviews with 11 individuals. This was to ensure that it was feasible to conduct the research within the given timeframe and that I was able to provide the necessary attention to each participant, respecting their commitment to the research, and giving sufficient time for analysis. Interviews were with women in their late 20s to late 40s, all of whom identified as autistic.

DATA GENERATION

I followed a general topic guide which was open to change based on responses, however, each interview typically went through four key stages: warm-up, body, cool-down, and closing. To warm-up, I found it helpful to ask questions to understand a little bit about the participants and their autism to learn more about how they viewed the world and themselves in it, for example:

> Could you tell me how you came about understanding that you were autistic? For example, when was this and what prompted this?
>
> What are your perceptions of autism and how you view yourself? For example, negative/positive feelings you may have, how this might have changed over time?

These warm-up questions felt like a good way to initiate the interview, particularly using a relatively uncommon method, as they were able to instantly talk about a familiar topic and get into the flow of the typed conversation. I sent these questions all at once in an email, as this often resulted in lengthy, high-quality responses. This was usually about their identity, diagnosis, life journey, and societal views, ranging from a few paragraphs per question to six pages of text. Multiple participants apologised for their 'rambling' after their first response, so I made a point to remind them that they could take the lead and write in whichever manner they felt suited them, without trying to put on any front or meet any preconceived expectations. When it felt right, I sometimes disclosed my own identity as an autistic person through relating to our shared experiences; participants were unsurprised due to the research topic and approach, and I felt it helped build our rapport. Participants relayed positive feedback for this stage, feeling content at the outset and happy to continue with the interview, for example, one person reflected:

> I was hesitant about the email interview method as I'd never heard of it used before and was a little unsure of what to expect or how it would actually work, but as the interview got underway I felt very relaxed with the process and realised it was perfect for me…It was explained simply at the start, which alleviated some of my hesitancy, and there was no need for protracted social chit-chat which I also appreciated as this put me at ease.

This warm-up stage also provided a useful backdrop into their experiences and opened opportunity to explore further in relation to support services, leading to the main topic of my research. At times, the response to the initial question naturally transitioned into the body of the interview, or I would help move it along by querying about support they may have had, for example:

> Did you reach out to access, or get offered any kind of support? If not, what were the reasons you didn't? If so, who was this with, and how did you come to get in contact with them?

This part of the interview involved back-and-forth communication, where I would send follow-up questions to their answers to dig deeper into the research topic, according to their experiences. Each time, I made sure the interview was tailored to the individual. When I received a new email, I would look back to remind myself of the conversation and ensure that I was not responding generically, but to their distinct experiences. I would also write up key field notes throughout on what we were talking about so that I could easily refer to these when I revisited the interview.

After I felt I had reached the saturation stage of the interview, I asked some more general cool-down questions to ease out of the exchange. This allowed me to understand how their experiences affected their wider perspectives of autistic women and support services, and gradually took some of the more personal aspects out of the conversation. For example:

> Thinking more generally about autistic women who have had similar experiences, how do you think they could be better supported?

On closing, I asked participants for feedback on how they felt about email interviewing, as I had been pondering the positives and negatives about using the method. This was also a useful addition to the cool-down approach to help end the interview after discussing sensitive topics and finish the conversation on something lighter. I then asked if they were interested in receiving the research findings before ending the interview.

Co-occurring Analysis

Generally, I interviewed multiple participants at once as there were no set timeframes to complete an interview and my recruitment requests were shared at various stages. For example, by the end of July, I had completed three interviews with two underway whilst still receiving emails of interest to participate. Taking a co-occurring approach, common with constructivist grounded theory (Charmaz, 2007), I also began data analysis as interviews were still ongoing. I found it a particularly useful analytical approach where data generation and analysis worked simultaneously in an inductive, comparative, and iterative process. I was thinking deeply about what the data was saying, whilst using this to help shape ongoing interviews; something which would not be as easily implemented in more traditional, face-to-face interviewing. This was useful as it meant I could use approaches or insights I had learnt to apply to the most recent interviews, such as question wording, or new knowledge prompting additional questions to others. For example, one participant put forward the idea of autistic people leading in training or resource development, and the email interview method allowed me to extend this question to my ongoing interviews.

Whilst data was continually being created, I undertook key analytical steps with the completed interviews. I collated email threads into word documents (already transcribed as the interview occurred) and the data was anonymised. This was followed by an initial coding stage, analysing and naming smaller fragments of data, followed by a focused coding stage to further categorise chunks in the text (Charmaz, 2007). Memo writing and spider diagrams were then used to write about and reflect on the data to visualise and connect it and begin the path towards theoretical categories, developing this until nothing new was found and all interviews were completed (Charmaz, 2007).

Ethical Considerations

As my research involved real-time, online data generation from participants and related to a sensitive research topic, ethical considerations were a critical component, going beyond just informed consent and confidentiality. I reviewed these elements in great detail, and they remained at the forefront throughout the research process.

The digital and online nature added an additional layer of risk surrounding data security and protecting participant information (Gibson, 2017; Sparks et al., 2016). I had certain digital protections and procedures in place to manage and reduce these risks, guided by McCoyd and Kerson (2006), Gibson (2017) and Meho's (2006) research. The university IT systems I used had virus detection software and firewalls and the email account was on a secure platform with strong password protection. Personal data was anonymised as efficiently as possible and saved on secure, password protected file systems and emails were deleted soon after.[4] With the sensitivity of the research topic, there was also the risk of harm for participants, but with the lack of visual and verbal cues in email interviews, detecting harm was a concern (McCoyd & Kerson, 2006; Ratislavová & Ratislav, 2014). I extended support to participants throughout our interactions, including ensuring their full understanding of the process; providing reassurance; regularly checking-in on their wellbeing; giving clear thought to wording to minimise confusion; and sending a list of relevant support services (Benford & Standen, 2011; Egan et al., 2006; McCoyd & Kerson, 2006; Ratislavová & Ratislav, 2014).

Time and Control

A prior concern to email interviewing was that it was time consuming, which could create difficulties sustaining interest and the risk of drop out, as well as raising ethical questions around the commitment required for participants (Benford & Standen, 2011; Gibson, 2017; Hawkins, 2018, see also Chapter 20, this volume). I avoided drawing out the interview period excessively and was conscious of swaying from the research focus where possible to help minimise the effects of time and maximise engagement for myself and the participants. However, from the outset, this was much more challenging in practice, and conducting the interviews did ultimately feel labour and time intensive, at least from my perspective.

Although it was an important stage and helped me to start building rapport with my participants, the time between initial contact and beginning of the interview questions felt lengthy and was not anticipated. There was a somewhat significant number of back-and-forth emails for sharing participant information sheets, ensuring understanding, and discussing consent which could feel onerous, albeit important. On commencing the interview, I had a rough rule of no more than three days between receiving a participant email and responding to it, as I wanted to be able to give it the thought and time

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[4] Since this research was undertaken, Pellicano et al. (2023) have uncovered threats to online methods in autism research where scammers disguise themselves as authentic participants for financial gain—this should be an additional consideration when planning online research.

each participant deserved without them waiting too long. Whilst participants reported that they enjoyed the process, they suggested it would be helpful to know when they would expect a response, how far they were from the end, or to receive an outline of the predicted interview timeline from the outset. This could set their expectations and reduce any anxieties around communications:

> I liked doing it via email… Sometimes I got anxious not knowing how long a response would take. Maybe each email could say 'you will hear back from me in x hours' or something?

However, as a researcher I also had little direction over the response lag from participants and when I would receive replies. This meant I had to chase some responses, but also that time to complete the interviews ranged between two and six weeks; slightly longer than anticipated for my research, but not entirely unexpected (Fritz & Vandermause, 2018; Gibson, 2017). It became apparent that some participants found it harder to manage their responses to emails, and tended to have a greater need for reminders throughout the process, and this appeared more prevalent for participants who were also ADHD or dyslexic.

> I think it was good in that I could do it in my own time and I could think a bit on the questions but bad in that it took up a lot more of my time (takes longer to type [than] talk) and I had to remember to reply vs a booked slot for a call.

In general, I found that interviews over a shorter timeframe tended to maintain a better, more natural flow of conversation, so there was the risk that extended delays to the interview process could negatively impact on the quality of the interview and researcher-participant relationship. However, it was important to me as a researcher to tailor the email interview process to each individual, and so I was willing to send reminders to support their participation, without badgering them.

Despite the challenges of time demands in email interviewing, I found that this was still offset by the benefits that came from using this method. Like myself, participants stated that they really enjoyed the minimal interaction and agency that came with this approach, and having control over the time and space they participated in, and how they used this, worked well:

> For me, this was the most suitable method as I could take it at my own pace and could take part from the comfort of my own home (where I'm most relaxed and able to think clearly without distractions) at any hour of the day or night that suited my erratic schedule. I didn't have to worry about appointment times or meeting new people (even online) or travelling somewhere unfamiliar.
>
> I could also respond to the email at a time that was suitable to me and I could take a break from writing if needed, without the awkwardness feeling you might get from asking for frequent breaks if had been a face to face interview.

Similar to what Gibson (2010), Egan et al (2006) and Bowker and Tuffin (2004) found in their research, participants could view, read, consider, and respond to interview questions without haste. The pace was slower, and they could participate whenever and wherever they chose, suiting their schedule and preferences. Both the participants and I responded to everything in our own time, when we felt ready and without pressure to do so quickly or with rash replies. As research has discussed relating to online communication for autistic people, these written accounts take away the pressure of the neurotypical ping-pong and faster-paced conversations, and allow for 'a delay in response that is almost never allowed in real life' (Brosnan & Gavin, 2015, p. 255; Davidson, 2008). In doing so, participants had more control over the direction of the conversation and how they told their story, giving them more time to formulate their responses in a manner that suited them, which may not have happened in a more traditional interview.

With this, participants also took the lead in their writing and approach to sending emails. Some sent very lengthy, detailed responses, whilst others were very concise and to the point; some were grammatically correct and organised, whilst others were somewhat less focused and filled with misspellings, and expressive punctuation, such as capital letters, exclamation marks, ellipses and emojis. They were able to choose how to express their personalities through their writing, and the time and effort they put into this. In my role as the researcher, I was guided by their approach and my way of writing adapted to match theirs, to aid in their comfort levels throughout the conversation and their ability to relay their experiences to me. This process of mirroring participants and responding to their language can help strengthen trust and support the researcher-participant relationship (Fritz & Vandermause, 2018) and allow for thoughtful and somewhat personal conversations to be shared.

Depth and Authenticity

Researchers have shared concerns over the misinterpretation of information that can occur through email interviews and questioned the authenticity of written word in expressing experiences (Benford & Standen, 2011; Bowker & Tuffin, 2004; Gibson, 2017; James, 2007; Meho, 2006). These are based on the fact that responses are solely textual-based data; the extent to which words can be rewritten and edited online; and that it is 'unconversational' interviewing, without 'natural' social interactions (Benford & Standen, 2011; Bowker & Tuffin, 2004; Gibson, 2017; James, 2007; Meho, 2006). This could result in challenges interpreting meaning or the emotional states of participants, resulting in a lack of rich data, and less opportunities to build rapport. However, I intended to help autistic participants feel more comfortable to take part in research, and, with certain adjustments, email interviewing had the potential to provide a platform for them to give a more 'authentic' representation of themselves. Written communication may be less natural to neurotypical people but could be fitting for many autistic people.

During the research, it was important for me to work on building a trusting relationship and provide a space where my participants could feel at ease and able to express their genuine self as much as possible whilst sharing their experiences. I endeavoured to acknowledge each participant as an individual, taking time to respond thoughtfully to every email. I was unable to use typical verbal interjections such as ‘mhmm’ or nodding to express interest, reactions, or encouragements to their email responses. Although arguably, these may be considered neurotypical encouragements, and not using them may have actually been encouraging for my participant’s engagement. Nonetheless, I felt it was important that for each reply I commented on or acknowledged a point they made in their previous response. This was to ensure they felt heard and alleviate any doubts they had about answering ‘correctly’, which appeared to be a common concern. I found that I got better quality responses and the discussions flowed better and were filled with depth by tailoring each interaction. Similar to Ratislavová and Ratislav (2014), personalisation and considered communication for each individual allowed me to get to know how the participant ‘spoke’ and brought out emotive elements from their text-based responses, helping to understand their story better and how they were feeling telling it. Feedback from some of this approach was also praised by participants:

> You gave me just enough feedback at every stage of the interview to reassure me that I had answered each question sufficiently but not gushingly so which would have made me feel uncomfortably patronised. I enjoyed it!

Where there may have been a delay between emails sent and received, at times this was awaiting a long, well-crafted response from a participant that powerfully portrayed their experiences; it was worth the wait. As James and Busher (2011) pointed out, through online research participants can be chatting away, you just can’t see or hear it yet. Whilst the changing nature of data through editing, rewriting and low spontaneity could be a concern, it allowed more time for introspective thinking and reflective responses (Gibson, 2017; James & Busher, 2011; Meho, 2006). Writing may take away the complexity and stressors for autistic people to follow social expectations and could be considered a more authentic and open representation of their experience and reality (Davidson, 2008; Howard & Sedgewick, 2021). My participants could remove the ‘mask’ and express themselves more easily, particularly through having additional time to think without pressure, contributing to a truer reflection of their reality. One participant commented favourably on this aspect of the method:

> I found the method of emailing really good. Having the questions sent via email was more accessible because I had time to think about my responses without pressure. It meant I was able to answer exactly what I wanted to say rather than

> give a quick answer on the spot… Another positive was that I didn't have the added pressures to socialise or communicate verbally.

My participants, and those in previous research (Beck, 2005; Ratislavová & Ratislav, 2014), used the terms '*healing*' and '*therapeutic*' in response to email interviewing as they wrote out their experiences in a journal-like manner, enjoying and embracing the time to think and reflect. Whilst writing can be edited, I believe this connection to journalling supports the authenticity of participants' voice through email interviewing to share their experiences. However, guidance in undertaking this method should provide clear instructions and expectations so that participants have a clear understanding of what it is and that they do not treat it like a diary. My participants also found it a much more accessible way to engage more deeply in research where they otherwise could not, bringing a sense of freedom, as well as convenience with how it aligned with their life, even over the extended timeframes:

> I really enjoyed the process of an email interview. I found it to be convenient for me, and I was able to put some thought into my answers in a way that I might not have been able to if the interview was done in person or via zoom (I can get very nervous in spoken conversations and say things I don't mean, also they take a lot out of me!).
>
> I felt much more able to stay on topic and discuss some very personal things in a more descriptive, factual way than I would have in person, on video call, or by phone… I actually really enjoyed it! It was therapeutic to type everything out in such an organised way … it already made sense in my head but I'd never actually put it down on 'paper' like that before. I don't think it would have been so therapeutic if I'd been trying to do it via video call or any other way because I'd have been less focused on accuracy as I worried about interpreting facial expressions and tones of voice etc. and I'd have felt more emotionally and socially drained by the process.

However, it is worth mentioning that some of my participants found the open-ended aspects of the interview questions more difficult, which was evident through their comparably smaller responses. Although according to participants, this was unrelated to the email method and more about the interview itself and would have been the case if it were a different technique. On learning this, I provided clear and more direct questions with examples to help guide them and alleviate these concerns—although it was a delicate balance between this and not influencing the research too much. On top of this, the value of email interviews is that any vagueness, misunderstanding or misinterpretation could be considered and clarified in follow-up emails from either party if necessary (Benford & Standen, 2011; Gibson, 2017; Meho, 2006). There is more time to pause and consider wording, phrases, and meaning and ensure they are being interpreted as intended; clarifying, and expanding on any responses as required whilst remaining in the context of the interview.

A Flexible Approach

In doing sensitive research with autistic women, my asynchronous email interview method was received favourably. However, there were opportunities for improvement in how the method played out in practice which could have helped it function more conveniently for participants and streamline the method for me as a researcher.

At the research design stage, it would have been useful to have a more efficient process of commencing the interview to reduce time spent with back-and-forth emails for administrative tasks. All the required information could have been more concisely collated into one email at the start. I would have benefited from taking more time to work out how I was going to pose questions to participants in the emails, such as my structure of doing this, and whether I was taking an approach of one question at a time or collating questions. Secondly, providing guidance and clearer expectations at the outset and throughout the email interview timeline, or at key stages, would have been beneficial for participants, such as the amount of time or number of exchanges remaining, or receiving questions in advance. This would have been useful to alleviate any unease about length and ongoing commitment and allow them to manage their own time and any individual preferences could have been discussed and pre-prepared.

Whilst most participants enjoyed and gained a lot from the email interview, a few also acknowledged that they might prefer doing the interview through alternative means:

> It was good so I knew the questions to have a think about them I would of preferred doing it via online video link as I find it hard to type too much and I could of included better answers giving them verbally.
>
> I'm fine doing video calls and phone calls most of the time. I know some autistics aren't.

Considering this, it may be beneficial to adjust the email interview approach slightly to suit different ways of thinking, working, and communicating, without losing the value uncovered from the method (see also discussion in Chapter 7, this volume). It could be more flexible, giving thought to other identities or intersections within the autistic community. For example, the interview could be primarily by email, maximising the benefits of an online, written, asynchronous approach. Alternative options (e.g., video calls) could then be offered for those who may prefer it—online or offline, verbal or written, to suit a mixture of communication styles. Although it is worth noting that this may have some limitations, such as coordinating the different techniques through interviewing and analysis, and the organisational risk that comes with this. There may be challenges in different platforms producing different types of responses and the impact this would have, particularly when the questions and prompts are framed differently as this may affect the consistency across interviews, and the quality and depth of exchanges. Despite this, a flexible approach would address some of the limitations of the email interview method, embracing different preferences and prioritising accessibility and comfort of autistic participants. Whilst this was not appropriate for the research in question due to the parameters of the study and timescales, this is something I intend to take on in future research.

Conclusions

In my research to understand autistic women's experiences of support services, I took steps within the research design and fieldwork to use a method that was accessible, comfortable, and enjoyable whilst generating the information required to inform the overall research project. Interviews were conducted via email to explore the applicability of this method to inclusively engage autistic women in qualitative research.

I found it to be an extremely worthwhile method for capturing reflective and vivid personal experiences as written from an individual's point of view. Flexible in time and space, it passed more control to participants and gave in-depth and rich responses about their life experiences relating to sensitive topics of victimisation and support services. The feedback on the method was very positive, and participants enjoyed it and felt included in research where they have often felt unable to participate in. However, future use of email interviewing should provide participants with clear guidance on how the method works in practice and expectations for them as a participant to help manage any anxieties for engaging in research.

Future autism research should consider making use of email interviews through a flexible approach, giving participants options for various communication modes where required and providing greater agency for the participants involved. To inclusively engage autistic people, research should incorporate methods to meet the requirements of participants, not expect them to adopt the requirements of a method which may not be suitable to them. Knowing this, reworking or introducing new methods in qualitative research in a manner that is flexible, considerate, and comfortable should be a priority for autism, broader neurodiversity studies, and criminological research.

Ethical Approval

Full approval was granted by the University of Glasgow School of Social Sciences Ethics Forum (PGT/SPS/2022/136/SOC) and informed consent was obtained from individual participants.

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CHAPTER 22

Unknowing as a Methodological Tool: Autism, Authenticity, and Epistemic Injustice

David Jackson-Perry

INTRODUCTION

It is "increasingly acknowledged" that only by shaping research agendas "together by researchers and community members" can "autism research adequately address the issues facing autistic people and their allies" (Pellicano et al., 2018, p. 1). This togetherness is often sought through participatory research (PR), that is, "incorporating the views of autistic people and their allies about what research gets done, how it is done and how it is implemented" (Fletcher-Watson et al., 2019). However, despite being myself the product of autism research circles that hold that the path to ethically and epistemologically robust research largely depends on implementing PR, I no longer feel that it is the fix-all that we may have hoped. Indeed, as things stand, I worry, with Orsini (2022, p. 5), that:

> bringing autistic voices or perspectives to the table may reproduce what many have decried in the past: participation or engagement for the sake of crafting a thin veneer of legitimacy.

Before going any further, a few words about what I bring to this chapter, personally and professionally. In 2023, I completed my PhD thesis[1] on

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[1] On which I have drawn extensively for parts of this chapter.

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autistic experiences of sexuality, intimacy, and authenticity, using a participatory methodology and a critical autism studies framework (Jackson-Perry, 2023). When I started that study six years earlier, I saw and presented myself as a neurotypical researcher: today I have a diagnosis of ADHD. I am also HIV project manager at Lausanne University Hospital, in Switzerland, where much of my work involves contributing to and implementing participatory processes in HIV research. 'Contributing to' because I also live with HIV. In all these roles—living and working with HIV, carrying out autism and neurodiversity research as a non-autistic, neurodivergent sociologist—I promote the integration of lived experience into research processes. However, as things stand, far from being the solution, I increasingly feel that PR itself presents a set of ethical and methodological challenges, similar in both HIV and autism research.

These challenges are particularly pertinent in the current climate where there is a certain pressure on researchers in both fields to be inclusive. Funding and publication may depend on it: researchers, more or (generally) less experienced in PR, more or (sometimes) less in agreement with PR principles (den Houting et al., 2021), are encouraged to carry out participatory research. This may not always be because they believe that it adds value to their research, but because it is a requirement, a box to tick.

This can be problematic on several fronts. Who is chosen to participate, and by whom, is rarely made clear. In my experience, it is often the same people who are called upon, those who are comfortable for researchers to work with, convenient to contact, known quantities. At which part of the research process they are involved is also largely left to researchers to decide. This may often come toward the middle of research processes (den Houting et al., 2021), the check-the-research-tools-stage ("what do you think about this questionnaire?"). Early collaboration or even consultation remains rare (for a counter example see Chapter 4, this volume), meaning that research priorities are generally fixed before seeking community input: unsurprisingly then, the mismatch between autistic people's research priorities and the research that is funded and carried out remains significant (Cage et al., 2024; Cervantes et al., 2021; Pukki et al., 2022).

In HIV research, people living with HIV are trotted out to explain to clinicians, researchers, and funders how and why we should be involved in research processes, so that they will continue to fund and carry out PR. I used to think this was a good thing and consider myself lucky to be called on. I now feel that it is closer to "epistemic exploitation" (Berenstain, 2016, p.569), an "additional labor created by the default skepticism of the privileged." Particularly when PR is carried out for pragmatic reasons rather than belief in its importance, autistic folk are also subject to epistemic exploitation, with, for example, funding mechanisms for payment often complex or inexistent (den Houting et al., 2021; also see Chapters 6,19,20, this volume). Leaving aside financial compensation, the risk of tokenism is never far away, for lay-people or researchers. "Autistic academics" say Thom-Jones and Lowe (Chapter 10, this volume), in a quote that echoes my own HIV experience:

> are all too familiar with the proposition of an informal zoom meeting to discuss autistic perspectives about a study that is already underway, being later positioned as a participatory approach or autistic community consultation.

None of this is to say that I think PR is a bad thing, or that it cannot be meaningful or useful: there are examples that clearly demonstrate the contrary (see, for example, Nicolaidis et al., 2019). However, we largely look to PR to fix all our problems, to move from deficit to difference, from questions important to researchers to questions important to autistic communities, from individualist medical narratives to more social leaning models. And yet, to borrow from the title (and content) of Botha and Cage's (2022) article, "autism research is in crisis": high proportions of autism researchers endorse ableist or dehumanizing language, lean on medical narratives over social, and associate autistic people with outdated and prejudicial stereotypes. It is difficult to see how the inclusion of people who are perceived in this way could bring about much change. Participatory research alone is not a panacea that can right the epistemic and ethical wrongs of autism—or indeed HIV—research.

In this chapter, I suggest a step that might be useful in this direction. That step—whatever one's neurotype—is to unknow what we have been led to believe is true about a condition constructed around outdated and fallacious assumptions of deficit tinkered for years by medical, psychiatric, and aligned disciplines. I want to think about unknowing as a tool that has the potential to get to the root of epistemic injustice and ignorance.

To do so, I first draw on my PhD thesis, in which authenticity emerged as crucial to participants as they navigated their social and intimate lives (Jackson-Perry, 2023). Despite multiple elements pointing to authenticity as a potentially central concept in autistic subjectivity, there is little sustained discussion of it in autism research.[2] I use this absence as a case study to take a critical look at epistemic injustice as it relates to both autism and authenticity, although it is also pertinent for Neurodiversity Studies more broadly. I conclude with some practical suggestions in the form of an unknower's toolbox.

The Case of Autistic Authenticity

Authenticity is often used in the social sciences "to refer to such different things as sincerity, truthfulness, originality, and the feeling and practice of being true to one's self or others" (Vannini & Franzese, 2008, p. 1621). While over-simplifying a contentious and complex concept, I use a similarly simple

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[2] A notable exception here is regarding the sexual and gender behaviours and identities of autistic people: these are generally read as constituting 'symptoms of autism' and so are, necessarily, *in*authentic (Jackson-Perry, 2020).

definition here for authenticity and its proxies: truth-telling, straightforwardness, and an understanding of self, others, and concepts that are less likely to be swayed by context or social bias (see Jackson-Perry, 2023, pp. 60–74 for detailed discussion).

Much thinking on authenticity draws on George Herbert Mead. He distinguished between the ‘I’ and the ‘me’: the subjective impulse-oriented part of the self (the ‘I’) coexists with the other-oriented objective component of the self (the ‘me’), allowing individuals to think of themselves as both subjects and objects, to take into consideration their own self-presentation and, by extension, to access authenticity. Mead remains highly influential, and symbolic interactionist Franks (2003, p. 621), for example, leans on his theory and that of a deficit in Theory of Mind[3] to discuss a report in which the authors “study cases in which the self is diminished or non-existent, as in autism.”

This categorical leap to a diminished or non-existent self, a person lacking “the capacity to construct persons and subjectivities beyond observable bodies,” *stated as fact*, is made possible here by drawing on Mead. Mead’s self develops through early stages of childhood socialization, notably “play,” whereby the “normally developing” child “begins to take the ‘view of the other’, imagining situations from another person’s perspective” (Scott, 2015, p. 6). This, Scott goes on to say, “echoes Theory of Mind in psychology.” And so, leaning on two speculative and contestable theories—Mead on the reflexive self and Baron-Cohen on deficit of Theory of Mind—autistic authenticity becomes unthinkable. If I do not have a self, or if that self is diminished, then what are my possibilities for authenticity, for “a commitment to self-values” (Erickson, 1995, p. 121) for which self-knowledge is a pre-requisite?

And yet, a great deal of empirical evidence points to high levels of authenticity and its proxies among autistic people. They may speak their minds “irrespective of social context or adherence to personal beliefs” (Kirchner et al., 2016, p. 3330). Authenticity is ranked significantly higher as a signature strength by autistic than non-autistic research participants both when self-scored (Kirchner et al., 2016, p. 3333) and in personality traits measurement (Strunz et al., 2015): “honesty,” the latter authors conclude (p.4035), “seems to be a primary strength in individuals with ASD.” On the other hand, “lying…is not a common phenomenon” among autistic people (Jaarsma et al., 2012, p. 272). Indeed, there is “empirical evidence that children with ASD use an effortful route via their working memory—when they engage in the sociocognitive process of deception,” leaving them eight times less likely to tell even a self-protective lie than non-autistic peers (Ma et al., 2019, p. 3374).

Cognitive neuroscientist Reubs Walsh and I (2021) suggested that autistic trans and non-binary people may have heightened access to authentic gender

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[3] This highly pervasive theory, which has been robustly and repeatedly refuted elsewhere (Fletcher-Watson and Bird, 2020; McGrath, Peterson and Pennington, 2020; Williams, 2021), seeks to both demonstrate and explain an assumed autistic inability to understand or take into consideration what someone else is thinking or feeling.

identity and expression: they may give a higher priority to how a person *experiences* their own gender, and a lower priority to social representations of what is considered possible or desirable. We drew on three cognitive theories to explore this: imperfect systems (Kristensen & Broome, 2015), bottom-up or unbiased processing (Goldman & Kernis, 2002; Mottron et al., 2006), and Bayesian theories of flattened priors (Pellicano & Burr, 2012). Broadly, these theories suggest that autistic people may be neurocognitively inclined to give less consideration to context, or to pre-existing experiences or beliefs, and more to their immediate experience of a phenomenon. We posited that this might leave autistic people less inclined to conform to rigid, pre-existing categories, preferring (and able) to evaluate their own experience authentically, even if that experience falls outside what is generally considered possible or desirable (see also Wattel et al., 2022). This appears to be supported in qualitative discussions of gender (see, for example, Kourti & MacLeod, 2018), with Späth and Jongsma (2020, p. 76) noting that autistic people appear "less prone to be influenced by habits or options others embrace, which makes them authentic and better 'guardians of their own interests' than non-autists."

Almost all the autistic participants in my doctoral research recurrently referenced honesty, straightforwardness, and authenticity as central to their intimate lives: desired in a partner, facilitating satisfying and trusting intimate relationships, and enabling them to resist heteronormative pressure to arrive at an authentic understanding of their own sexuality or gender. Conversely, participants considered inauthenticity, conformity, a lack of honesty, lying, and so on, to be typically neurotypical traits. This echoes parodic autistic community writing, with Main (2003), for example, detailing a set of diagnostic criteria for "allism" ('non-autism'). The author describes the "underlying trait" of allistic people as lacking:

> the capacity to independently experience emotion…(their) emotional state is not determined by their own thought processes but instead is borrowed from other people that are expressing emotion nearby.

Allistic people, Main goes on, have:

> difficulty with the difference between truth and falsity. In many circumstances, they find it difficult to say accurate things, and will instead say inaccurate things that they find more pleasing.

The Institute for the Study of the Neurologically Typical (ISNT, no date) similarly parodies diagnostic criteria for neurotypicals, who, as well as having an "obsession with conformity," says ISNT, also "find it difficult to communicate directly, and have a much higher incidence of lying as compared to persons on the autistic spectrum."

To summarize, the concept of authenticity and its proxies appear to be "especially pertinent to autistic individuals" (Stark and colleagues, 2021,

p. 195). There are intriguing indications that they may be cognitively predisposed to a tendency for truth-telling, open-ness, honesty, straightforwardness, and attachment to a sense of authentic experience over imposed beliefs. Socially, those same attributes form part of how some autistic people and communities narrate themselves, in contrast to non-autistics who are perceived as having deficits in these same areas (see also Brownlow, 2010). And yet, despite all indications that authenticity might be central to autistic experience, sustained discussion of this overwhelmingly positively perceived attribute (see, for example, Schlegel & Hicks, 2011; Stark et al., 2021; Bottema-Beutel et al., 2018) is missing from the literature. I noted at the beginning of this section that theories formulated by Mead had in a sense definitionally written out any possibilities of autistic authenticity. I now turn to a discussion of this and other forms of epistemic injustice relating to authenticity and autism research more broadly.

Epistemic Injustice: "Very Easy to Commit…Extraordinarily Difficult to Avoid"?

> The reality is that epistemic injustice is very easy to commit. In fact, it is extraordinarily difficult to avoid it (Pohlhaus, 2012, p. 717).

Miranda Fricker (2007, p. 4) proposes that "shared social-imaginative conceptions of the social identities" of "social types" (here, autistic people), produce "testimonial injustice," reducing the credibility given to a "speaker" from a group that the "hearer" is prejudiced toward. This prejudice "typically enter(s) into a hearer's credibility judgement by way of the social imagination, in the form of a prejudicial stereotype—a distorted image of the social type in question" (p.4). A second form of epistemic injustice suggests (a) that there is no existing framework through which a person's experience can be read, and (b) that members of some social groups are marginalized from the creation of knowledge about themselves. Fricker calls this "hermeneutical injustice," whereby "some significant area of one's social experience (is) obscured from collective understanding" (p. 158).

Autistic people are subjected to both types of epistemic injustice. They are disadvantaged testimonially, as Yergeau (2018, p.8) reminds us:

> autism's essence…has been clinically defined as a disorder that prevents individuals from exercising free will and precludes them from accessing self-knowledge and knowledge of human others.

They are also disadvantaged hermeneutically when making sense of their own experiences. When knowledge about autism is overwhelmingly (re)produced by medical and psychological authorities based on assumptions of deficit, it may be complex, for example, "for autistic people to imagine themselves and their intimate experience other than through deficit" (Bertilsdotter Rosqvist & Jackson-Perry, 2021, p.340), or doing so will require a certain level of labor: will require, in fact, *unknowing*. This labor of unknowing may involve participating in autistic spaces in which to "unlearn everything your parents said was wrong with you" (Belek, 2022, p. 2). It may involve meeting neurodivergent and/or professional allies, interacting with, reclaiming, and renaming diagnostic criteria, navigating definitions of what it means to be autistic (Jackson-Perry et al., 2020).

In an editorial of the journal Autism, *A new era for autism research, and for our journal*, autistic participation in research processes is considered crucial (Pellicano et al., 2018). PR is, of course, an element in creating research that on the one hand directly and positively impacts issues of relevance to autistic people's needs, and on the other potentially positions autistic people as holders of knowledge, thus theoretically perhaps going some way to righting the testimonial injustice of which Fricker speaks.

However, in an article published a few years earlier in the same journal, Hobson (2010, p. 398), discusses, among other things, the autistic:

> difficulty in shifting among person-centered perspectives (which) undermines both their grasp of what it means to hold a perspective and, beyond this, what it means to claim that any given perspective is true of that which transcends individuals' perspectives, namely reality.

While this is not a recent publication, nor is it ancient, and variations of statements of this kind litter autism literature to this day. There is, for example, considerable, robust, and long-standing body of literature that refutes the notions that Theory of Mind tests are rigorous, that autistic people are necessarily lacking in Theory of Mind, or indeed that non-autistic people have mind-reading super-powers (see, for example, Fletcher-Watson & Bird, 2020; McGrath, Peterson & Pennington, 2020; Williams, 2021). However, apparently, we 'know' much about autistic people: that "individuals with ASD have a specific deficit in taking into account their reputation in the eyes of others" (Izuma et al., 2011, p. 17,305); that "(A) hallmark of autism is difficulty with social-emotional reciprocity, and…(impairments in) the ability to reflect on one's own mental state, (and) infer others' mental states" (Sala et al., 2020, p. 4135); that in autistic people "the self is diminished or non-existent" (Franks, 2003, p. 621). Pages are filled with examples of what we 'know' about autism and autistic people, most of it along similar lines. Autistics have been constructed as imperfect versions of non-autistics, as representing "the disordered and damaged other" (Milton & Sims, 2016, p. 524), and, perhaps most pertinently to discussion of authenticity, and most damagingly given the centrality of these qualities to what it means to be human, as lacking capacity "to be volitional, to be social, and to be selves" (Yergeau, 2018, p. 12). In various forms, this line of thinking has become so pervasive as to be routinely stated as fact both within and beyond medical or psychological frameworks.

Despite being "qualified knowers with deep, situated knowledge of how they engage with the world and with ableist structures" their knowledge risks being considered, at best, as an "adjunct" to existing research (Orsini, 2022, p. 10), epistemic injustice *oblige*. At worst, their knowledge might simply be discounted: as Yergeau (2013, p. 10, original italics) notes, "I am writing this essay, but anyone with a Theory of Mind can refute it, can refute *me.*" Can change be expected from autistic input into knowledge production in the context of a psychopathological reading of autism considering autistic people to stand outside the possibility of grasping reality?

This could constitute what Fricker (2007, p. 152) refers to as "circumstantial epistemic bad luck" both for researchers and for autistic people: that rather than being a purposeful injustice perpetuated by one person on another, the injustice done is harmful for the 'accidental' perpetrator as well as the 'victim' and is reliant on historical contingencies. Fricker (p. 152) gives the example of what could describe autism when she says:

> If, for instance, someone has a medical condition affecting their social behavior at a historical moment at which that condition is still misunderstood and largely undiagnosed, then they may suffer a hermeneutical disadvantage that is, while collective, especially damaging to them in particular…But they are not subject to hermeneutical injustice; rather, theirs is a poignant case of circumstantial epistemic bad luck.

In this situation, Fricker says (p. 33), "it is simply too much to expect the (possessor of this "bad luck") to achieve awareness that a certain prejudice is structuring his social consciousness."

However, the generous reading that those clinging to assumptions of deficit are victims of epistemic bad luck is leaky. "Ignorance," counters Pohlhaus (2012, p. 731), "is not something to which one is doomed because of social position, but rather something one chooses to maintain." There is so much literature that refutes, for example, deficits in Theory of Mind as being a hallmark of autism, that to ignore it looks less like bad luck and more like bad science, the willful epistemic ignorance of Pohlhaus' title. This bad science in turn demonstrates the extent to which autistic people and their accounts are "hermeneutically marginalized," subordinated to and excluded from "a practice that would have value for the participant" (Fricker, 2007, p. 153).

Unknowing

> The traditional systems of epistemology may be said to result from yes-answers or no-answers to the questions about the sources of knowledge. *They never challenge these sources, or dispute their legitimacy*: the questions are taken as perfectly natural, and nobody seems to see any harm in them (Popper, 1960, p.65, original emphasis).

Sweeping statements of what we know about autism like those I mentioned above not only do not challenge the sources or dispute their legitimacy: they do not even consider, are in blissful ignorance of, research that *does* this work. This results in circular logic, re-demonstrating and confirming what is already considered, uncritically, to be known. As Kourany (2023, p.178) points out, "(I)gnorance as well as knowledge is produced by science…such as by framing research problems to foreground certain issues rather than others."

The problem, then, is not what we *don't* know about autism and autistic people, but what we think we *do* know, or what we are unwilling, through arrogance or laziness, to *unknow*. Medina (2013, p.33) describes "a socially produced and carefully orchestrated lack of curiosity" that he calls the "epistemic vice of laziness" that compromises "one's learning potential and contributions to knowledge" (p.34). Like other forms of epistemic vice and injustice, "epistemic laziness" negatively impacts and limits both the "subject" (here, the autism researcher) and the "cognitive perspectives of those around the subject, and on the social knowledge that becomes available or unavailable to the relevant communities" (p.34).

In a Foucauldian sense, of course, the oppressive discourses in much autism research that produce autistic people as just so many examples of deficit also produce the possibility for "reverse discourse," whereby autistic people form communities and create knowledge that resists that oppression (Foucault, 1990, p.101, concerning sexuality). However, the processes supporting and perpetuating epistemic injustice in autism research are intricate, long-standing, deeply entrenched, and powerful. As things stand, including autistic voices in research cannot alone constitute a serious challenge to existing knowledge systems, does not have the weight to undo stereotypes and prejudice so heavily fixed in the popular and scientific imagination.

Much autism research goes in circles, sticking to safe paths, it "confirms what is already known according to approved methods of knowing" within disciplinary silos (Halberstam, 2011, p. 6). It is not for nothing that critical autism studies (see Chapter 2, this volume), and Neurodiversity Studies in its turn, put considerable value on interdisciplinarity, for, as Gross and McGoey (2023, p.3) point out, "disciplinary silos can compound ignorance." Disciplinary assumptions "signal a form of training and learning that confirms what is already known according to approved methods of knowing, but they do not allow for visionary insights or flights of fancy" (Halberstam, 2011, p. 6). In succeeding scientifically, in confirming what we/they know about autism, researchers are also failing. This is not a creative failure allowing for visionary insights or flights of fancy, or for the creation of new and unexpected knowledge. It is a stultifying failure that allows us only to see what is already (assumed to be) known.

We need to go back to the sources, to reread the corpus, in order to "detect(ed) and correct(ed) for" identity prejudice (Fricker, 2007, p. 6). As Murray et al., (2005, p.140) put it, rather than "attempting to establish new facts about autism" we might already start by "trying to interpret what is already known.” Going back to sources, unknowing the assumptions on which their hypotheses rest and coming with a new eye to what results might suggest if we did not ‘know’ about, for example, deficit in Theory of Mind (which in turn shuts down knowledge creation around authenticity) opens up possibilities for ‘reknowing’ that are otherwise left disregarded.

In this regard, Hoeyer and Winthereik (2022, p. 228) encourage the use of “playfulness,” by which they mean:

> to dare to leave the path you know—as well as to dare to return to ‘old’ insights, those that are no longer in fashion, when they can help us approach a problem from a new, or a forgotten, angle.

Unknowing of the type I am suggesting, then, is not a lack of knowledge, but rather an intentional, creative, curious, and playful act rejecting a priori premises (notably of deficit) with the aim of coming to new understandings rather than confirming and contributing to existing assumptions. This process, that could also be called unlearning and then rereading, “demands no less than immersion in acts and practices of unknowing, a vigorous movement to flood the institutions that govern autism with the many ways in which autism must be unthought” (Orsini, 2022, p. 12). In the unknower’s toolbox below I share, some tentative tools that I find useful in contributing to this movement toward creative unknowing.

Conclusion

In this chapter, I have shown how autistic people have largely been written out of authentic possibility through deficit-driven theories positioning them as impaired in reference both to self and to (non-autistic) others. Research recurrently points to enhanced truthfulness, lack of guile, straightforwardness, and originality on the part of autistic people—all of which direct us to the concept of authenticity (Vannini & Franzese, 2008). Neurocognitive theories, albeit tentatively, suggest that autistic people may have facilitated access to those same proxies of authenticity. The concept of authenticity also circulates through autistic communities and writing, to function as a sort of community marker.

However, I am aware that this line of thinking comes with certain risks. I agree with Burks-Abbot (2022, p.3) when he says that:

> As it stands now, autism research tends to divide the world into two distinct groups—autistics and non-autistic—and treat them as if they have little in common; this approach only serves to further marginalize autistics by positioning them as an ‘Other’ that no ‘normal’ person could ever really fathom.

So, does authenticity as a potential autistic specificity—particularly when looking to neurocognition as one of the pathways to this theory—risk essentialising and reifying difference? Does it reinforce the positioning of autistic people as unfathomable others?

Just as, in considering ToM, "the understanding of others' minds is not all or nothing in autism" (Davis et al., 2022, p. 1), neither is authenticity all or nothing, whether 'in' or 'elsewhere than' autism. Autistic people—contrary to how much scientific literature portrays them—are "as different from each other as 'neuro-typical' people are" (Schneid & Raz, 2020, p. 7). However, while Robert Chapman (2020, p. 424) notes that no core traits "have been found to be shared by all or most autistic people," he also considers that "there may be very general statistical tendencies toward certain cognitive and neurological characteristics." This is echoed by Dinah Murray (2020, p. 24), who suggests that "there is a common thread that unites autistic dispositions and perspectives." Murray[4] proposes an important thread as being 'a "tendency to give more to one's current self-generated, authentic, interest…and commensurately less to all other processing needs."

A consideration of authenticity and its proxies in what being autistic means for some autistic people may constitute a general statistical tendency, an understudied common thread. Notwithstanding the risks of reification, research in this direction holds both epistemological and ethical potential. The former has been demonstrated here: I have briefly illustrated how autistic people are largely written out of authentic possibility. I hope also to have shown how—if we unknow deficit as being the whole story—various disciplines point to interesting paths of exploration (see, for example, Chapter 14, this volume), including that of neurological predispositions to authenticity and its proxies.

Coghlan (2008, p. 360) defines authenticity as being "at the heart of being human," which "means to be experiencing, understanding, judging and deciding/acting." Autistic people, through metaphor, through identity prejudice, through medical certainty, have been constructed as being on the very edge of humanity (Botha et al., 2022; Danforth & Naraian, 2007). The question of authenticity repositions autistic people as holders of knowledge, as reflexive, autonomous beings: as *human* beings. The epistemic and the ethical are here inextricably linked, for as Pohlhaus (2012, p. 733) points out:

> the more unjust one is with regard to the development and maintenance of epistemic resources, the less accurate and robust will be one's account of the world we inhabit together.

Correcting the epistemic injustice implicit in much autism research is not just a question of including as many neurodivergent voices as possible. It requires—whatever our neurotype—unlearning what we think to be true, creatively

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[4] Murray was discussing focus, monotropism, also pointing to authenticity in the context of passionate interests that may not follow social expectations of what constitutes a credible or acceptable 'hobby.'.

and critically engaging with and rereading existing literature, and intensifying epistemic pushback as to how we are able to know—or unknow, unlearn, re-imagine—what it means to be autistic.

An Unknower's Toolbox

Be alert to—and suspicious of—sweeping statements of certainty

Phrases like "it is well-known that…," "A hallmark of autism is…", "individuals with ASD have a specific deficit in…," etc., should send alarms ringing! Articles starting like this may well conclude with "our findings confirm that…." Allow yourself a wry smile as you see research going about business as usual.

Go back to the sources

Related to the previous point: once you have had your wry smile, wonder, could those results have been interpreted in any other way if we did not already "know that…"? For example, an article might start "it is well-known that autistic people have a deficit in managing their social reputations." The authors might then find that autistic people give more to charity when they are *not* observed than when they are observed, whereas non-autistic people give more when they *are* observed. The authors might conclude by stating "this confirms that autistic people have a deficit in managing their social reputations" (I am going to ignore one of my following tools, citational policies, and say that Izuma et al., 2011 is a great example of this, but plenty of others operate similarly). Had the authors *not* gone into their study knowing what they did, how might they have hypothesized their findings differently? Heightened altruism or authentic gifting processes in autistic folk? Heightened social conformity in non-autistics? Unknow the assumptions on which their hypotheses rest and come with a new eye to what results might then suggest.

Your discomfort is your friend

As an ADHD academic working largely in autism research, I have often felt an extreme sense of discomfort, a lack of legitimacy given the attention paid in certain UK contexts to the importance of autistic voices speaking about autistic experience (see Chapter 20, this volume). I now realize that this discomfort, however, well, uncomfortable, at the time, pushed me to engage as intensely as possible with autistic communities, lay-people, and colleagues, to listen and to collaborate. Instead of fighting the discomfort, stay with it, use it as a motor: it may just turn out to be your best friend and guide.

Be aware of who you cite and why

Feminist theorist Sarah Ahmed (2017, p. 270) has a "blunt citational policy" of not citing those she sees as "part of the institutional apparatus of white men." This allows her to follow what she calls "desire lines," paths of thinking other than those we are expected to follow, or that simply reproduce what has come before. This echoes Halberstam (2011, p. 6) warning us against "learning that confirms what is already known according to approved methods of knowing." Citing Baron-Cohen on Theory of Mind, for example, adds to the weight of his words. It is difficult to ignore Theory of Mind, if only to refute it, but how about citing research that critiques it, rather than that propagates it? I am a beginner here, and unable to be as blunt or radical as Ahmed in this chapter, but I have tried to be aware of who I am citing and why. A choice of citation is also a choice of reading: are there any articles or books or blogs written by neurodivergent folk and their allies on the subject I am interested in? If yes, read them, cite them, and give them space in your mind and on paper. Don't be afraid of engaging with (and citing!) non-academic neurodivergent sources (see Chapter 19, this volume; for an annotated list of resources, see Zisk, 2023).

Be playful!

Playful is perhaps not the first word that comes to mind in a toolbox of epistemological unknowing, but, following Hoeyer and Winthereik (2022), it is perhaps the most important tool here. This could mean creating new research paths or revisiting old ones to see where they might take us if we approach them differently. Another way of getting off the epistemic hamster wheel confirming what we already (think we) know, might be to mix up disciplines. Approach someone in another area to work with, as Reubs Walsh and I did (2021, p. 50), putting cognitive neuroscience (Reubs' area) in play with sociology to critically review the literature that "attempts to describe and explain (away) people who may be both trans/non-binary and autistic." It is not easy, it takes time to get to grips with another discipline's language, but we both learnt from it and had some ideas that I do not think we would have had otherwise.

Or you might have a new idea but are worried that it might be unpopular or has not been identified in the literature. Does everything we say need to have been said before, do we always need to stand on someone else's shoulders? Unfortunately, the answer to that is often yes: but is not the point of this chapter, of this book, to think about how to do things differently?

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PART III

Looking Back to the Future

CHAPTER 23

ADHD, Academics, and Communities: Who Are the "ADHD Experts"?

Andrew Ivan Brown

Introduction

Several years ago, when I was still a graduate student, I attended the 2016 annual Canadian ADHD conference hosted by CADDRA (the Canadian ADHD Resource Alliance). I was not a presenter. I only went to observe and learn from the established "ADHD experts." I figured that they must be experts to have been invited to speak at Canada's largest ADHD conference. I did not recognize most of the names of the speakers or panelists, but they all had credentials like "PhD," "PsyD," or "MD" beside their names (graduate students were relegated to poster presentations only). The talks were about the history of ADHD science, emerging genetic research, functional outcomes of adults with ADHD, problems with treatment adherence, parent satisfaction outcomes, teacher strategies, and so on.

As I sat through these various talks and panels, it quickly became clear to me that I was an outsider. Nobody at the conference—not the speakers, panelists, graduate students, or anyone I spoke to—came out as having ADHD (except for me—I outed myself on multiple occasions). Despite researching ADHD for my doctoral studies, all the presentations, posters, and people felt alien to me and my project. They did not seem to me to be studying ADHD at all, at least not the ADHD I knew through my own experiences and the community approaches I was familiar with. They were treating ADHD as an

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object of research, viewed through a largely medical lens. I ultimately left that conference feeling demoralized and skeptical that I would ever be an "ADHD expert," at least in the eyes of these researchers and clinical practitioners who appeared to control the dominant discourse on ADHD (c.f. "credibility deficit" as well as testimonial and hermeneutical injustice discussed by Hultman and Hultman, (Chapter 12, this volume).

Jumping forward a decade to 2024: CADDRA now accepts conference proposals relating to "community approaches" as well as "equity, diversity, and inclusion," and has opened up presenter slots so that anyone—not just established "experts"—can give a talk (assuming their proposal is accepted). In a similar vein, the American-based, and much larger, Annual International Conference on ADHD, hosted by CHADD (Children and Adults with ADHD), ACO (ADHD Coaches Organization), and ADDA (ADHD Association) includes spaces for ADHDers (usually ADHD coaches or social media influencers) to present, innovate, workshop, lead peer support groups, and more. Indeed, I was recently contacted by a well-established ADHD coach who suggested I apply to present at the 2024 International Conference, as he felt my dissertation theory of ADHD (Brown, 2023) could be "big." But even if I am accepted to present as an "expert," something feels off about this individual pursuit of mine. Why do I want so badly to be accepted as an "ADHD expert"? Am I pursuing stardom? Is my intention to write a trade book on ADHD and make money? The problem I am conveying here is that these individual pursuits toward "ADHD expertise" represent a structural issue: ADHD communities and conferences—at least in Canada and the United States—are often structured in a way that relies on and rewards (fame, money, careers) individual "experts," but at what cost to collective organizing and theorizing?

In this chapter, I provide a brief commentary on the structure of "ADHD expertise," drawing on both my own experiences attending various ADHD community groups over the years, and from my decade-long, interdisciplinary research project on ADHD. I suggest that cultivating "expertise" in ADHD communities has traditionally been an individual rather than a collective pursuit, and that future ADHD researchers should instead aim to foster community knowledge production and collective theorizing. I do not take a systematic or methodologically rigorous approach here. Still, in writing this, I hope to give researchers of ADHD a sense of some of the less-discussed, micro-social changes I observed in the ADHD community landscape before and during the popular rise of neurodiversity movements, and to think about the future of "ADHD expertise."

This chapter is divided into three sections. In the first section I ask, who gets counted as an "ADHD expert"? Who gets included or excluded from receiving this status? I provide a brief sketch of the "individual ADHD expert" classifications that I have observed over the years. First, traditional academic researchers of ADHD (who are almost exclusively non-ADHDers). Second, practicing clinicians (who are sometimes ADHDers themselves) specializing in ADHD. Third, ADHD coaches. And fourth, social media influencers who, despite not fitting into any of the aforementioned kinds of "ADHD experts," produce ADHD-related content for their followers. In the second section I ask, how does "ADHD expertise"—even if this specific phrase is not always used—operate in and on some ADHD communities? To answer this, I provide short vignettes of two paradigmatic types of ADHD community groups: those that are facilitated by individual "ADHD experts," and those that are not. In doing so, I describe two operations of "ADHD expertise": what can be called "self-cultivated expertise" (the individual pursuit of learning from the "experts") and "community expertise" (a form of "ADHD expertise" that lends itself to community building). In the third section, I consider how participatory research methodologies discussed in this handbook demonstrate ways that future researchers can challenge individualistic structures of "ADHD expertise." With these examples in mind, I also ask, what mistakes from the past should academic ADHDers avoid repeating? What role might "individual ADHD experts" play in critical ADHD collectives of the future?

Individual "ADHD Experts"

Googling "ADHD expert" returns a link to Russell Barkley's website followed by a link to Edward Hallowell's website (Barkley, 2024a; Hallowell, 2024). They exemplify two kinds of traditional "ADHD experts," similar to the contrast Pearson et al. (Chapter 7, this volume) made between "researcher expertise" and "professional expertise or 'expertise through experience.'" Akin to the "king" and "queen" of autism (Simon Baron-Cohen and Lorna Wing), Barkley, a neuropsychologist, might be considered the de facto king of ADHD, with over 800 presentations, workshops, and public addresses on the subject, and his executive dysfunction theory of ADHD remaining widely influential (Barkley, 2024b). Yet, he does not have ADHD. He is an exemplar of the first traditional kind of "ADHD expert": academic researchers (almost exclusively non-ADHDers) who study ADHD, often in neuropsychology but also in education, genetics, and other various disciplines and fields that cooperate with the medical model of ADHD. These non-ADHDer academic researchers generally do not treat ADHDers as knowers, positioning them instead as passive research subjects. The knowledge that is produced by these researchers is usually disseminated in academic publications, but also in some cases, popular trade books, usually in the self-help genre.

Hallowell and his colleague John Ratey, on the other hand, represent the second traditional kind "ADHD expert": practicing clinicians (psychiatrists, pediatricians, therapists, physicians, and so on) specializing in ADHD, and who are sometimes ADHDers themselves. Hallowell and Ratey are both ADHDers, for example, and their seminal trade book from 1994, *Driven to Distraction*, introduced ADHD self-advocacy to the world (Brown, 2023). What most differentiates this second traditional kind of "expert" from the first, in my view, is that clinicians are far more likely to treat their patients as active knowers. That is, through years of clinical experience listening to ADHD patients (or parents of ADHD children) talk about their struggles, clinicians start to notice patterns between patients, and can create new discourse about ADHD. As Hallowell writes, “all through the 1980s and into the 1990s, John and I explored the topic, comparing notes on patients, speculating on what more went into ADD than was in the [academic] books” (2011: introduction, para. 7).

Still, treating ADHD patients as knowers is not the same thing as including ADHDers as co-collaborators in collective theorizing. *Driven to Distraction* and many of the popular ADHD self-help books that followed still emphasize individual “experts”—the authors—telling stories about ADHDers, rather than, to use Romy Hume’s language, having a “dialogue with” ADHDers in a collective storymaking sense (Chapter 13, this volume). For example, *Driven to Distraction* is mostly a collection of (fictional retellings of) case studies of ADHD patients and their specific problems, and how Hallowell and Ratey helped them to figure out solutions to their problems over the course of their therapy sessions. In other words, the kind of knowledge that is produced through clinical practice is still filtered through the therapeutic lens of the “ADHD experts” who write these books. Hultman and Hultman discuss this same “power asymmetry” between patient and clinician in their chapter on ADHD-led research (Chapter 12, this volume; see also Hultman and Hultman, 2023).

Recognizable “ADHD experts” expanded over the years to include ADHD coaches and social media influencers. ADHD coaches are similar to the second kind of traditional “ADHD expert.” While usually not practicing clinicians, ADHD coaches can become certified by accredited coaching organizations like ADDCA (ADD Coach Academy), and work with several ADHDers (clients) over the years. They sometimes write trade books based on what they learn through their coaching experience.

Social media influencers, on the other hand, may represent a whole new kind of “ADHD expertise” and I can only offer a cursory analysis here. I am not referring to traditional “ADHD experts” who try their hand at social media and become popular gurus. Traditional “ADHD experts” and coaches have been using various forms of multimedia to spread the word about ADHD since at least the 2000s (TotallyADD.com, for example). Rather, I am thinking of the “influencer-turned-coach” phenomenon (Berkoben et al., 2023: 20). What sets these influencers apart is that they do not need the credentials—academic/clinical degrees or coaching certificates—that would traditionally be required to obtain the status of “ADHD expert.” Instead, social media influencers can become “ADHD experts” simply by virtue of having an engaging personality and skill at using a particular platform and developing a large following. From my observations, these kinds of influencers are almost always ADHDers themselves, and sometimes talk about their own experiences. However, most of the knowledge they are presenting about ADHD tends to be re-filtered from traditional “ADHD experts,” or, in some cases, a curation of social media posts by other ADHDers. The latter case can lead to a potentially concerning proliferation of ideas of what counts as ADHD, such as reproducing stereotypes or spreading an "epistemic infection" of deficit narratives (Bertilsdotter Rosqvist & Jackson-Perry, 2021: 341).

Since the mid-1990s, the status of "ADHD expert" has increasingly been conferred to ADHDers in various roles. While there are still plenty of non-ADHDers who are considered "ADHD experts," especially in areas of neuropsychology, pediatrics, neuroscience, genetics, education, and even the emerging field of neurotechnology (neurofeedback and deep brain stimulation), there is an ever-growing number of ADHD-specialized therapists, coaches, and social media influencers who are all ADHDers themselves. While this is no doubt a favorable development in the sense of "Nothing About Us Without Us" (Charlton, 2000: 14), the issue I presented at the beginning of this chapter remains: the structure of "ADHD expertise" still appears to be highly individualistic and, in many cases, reliant on non-ADHDer-produced knowledge (e.g., Barkley's executive dysfunction theory of ADHD). Deficit narratives such as these are still pervasive even in community discourse professed by ADHDers as affirmative. Finally, while it is true that ADHDers have collectively played a role in cultivating much of the knowledge on ADHD claimed by the "experts," these community ADHDers often do not consider themselves as "expert knowers" in their own right, as the next section demonstrates. They appear to largely depend on the "experts" to guide them in one way or another, directly or indirectly.

Vignettes of Two Paradigmatic Types of ADHD Community Groups[1]

ADHD community groups are not standardized but are entirely dependent on how the organizers decide to set up the group and the demographic it is tailored for. Nevertheless, for the purpose of exploring how "ADHD expertise" operates in and on these groups, I provide vignettes of two types that I consider paradigmatic: groups that are not facilitated by an "ADHD expert," and groups that are. The first type is common in online community groups, but also sometimes found in student peer support group organization, and, as demonstrated by the first vignette, adult (non-student) ADHD support groups. The second paradigmatic type is, in my experience, more prevalent than the first, and usually facilitated by a psychologist, or by a non-profit ADHD organization that brings in various "experts" on a rotating cycle to lead the group each session. For my second vignette, however, I describe a somewhat peculiar case of a group led by an ADHD coach who operationalizes "community expertise," a form of "ADHD expertise" that lends

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[1] The following descriptions are not "qualitative data." I attended these community groups many years ago for personal support, not for research. The descriptions are instead anecdotal, drawing from memory and journal entries I made long ago. The quotations are reconstructions. The individuals described are amalgamations of multiple individuals I remember encountering.

itself to community building, and which may prove useful for critical ADHD collectives of the future, as I discuss below.

Group I. Self-cultivated "Expertise"

There are approximately 20 ADHDers, including myself, sitting in a large circle facing inwards. The floor is open to anyone who wants to speak. One member puts up her hand and begins talking about something called "CAPD" (central auditory processing disorder). It's something about "how you can't hear the beginning of sentences when someone speaks to you because you can't process the low tonal resonances in people's voices until you tune in." She says everyone she's ever talked to with ADHD has CAPD, and that it's a "symptom of ADHD." A man cuts in stating how that's very interesting and that he must have CAPD too. Another member, in rebuttal, then states that "not everyone with ADHD has CAPD." The initial speaker yells at her that she's not right, and everyone with ADHD does have CAPD. The other member then holds up her phone and yells back, "I just looked it up!" A battle of self-cultivated "expertise" ensues.

ADHD physician Gabor Maté, in his trade book on ADHD, writes, "so few doctors or psychologists are familiar with attention deficit disorder that people are forced to become self-cultivated experts" (2000: 5). Indeed, this support group prides itself on being self-driven without the help of professionals. Professional psychologists are not allowed to attend unless invited for a special talk. One problem I observed with this rule, however, is that those members who are loudest and most assertive tend to receive the most speaking time, and so their self-cultivated "expertise" ends up being passed around regardless, no matter how dubious it is or where it came from.

A woman who appears to be in her late 60s suddenly wanders into the room and exclaims to everyone that she is covered in cat hair in case anyone is allergic. She sits down and the group conversation continues. She begins yelling at people to speak up because she can't hear them. A bunch of members start simultaneously telling her that she has CAPD. "CAP-*what*?" she yells back. Everyone replies in unison, "*CAPD!*" A big, burly looking guy tells her he's in the same boat as her, that he can't hear well because he was in the military blowing stuff up when he was nineteen and didn't care about whether it was harmful. She cuts him off—"yeah, yeah, I understand, but people need to speak louder." After the meeting ends, I have a chat with the only other person in their 20s in attendance. He tells me that this group is "scary" and that he won't be coming back. He thinks there are "lots of comorbidities here, lots of negativity, and lots of people talking about issues that he's never experienced or heard about" in his own self-guided research on ADHD. "God, I hope I don't end up like this when I'm older," he concludes.

Group II. Community Expertise

An ADHD coach runs this group. It is free and open to the public. Every month, we show up, take a seat, and wait for the coach to begin his lecture on the chosen topic for the day. He is our community expert. He gets quoted a lot in local newspapers since he is big into ADHD political activism, lobbying the mayor on issues like jail reform for ADHDers, and challenging stereotypes about ADHD in schools. I see him as a role model. He even taught us that ADHD can have its positives. It is clear to everyone in the group who the “expert” is. He is not a psychologist or medical practitioner, but knows ADHD well, and can often recite statistics about ADHD off the top of his head. Most importantly, he is an ADHDer himself. After about 30 minutes of lecturing, he has us get into small groups to discuss specific issues we have been experiencing related to our ADHD (usually in connection to the topic of the lecture). 30 minutes later, we reconvene and tell him what our group talked about. He connects our ideas to ADHD literature, and often provides additional pointers for us relating to the issues we discussed, sometimes on a very individual level based on specific circumstances or contexts.

From Neurodivergent Care Communities to Critical ADHD Collectives

The two vignettes above offer some micro-social glimpses into some of the ways that “ADHD expertise” operates in and on ADHD communities. Self-cultivated “expertise” usually consists of an ADHDer doing their own research, such as reading ADHD trade books, online blogs or articles, following social media influencers specializing in ADHD, watching YouTube videos, listening to podcasts with rotating “experts” as guest speakers, and if inclined, reading academic publications on ADHD. One might even consider therapy a form of self-cultivating one’s “ADHD expertise,” insofar as one begins to better understand themselves, their struggles, and their differences through a lens of ADHD knowledge conveyed to them with the help of their therapist.

With some exceptions, developing self-cultivated “expertise” in ADHD communities tends to be an individual rather than a collective pursuit, and is mostly dependent on extraneous “ADHD experts” from which the knowledge is obtained or filtered. This individual approach can become antagonistic to developing care communities. I have seen countless attempts of ADHDers telling other ADHDers that they are wrong about something, that they should read this or that article or book, or look up this or that term on the internet, or listen to this or that podcast. This kind of self-cultivated “expertise,” in my view, is not a good model for community knowledge production or collective theorizing. We end up treating the “ADHD experts” as the only credible knowers, and in doing so, we don’t treat each other as experts in our own right. We don’t look up to each other as co-collaborators in ADHD knowledge production. Respect is rather given to those we perceive as having done their own research on ADHD.

A growing number of online neurodivergent care communities emerged in the late 2010s and early 2020s, a few of which I became a part of. These differed significantly from the traditional ADHD communities and groups I had previously attended. For one, they were not exclusive to ADHD, but included autistic members, AuDHDers, and others who broadly identified as neurodivergent. More than that, they emphasized care over sharing knowledge. There was little discussion of strategies, or recommendations of "experts" to follow, watch or read. In other words, these communities were not so much about cultivating expertise, but caring for each other. As crip theorist Logan Smilges writes of such communities, they are more about "holding space for bad feelings in the present than about making promises to fix the future" (2023: 73).

In our introduction chapter to Critical ADHD Studies, myself, Hanna Bertilsdotter Rosqvist, and David Jackson-Perry (Chapter 3, this volume) emphasize the need for phenomenological and community theorizing approaches to ADHD in academic research, some of which has already begun in recent years (Bertilsdotter Rosqvist et al., 2023a, 2023b, 2023c, see also Chapter 12, this volume). These novel approaches position all ADHDers as equal knowers and co-contributors in the realm of ADHD research. They start with the model of collective care communities—such as acknowledging how neurotypical epistemic privilege disables us neurodivergents and make us feel miserable in so many ways (see Chapters 16,17, this volume)—and go from there, drawing from well-established academic methodologies (such as phenomenology). As Pearson et al. put it, "creating safe spaces for neurodivergent scholars [serves] as a vehicle for scholars to work together" (Chapter 7, this volume). It might be said that Critical ADHD Studies is partly an attempt to hold new spaces for collective ADHD expertise to develop outside of the individual forms. These critical ADHD collectives of the future would be grounded in neurodivergent caring for each other in the senses just described, but also use such care as a way of producing new kinds of ADHD knowledge not previously possible.

Indeed, many of the chapters in this book provide examples of methods that may help to push back against the individualistic structures of "ADHD expertise," and make this new kind of knowledge production flourish. Shruti Taneja-Johansson notes that many of her ADHDer research participants take her to be the "expert," and that to help counter this, she downplays her "expert status" and tells them that she sees them as the experts—that this research is about *their* lived experiences (Chapter 11, this volume). Romy Hume makes a similar point, and emphasizes "dialogue *with*" rather than "story *about*" (Chapter 13, this volume). In their chapter exploring the limits and possibilities of ADHD-led research, Lill and Maya Hultman test out a method that future researchers might want to try out. They both take turns as ADHD researcher and ADHD research participant, and try to identify negative consequences that arise with this power asymmetry, in hopes of finding ways to counter it in future research (Chapter 12, this volume).

In his chapter on developing autistic-friendly phenomenological research design, Ned Redmore reminds us that, given how neurodivergent research participants have historically been situated as "voiceless subjects," the "tools with which to conduct research with people from this group are historically underdeveloped" (Chapter 15, this volume). He stresses the need for "dialogue" so that "trusting relationships can begin to form" between participants and researchers; such dialogue includes an "openness to all forms of communication, expression and engagement" (Chapter 15, this volume). From their experiences of working in a neurodiverse group of authors, Pearson et al. suggest a move to "collective storytelling," and facilitating "an ability to be vulnerable with each other, sharing our inner thoughts and feelings about the working process" (Chapter 7, this volume). In the same vein, Hultman et al. describe that forming a "tight-knit group" of community researchers can be helpful (Chapter 8, this volume). In terms of research design, Joke Struyf et al. argue that "co-creation and inclusive research are […] more than just asking the community for feedback"; they also mean including the community in discussions of how this kind of research should be defined, and how ways of doing research should be changed to be more emancipatory (Chapter 5, this volume). They imagine "involving participants from the beginning," even at the stage of writing the project proposal (Chapter 5, see also Chapter 6, this volume). Sandra Jones and Jennifer Lowe describe these sorts of processes as "adopting an autistic approach to designing autism studies," and building "autistic comradery in research" (Chapter 10, this volume)—something that could surely apply for ADHD research as well.

These various methods—and I have only listed a few of the many examples available throughout this handbook—will help future ADHDer researchers avoid repeating the mistakes made by traditional, non-ADHDer researchers. They also point to the benefit of conducting collective ADHD research in academic institutions: there are rich, methodological tools out there that can help us avoid falling into the "individual expert" trap so prevalent in existing ADHD communities. This trap, of course, is also common in how academic institutions are structured, and future researchers need to be extra careful to avoid falling prey to it. To elaborate, some critics have argued that the term "ADHD" refers not only to the condition itself, but is also symbolic of a "field of force relations" through which specific regimes of knowledge (behavioral psychology, medical sociology, psychiatry, psychoanalysis, neuroscience, genetics, neurotechnology, etc.) "are constantly in flux" as they attempt to gain "temporary dominance over one another," "strategize" for claims over ADHD's truth, try to assert their fields of expertise as the most authoritative, compete for funding, and the like (Rafalovich, 2002: 87–88). Critical ADHD Studies is not meant to be just another addition to the many regimes of knowledge vying for control over ADHD's discourse, using the guise of "new interventions" to build the careers of individual researchers. It is meant to break the individualistic structures of "ADHD expertise" by collectivizing ADHD knowledge production in new ways that are geared toward emancipatory, rather than capitalist, ends.

With that all said, I end this chapter by considering one last question: what role, if any, might individual "ADHD experts" play in critical ADHD collectives of the future? The reason I described "community expertise" in my second vignette was to remind us that individual "ADHD experts" can often be inspirational, affirming, and dedicated to ADHD community building. They can be especially helpful for "new" ADHDers who are seeking to learn more about ADHD. Above all, many "ADHD experts" have already provided us with so much knowledge to build our communities around—for instance, several chapters in this handbook cite Hallowell and Ratey's 2021 trade book, *ADHD 2.0*. At the same time, we must also be wary of much of this pre-produced knowledge on ADHD, because so much of it is still grounded in deficit narratives. As David Jackson-Perry notes in his chapter on autistic research, countering deficit narratives requires a "labor of unknowing" (Chapter 22, this volume). We may have to unlearn much of what the individual "experts" have told us, even if some of those "experts" are ADHDers themselves.

The individualistic structures of "ADHD expertise" will not disappear overnight, and this brings me back to why I want to try to present my dissertation theory of ADHD at the Annual International Conference—if not this year than next year, or the year after. While I cannot completely divorce myself from the seductive rewards that would come with obtaining the status of "ADHD expert," my deeper aim is strategic. The participatory research methods and collective theorizing approaches described throughout this handbook are no doubt central to developing Critical ADHD Studies, but in the meantime, I want to test out an alternative strategic approach: I want to get inside the power structures that currently exist—to become an individual "ADHD expert"—and then use that position of power to push back against deficit narratives. Update: while working on revisions for this chapter, I received an email informing me that my proposal for the ADHD conference was rejected after careful review by a "panel of ADHD experts"—their words. It's been eight years since I attended my first ADHD conference, and I still feel just as much of an outsider to the field as I did back then.

Regardless of the approach future ADHD researchers decide to take, Critical ADHD Studies will have to continue to think deeply about the evolution of "ADHD expertise" I outlined in this chapter, and how to contend with its individual forms still present in the heart of many ADHD communities.

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CHAPTER 24

Power to the People

Jacquiline den Houting, Abby Sesterka,
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The Changing Tide

There is much to be positive about. A mere decade ago, only two published papers had reported community engagement in autism research, both from the ground-breaking Academic Autistic Spectrum Partnership in Research and Education (AASPIRE) (Jivraj et al., 2014; Nicolaidis et al., 2011; Nicolaidis et al., 2013; see also Chapters 4, 19, 25, this volume). Across the intervening ten years, we have seen an exponential increase in participatory autism research, with a recent systematic review (Tan et al., 2024a) identifying 312 autism research papers that reported community engagement. Of these, more than 200 reported involvement by autistic people; many also reported engagement with professionals, family members, and other relevant stakeholders.

During this reasonably short time, we have also witnessed a growing cohort of openly autistic (and otherwise neurodivergent) scholars joining the

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field (e.g., Bertilsdotter Rosqvist et al., 2023; Botha, 2021; Jones, 2021; Nuwer, 2020; Poulsen et al., 2023). In addition to academic expertise, these researchers bring to their work insights gained through their own lived experience of neurodivergence. They can also bring rich knowledge of neurodivergent experiences beyond their own, gained through deep immersion in the autistic and/or broader neurominority communities. Though openly autistic researchers remain a minority amid the global cohort of scholars researching autism, we have seen some of the more conventional structures in the field of autism research make space for autistic scholars. One such example is the International Society for Autism Research's (INSAR) Autistic Researchers Committee, established in 2020 to advance the interests of autistic researchers within INSAR (Poulsen et al., 2023).

Along with this shift in *who* is producing autism research, change is afoot in *what* and *how* we research. Australia, for example, has seen considerable changes to the national landscape of autism research investment, with a pattern of disproportionate investment in biological research (seen in many Western Countries; OARC, 2019; Pellicano et al., 2013) giving way to more equitable distribution of funding across research areas (den Houting & Pellicano, 2019). Encouragingly, there has been increased investment in research areas aligned with established community priorities, giving precedence to research with tangible, real-world impact as has long been called for by the autistic community and other stakeholder groups (Gatfield et al., 2016; Robinson, 2010; see also Chapters 10, 13, 14, 20, 21, 22, 25, this volume).

More recently, conventional autism science has increasingly drawn inspiration from the experiential expertise of autistic people. The Double Empathy Problem, proposed by autistic scholar Damian Milton (2012), was initially theorised largely on the basis of personal experience and observation (Milton et al., 2022), and has since become a defining work. Arguably, Milton's (2012) landmark paper deployed unconventional scientific methods. It did not put forth novel empirical findings. Rather, it offered an alternative perspective of a well-established phenomenon; casting aside the trappings of pathology to suggest that the autistic experience is, at its core, an aspect of shared human experience. Milton's Double Empathy Problem has now prompted a wide range of empirical investigations seeking to shed light on the mechanics of cross-neurotype social interaction (Crompton et al., 2020; Sasson et al., 2017; Sheppard et al., 2016). In recent years, there has been rapid growth in the body of autism research that is rooted in lived experience, investigating concepts first identified in the autistic lay community (see Chapter 19, this volume). Stronger ties between researchers and the autistic community have facilitated growing understanding of important community-driven phenomena, including autistic burnout (Higgins et al., 2021; Raymaker et al., 2020), masking/camouflaging (Cage & Troxell-Whitman, 2019; Hull et al., 2017), and inertia (Buckle et al., 2021; Rapaport et al., 2023).

Scanning the most-read and most-cited work published by leading autism-specific journals in recent years suggests that readers are embracing these emerging foci. Extremely widely cited papers feature an empirical evaluation of the Double Empathy Problem (Crompton et al., 2020) and an examination of autistic masking (Pearson & Rose, 2021), as well as guidelines for avoiding ableist language (Bottema-Beutel et al., 2021), an intervention aimed at increasing autism acceptance (Jones et al., 2021) and recommendations for promoting inclusive tertiary education (Dwyer et al., 2023). Notably, openly autistic authors are represented in eight of the 10 most-read publications across the field's two leading journals (Mary Ann Liebert, Inc., 2024; SAGE Publications, 2024).

Following these trends, recent years have also seen significant developments initiated by dominant journals in the field. In 2020, *Autism* joined the likes of *The British Medical Journal* in requiring that scholars report on stakeholder engagement (or lack thereof) in their work (Tan et al., 2024b). The journal *Autism in Adulthood*, established in response to calls for greater focus on autistic needs across the lifespan (Roche et al., 2021), aims to represent both scientific and community perspectives, with lay autistic people contributing to both peer review and authorship (c.f. Chapter 19, this volume). When *Autism in Adulthood* recorded its first impact factor in 2023, it outranked all other autism-specific journals, attesting to the shifts evident in the field.

Continuing Challenges

All of this progress is extremely welcome. Yet, early analysis suggests autism research that involves community members in some or all aspects of the research does not always live up to its stated objectives.

As many of this book's authors attest, community engagement can lead to more accessible, acceptable, and rigorous research that better reflects the realities of people's everyday lives and more closely aligns with community priorities (Cornwall & Jewkes, 1995; Lloyd & White, 2011; see also chapters 4, 10, 19, this volume). There are also ethical and moral prerogatives for participatory research approaches (Cascio & Racine, 2018); community engagement can facilitate a degree of self-determination for marginalised groups (including the autistic community), who have often been denied this right. Furthermore, effective participatory research can generate long-term cultural change, through (a) the production of epistemic resources that reflect community knowledge and values, and (b) the bias-reducing effects of relationship-building across disparate stakeholder groups (Cornish et al., 2023).

An umbrella term encompassing diverse methods and methodologies, *participatory research* refers broadly to research produced through collaboration between academic and community stakeholders. Grounded in the understanding that "to address complex problems, scientific expertise alone is not sufficient", participatory research approaches meld academic expertise with community insights to generate knowledge that is "not only of scientific high quality, but also socially robust" (Turnhout et al., 2020, p 16). Commonly conceptualised as a hierarchy or 'ladder' of participation (Arnstein, 1969), the degree of engagement by community stakeholders spans from relatively limited involvement via consultation, through collaborative co-production partnerships, to—at the highest levels—community-led and community-controlled research endeavours (den Houting, 2021; see also Chapters 5, 8, this volume).

Sharing power between academic and non-academic stakeholders is the cornerstone of effective participatory research, and co-production in particular (Israel et al., 2005; Turnhout et al., 2020; see Chapters 5, 6, 7, 8, 12, 14, this volume). Deep-rooted power imbalances are embedded in the systems and structures that govern knowledge production (e.g., Boveda & Annamma, 2023; Ocloo & Matthews, 2016). Equitable research co-production, therefore, necessitates careful navigation of power dynamics and a concerted effort to understand and mitigate inequities between research partners (see Chapters 8, 12, this volume).

Despite heartening increases in community engagement over the past decade, these crucial efforts to disrupt established power structures remain largely absent in autism science. Though Tan et al. (2024a) found 312 published examples of community engagement in autism research, these were drawn from a corpus of more than 40,000 papers. Participatory research, therefore, represents less than 1% of published autism research. Tan et al. (2024a, 2024b) also highlight the relatively limited nature of community engagement across much of this work; community members most commonly acted in consultative roles, with input often limited to research design activities such as the development and/or modification of interview or survey questions (see Chapters 4, 9, 10, 19, 20, 22, this volume). Notably, community engagement was distinctly lacking in basic scientific research. While applied research including lifespan, intervention, and service-focused research was relatively well represented, none of the included studies reported on genetic research.

It is unsurprising, therefore, that many in the autistic and autism communities continue to feel let down by research. Recent findings (Haar et al., 2024) indicate that community members feel the autistic experience continues to be poorly understood and pathologised by non-autistic researchers, and by society more broadly. Autistic people describe feeling an ongoing pressure to conform in the face of barriers posed by a neurotypical society that remains reluctant to accommodate autistic needs (see Chapter 5, this volume). Community members also report feeling ignored by non-autistic researchers, despite having valuable expertise to share—and a keen desire to co-produce research. Haar et al.'s participants call for research "with our voices centred, our experiences validated, and with our control" (p. 15).

Our own work (den Houting et al., 2021, 2022) offers some insight as to why this call remains unanswered. Among the Australian autism research community, we found that academics and community members alike were strongly supportive of community engagement in research, but felt that many factors within the academy posed considerable barriers to meaningful engagement. This concern was shared by autism researchers in the United Kingdom

(Pickard et al, 2022). While these factors, including constraints on funding and time, can impede participatory research efforts, our findings also highlighted the possibility of "bottom up" (Pellicano, 2020) change enacted by individuals (see Chapters 10, 18, this volume). Crucially, few of our academic participants identified navigation of power dynamics as a fundamental element of research co-production over which they could, themselves, effect change. Of those who did acknowledge issues of power, most described firmly entrenched inequities, with academics retaining the bulk of power even in ostensibly co-produced research. These deep inequities were reflected in participants' language, with many academics blurring the distinctions between different kinds of community collaboration and engagement. Concerningly, some academics explicitly expressed resistance and doubt regarding power sharing, perceiving it as impractical and (in some cases) inappropriate (see also Pickard et al., 2020).

We believe that further progress in participatory autism research requires us all to challenge existing power dynamics. Although structural obstacles are real, the academic role remains inherently imbued with considerable social power, especially in research contexts. Contrastingly, marginalised communities—frequently the focus of participatory research—contend with commonplace oppression, injustice, and disempowerment. In autism research, efforts to confront prevailing structures of power are particularly imperative in light of the ways that research has contributed historically to the disempowerment of autistic people.

Next Steps

Throughout this book, epistemic injustice (Fricker, 2007) is an aptly ubiquitous theme. Through neuronormative narratives of deficit and incapacity, the field of autism research has unequivocally characterised autistic people as uncredible epistemic agents, systematically and wrongfully undermining autistic capacity to contribute knowledge (Botha, 2021; Catala et al., 2021). With many in the field now seeking to embrace a more participatory autism science, the enduring impacts of this epistemic injustice have significant implications.

To achieve equitable co-production, stakeholders must work to establish a partnership culture in which a diversity of knowledge and skills are valued (see Chapters 5, 7, this volume). In particular, the cultural intelligence (Ghanbarpour et al., 2020) of community stakeholders should be recognised and understood as a valuable form of expertise. In autism research, though, aspects of the prevailing culture have for too long devalued autistic expertise and disempowered those who hold it. If this prevailing culture is perpetuated within a co-production partnership, community stakeholders' insights may continue to be dismissed, or utilised to serve academic—not community—interests (see Chapters 2, 22, this volume). As a result, project processes and outputs—now legitimised as products of "co-production"—may wrongfully reinforce conventional knowledge and structures of power (Turnhout et al., 2020). How, then, can we challenge these long-established inequities and foster egalitarian research contexts? What, in other words, are the crucial next steps?

Capitalising on the current enthusiasm for community engagement in autism research begins with capability building. It is essential that academic and community stakeholders alike develop the expertise and skills needed to conduct high-quality participatory research. To achieve equitable research co-production, it is not sufficient to merely implement the practicalities of a participatory research process; a deep commitment to the principles and values underpinning co-production is required. In recent years, a range of resources have been published, providing guidance and insights specific to participatory research conducted with the autistic and autism communities (e.g., den Houting, 2021; Nicolaidis et al., 2019; Pellicano et al., 2020). Several training programmes have been developed (Autism CRC, 2024; The University of Edinburgh, 2017), each aiming to upskill autistic people and/or autism researchers in research co-production. Beyond the autism research field, there exist many useful guides and toolkits designed to inform participatory and co-produced research (e.g., Cornish et al., 2017; Farr et al., 2020; Strnadova et al., 2020).

Autism research is, of course, neither the first nor only field to grapple with academic-community power inequities and to attempt to build the requisite capabilities in response. Valuable lessons can be learned by turning to expertise from fields with long-established traditions of community engagement in research. First Nations research, for example, demonstrates how communities can assert sovereignty over the research conducted within their communities, resulting not only in community-led research, but community-controlled research policies, practices, and methodologies (Drawson et al., 2017). As First Nations communities have enhanced research capacity, many within them have also developed a range of Indigenous research methods and methodologies based in cultural values and ways of knowing, thereby grounding research in community strengths. Autism research can learn from these examples.

Capability building alone will not be enough, however. Establishing a new norm of power sharing requires a concerted effort over time. Effective co-production partnerships are developed across a long-term process of relationship-building (see chapters 5, 6, this volume). These processes will, ideally, be undertaken independently of any specific research project, with the partnership established *before* a research project is planned and maintained *after* the project concludes, according to the mantra developed originally in community organising practice that “relationship *precedes* action”.

Establishing and maintaining trusting relationships between disparate stakeholders of this sort, therefore, requires deliberate attention, with long-term partnership processes planned as thoughtfully as the research itself (Jagosh et al., 2015). Equitable partnership processes can be developed through deliberative communication among stakeholders; that is, creating space to discuss the partnership itself (Wallerstein et al., 2019). This may include, for example, collaboratively establishing explicit partnership practices and values such as methods of communication and decision-making; stakeholder roles and responsibilities; and partnership purpose and goals. At the same time, it is important to recognise that these partnerships will not always be smooth or straightforward. Incorporating a diversity of perspectives can, after all, draw implicit tensions and disagreements to the surface (see Chapters 5, 6, this volume). As such, a key element of building sustainable partnerships will involve learning to cope with disagreements and generating respectful exchange in the face of them. In time, it should become clear that tensions within relationships can enable new ideas to emerge and new challenges to prevailing orthodoxies to be taken seriously.

This last theme further reminds us that efforts both to build capability and to establish long-term partnerships must be paired with explicit efforts to grapple with the power differentials described above. Researchers themselves can initiate this process by identifying their own potential roles in the complex power dynamics present in the research process (see Chapters 11, 9, this volume). Just as the chapters in this volume outline, strategies of participatory research are far more likely to be successfully embedded when it becomes commonplace for all stakeholders to engage in difficult conversations about past and present injustices, in addition to future possibilities. Practical tools are already available to enable this. Techniques like "power mapping", once again borrowed from community organising, enable partners to examine the distribution of power within their partnership; reflect on the contextual factors that shape these power structures; and identify strategies to facilitate more equitable redistribution of power (Arleskog et al., 2021; Roper et al., 2018; Wallerstein et al., 2019). Some academic researchers might wish to go further still and use their power to actively advocate against inequitable research systems and structures on behalf of other members of the partnership, thereby siding with the non-academic partners instead of the conventional positions of the academy, or, as Wallerstein puts it, "taking an oppositional stand against their own privilege and toward sharing power with the community" (Wallerstein et al., p. 29S).

Taken together, these three tasks—building capability, sustaining partnerships, and challenging power differentials—can enable each of us to make a positive contribution to the broader shift towards participatory research approaches. And, as this volume demonstrates, that should be to the benefit of everyone.

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CHAPTER 25

Neurodivergent Futures

Dora M. Raymaker and Christina Nicolaidis

The Weight of History and the Push of the Present

In 2010, we (Dora and Christina, this chapter's co-authors) took part in a critical autism studies workshop at the University of Ottawa. The workshop brought together academics who were engaged in critical theory and had a personal interest in autism, but whose scholarship largely centered in fields other than autism research (e.g., classics, political science). As, essentially, a group of outsiders to autism research, the workshop created a unique lens on how the epistemologies of autistic people might interact with scholarship without the theoretical and philosophical assumptions of autism research at that time, both in its "normal science" (i.e., status quo pathology framing with an eradication and/or normalization goal) and in the rising push back to that science by the marginalized voices of the autistic and disability rights communities. Despite our activist connections to the neurodiversity movement, we, too, felt like outsiders to the world of autism research, with our scholarship resting in action research and public health, and our research focusing on improving healthcare access and quality for autistic adults.

At the time of the workshop, four years after co-founding the Academic Autism Spectrum Partnership in Research and Education (AASPIRE), and a year into our first externally funded autism-related study, we were still struggling to convince the scientific community that it was possible to do

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community-based participatory research with autistic people. We were even struggling to convince people, who largely saw autism as a childhood affliction, that autistic adults existed, let alone had developed autistic culture and community. The paper we presented (ultimately published as Chapter 7 "Participatory Research with Autistic Communities: Shifting the System" in *Worlds of Autism* (Raymaker, 2013)) focused on our theory of how participatory research can shift paradigms by centering and empowering neurodivergent epistemologies in knowledge production. Would those dynamics play out in practice though? We thought they might, based on how participatory research generated similar paradigmatic shifts for other oppressed communities. But at the time it was a grounded vision—an untested, though plausible, theory.

There has been a tremendous infusion of neurodiversity frameworks and paradigms into research since that 2010 conference asked attendees whether there even existed a critical autism studies. An analysis of that shift—including the impact of participatory and inclusive methods as we theorized—could easily occupy its own textbook. A loose "follow up" chapter to "Shifting the System" exists in "Shifting the System: AASPIRE and the Loom of Science and Activism" in the book *Autistic Activism and the Neurodiversity Movement* (Raymaker, 2020)—a book that likely would not exist—at least not from an academic publisher—had the shift not occurred. The chapters in this book also present ample evidence of the shift. For example, discourse about neurodivergent scientists requires that the world acknowledges the existence of autistic adults, and discourse about participatory research requires the existence of more than just one participatory research group. We are continuously delighted and amazed by how quickly paradigms in academics have shifted away from pathology framing and toward neurodiversity framing in the past near-twenty years.

However, the weight of historical injustices and the push of present oppressions are inevitably a part of what we carry into the future. Our present progress in participatory methods, inclusive research, cultural recognition, and connecting community priorities to researchers and research agendas does not erase decades of marginalization and outright harm and abuse, especially for those of us who came of age in a strongly eugenics-oriented and medical model culture. The present pushes us toward equity and justice while the past encumbers us not just with the inertia of the status quo within science and society, but with its own individual and collective trauma. These weights are as evident as progress in the substance of this book (e.g., in discourses around epistemic in/justice or discussion of tokenism in research, see Chapters 5, 9, 10, this volume).

But futures aren't forged by the weight of the past and the push of the present alone. Futures have their own pull, and no future, no matter how imminent, is fully in our control. We can, however, consciously work toward the kinds of futures we would like through our dreams and visions, and how we respond with action to opportunities and threats along the way.

APPROACH

The futures field has a saying that "the future is plural"; indeed we have been careful to pluralize the word throughout. Until something happens, it is not fixed; although the more the distance closes between present and future the smaller the number of possible outcomes.

Futures thinking asks six basic questions: (1) What will the future be like? (2) What future do we fear? (3) What are we assuming about the future ? (4) What are some alternatives to the future we fear? (5) What futures do we prefer? And (6) How might we get to those preferred futures? (Inayatullah, 2008). These questions entwine and influence each other. As such we have approached our own futures thinking holistically.

Frameworks

In his seminal 1962 book *The Structure of Scientific Revolutions*, Thomas Kuhn observed that science seems to go through patterns of stability and disruption. The status quo of "normal science"[1]—which defines the underlying paradigms, theories, and norms for an area of inquiry—is a usually lengthy period of stable growth. Then, something revolutionary perturbs the science—a new discovery, the nullification of a key assumption—and it changes everything. After a period of instability from the disruption, the science again settles and what was once revolutionary becomes the new "normal science" (Kuhn, 2012). An example of this from the natural sciences is when the discovery of radioactivity changed the science of geological dating.

This chapter explores the neurodiversity paradigm as a disruption to the normal science of neurodivergence. We have structured it using a futures triangle framework to describe the nature of the disruption, its impact on the present state of the science, and the types of futures it could pull us into as it continues to develop. Specifically, the futures triangle considers how the past weighs on any forward motion, the present provides us with a view of trends and motivators—an indication of where we may be pushing toward—and the future pulls us forward into its potential both terrible and hopeful. A holistic examination of these forces results in a vision of plausible futures at the center (Inayatullah, 2008).

Aims

Initially, we started this project with the aim of a broad exploration of neurodivergent futures. What might they look like? We intended to use a futures cone framework (Voros, 2017) to help us imagine a range of futures from likely to preposterous, and then identify pathways to desirable futures and wrong turns

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[1] When "normal science" appears in quotes in this article, we intend this special meaning as defined by Kuhn.

to undesirable ones. The conversation, however, quickly turned both existential and dark. For example, did these futures include biological malleability, such as pharmaceuticals to induce any arbitrary neurology? And, if so, would that enable people to freely experience and celebrate different ways of being in the joyous sense of Walker's neuroqueer (Walker, 2021), or would it erase neurodivergent identities or even neurodivergence itself? How much do our neurological experiences contribute to our personalities? And how likely are such futures to lead to horrific exploitation?

At the end of an increasingly disturbing (and wildly associative—this is both a power of our combined neurodivergence and, at times, a massive distraction) two hours, we realized we had only imagined a small number of increasingly catastrophic futures in which evil masterminds nefariously manipulated people's neurodivergent traits to create dystopias. We needed more structure.

However, finding more structure for that original aim proved elusive. Neurodivergence is a fundamental way of experiencing embodied existence; it is an epistemology and thus applies to everything that people can experience. Aiming to describe "neurodivergent futures" is like aiming to describe "futures." Our aim was vastly underspecified.

So, we narrowed our aim to futures in neurodiversity research (i.e., research about topics related to neurodiversity or neurodivergence). Specifically, (1) If we could imagine a best possible future for neurodiversity research, a new "normal science" that operates from within a neurodiversity paradigm, what would that science look like? (2) What could facilitate or jeopardize that vision? How do we seize current opportunities to get there and what should we, as a field, guard against as we become "normal science?".

Positionality and Philosophy

Dora (Autistic) and Christina (ADHD) are the founding co-directors of AASPIRE and interdisciplinary/transdisciplinary scientists and educators who have worked together since 2006. Much of our collaborative and individual work explicitly aims to infuse neurodiversity principles into the "normal science" of autism and public health research to generate a paradigm shift both in science and in society more broadly. Dora is a systems scientist and disability and queer rights activist with theoretical, applied, and grassroots interests in the dynamics of social change. Christina is an internal medicine physician and community-based participatory researcher who has partnered with multiple marginalized communities, including those defined by race, ethnicity, disability, chronic illness, or trauma history, to conduct action research to improve health or well-being. We are epistemological insiders and disciplinary outsiders with respect to autism and neurodiversity research.

As interdisciplinary and transdisciplinary scientists whose flavor of neurodivergence favors nonlinear thinking and a resistance of absolutes, we are philosophical and methodological omnivores. We strongly advocate for appropriately matching paradigm and inquiry over the elevation of any one philosophy of science or scientific methodology. Our philosophical positionality for this paper uses aspects of constructivism with a critical realist ontology (Rees et al., 2020), critical theory (Paradis et al., 2020), and transformative paradigms (Mertens, 2007) as we engage with qualitative futures thinking methods. Specifically, we acknowledge the co-creation of reality through the legitimacy of multiple epistemologies interacting with the generative structures of reality, in conversation with power, and with a goal and praxis of continuous movement toward greater social justice.

Methods

As our research questions are largely descriptive (what would desirable futures for neurodiversity research look like and what could get us there?) with intent to develop ideas for strategy, we selected two "Tools for describing what the future might be like" from *The Futures Toolkit: Tools for futures thinking and foresight across UK Government* (Government Office for Science, 2017).

The first tool is a two-part visioning exercise with questions designed to stimulate futures thinking. Part 1 asks participants to imagine that they successfully created a desired future, and to talk about their accomplishments. Questions include, "What have we achieved?" "Who are our stakeholders? How have they benefited from what we've done?" and "What are the challenges we face now?" Part 2 asks participants to form consensus about the current reality relative to the vision. Questions include, "How close are we to our vision?" "Which changes are in our control? Which aren't?" and "Who will be the winners and losers in this change? How do we bring people with us?".

The second tool is a SWOT Analysis to identify relevant Strengths, Weaknesses, Opportunities, and Threats moving from the present into desired futures. A SWOT Analysis asks participants to fill a grid with one field for each of the four items. Strengths and weaknesses are internal factors to realization; opportunities and threats are external factors to realization. While SWOT Analysis is a tool commonly used in business and policy planning, in a futures thinking context it can be helpful in strategic planning about the future. For the purposes of our SWOT Analysis, we defined internal forces as the people who are actively working toward our vision of desirable futures for neurodiversity science. We defined external forces as people who are working in neurodiversity research or consuming neurodiversity research broadly including other researchers, clinicians, policymakers, and communities.

We held three two-hour meetings to complete our futures exercises. The first meeting centered our futures cone exercise with the broader aim of "neurodivergent futures," which led us to narrow our scope (see Aims above). The second meeting, re-focused on the futures of neurodiversity research, centered the visioning exercise. In the third meeting, we conducted our SWOT Analysis.

At the start of the visioning meeting, we talked about where we came from and where we are. That discussion comprises the narrative in "The Weight of History and the Push of the Present" section above. We then used that conversation as input to our visioning exercise. We imagined the first part of the visioning as having succeeded at bringing the neurodiversity-framed neurodiversity research we've been working toward since 2006 from its current state of disruption into equilibrium as the new "normal science." We then used that imagining of the new normal science as input the second part of the visioning exercise. We took notes on a white board and recorded our conversation. After the meeting, Dora organized the visioning data into coherent concepts and then together we further organized the concepts into (1) a coherent and explicit futures vision for neurodiversity research and (2) an initial set of recommendations for how to get there.

In our third meeting, we used the futures vision as input to the SWOT Analysis and identified items for each quadrant of the SWOT table. After the meeting, we organized the bullets in our SWOT table into themes and synthesized the individual items into a short narratives for each theme. Lastly, we synthesized the narratives and the recommendations from the visioning into a final set of actionable recommendations that include both how we can leverage our existing strengths and opportunities, and ways we need to guard against internal and external risks to futures that, while well-intended, could undermine a long-term movement toward justice.

These findings gave us the third point of the triangle, the pull of the future.

The Pull of the Future

In our futures vision for neurodiversity research…

Neurodivergence is normalized. Political activism cools as neurodivergence normalizes. As discrimination and stigma fade, the full range of neurodivergent experience emerges—both the affirming and the destructive, the idiosyncratic and the stereotypical. As the power/knowledge dynamic (Foucault, 1980) begins to reinforce neurodivergence as a legitimate way of being, people stop dismissing neurodivergent epistemologies in neurodiversity research as either irreparably biased or untouchably sacred, reducing their risk of promoting of bad or harmful science.

Complexity is celebrated. With the normalization of neurodivergence and its subsequent de-politicization, neurodivergent experience no longer needs to be over-simplified to counter harmful social narratives or to gain legitimacy. Both researchers and broader society appreciate neurodivergent people with the same range of nuance as they do neurotypical people; outgroup homogeneity bias dissolves.

Intersectionality is assumed. Research and intervention design accounts for and incorporates the synergetic interactions between neurodivergent and other identities (race, gender, religion, etc.). Scientific inquiry and praxis include intersectional epistemologies within the neurodivergent experience.

Ableism is socially and scientifically unacceptable. Therapy supports function and quality of life, not identity change, normalization, or masking. Research domains once closed due to a high risk of eugenics open to new opportunities; researchers make advances in precision medicine. The mental and physical well-being of neurodivergent populations increases. Health disparities related to neurodivergence are largely eliminated.

Neurodivergent voice is always included. This inclusion is authentic, equitable, considered, and deliberate. Inclusion happens anywhere knowledge production happens, including on research teams, in education, in research policy, on institutional review boards, in academic journals and other dissemination venues, and among research participants. The systems that scaffold knowledge production shift their processes and environments to support neurodivergent presence. Strategies exist to include people with all types and sub-types of neurodivergence, all functional needs, and all types of capabilities.

Neurodivergent cultures are centered, respected, and integrated. Neurodivergent cultures shape how systems and environments shift to include neurodivergent populations in neurodiversity research. The workday includes time for silliness, joy, and stimming. Projects have longer timelines to run on neurodivergent time. Multiple modalities of communication enrich scientific collaborations. A culture of accessibility supports everyone without anyone needing to expend emotional or physical labor.

Epistemology is multiple, simultaneous, and fluid. Science celebrates all ways of knowing. Like neurodivergent minds, researchers may move fluidly between different epistemologies, acknowledging their simultaneous, nonlinear, and associated truths through many philosophical lenses—or allowing the multiplicity to exist while focusing on a single point within the larger universe through a single philosophical lens.

In reconciliation of that futures vision with the present…

Positioning the future. Understanding how close we are to the future gives us an idea of the distance we need to cover. There is most certainly a tipping point between the current more neurotypical-led "normal science" and the revolutionary more neurodiversity-fueled science. But where are we relative to that tipping point? And after we tip, will we equilibrate with neurodiversity as the new “normal science” (in Kuhn’s sense of it becoming the accepted status quo for the field) or continue to oscillate between today’s normal science and neurodiversity until something new disrupts the dynamic? Without a rigorous study of the dynamics, it’s hard to tell where we are now, how close to any tipping point into a neurodivergent normal science. However, we are sure that we are much closer than we were when we first met in 2006, and that this present moment is fertile with both opportunities and dangers. Could we tip too slowly and be crushed by the status quo? Could we tip too quickly and make mistakes that cost us trust with the community?

Controlling the future. Humans cannot control highly complex systems like knowledge production. Learning to relax the urge to control is an early and difficult lesson for anyone interested in the science of social change. However, such systems can be, as Donella Meadows says, "danced with" (Meadows, 2002). Knowledge production is a system designed to shift paradigms. The process is typically slow and incremental, but “advancing the state of the science” can be a fast leap too. In our opinion, what we are witnessing right now in neurodiversity research is one of Kuhn’s scientific revolutions. In 2010’s critical autism studies workshop, we theorized that by infusing autistic voice into the machine of knowledge production we could shift the system toward neurodiversity paradigms. In 2023, we seen substantial evidence that shift in practice. Science is how we’ve been dancing our vision future-ward, and we still strongly feel it has powerful leverage.

Leading the future. One of the ten Disability Justice Framework principles is “Leadership of the most impacted” (Berne, 2018). This means that those who have been most marginalized, most left out, should be the ones to lead since they have the strongest epistemological grounding in the issues, having lived them. In order to reach our vision of the future, it is essential that those whose voices have been most silenced, most left out, be at the center of change. This, too, has been happening steadily over the past few decades, helping to push us (near? to? over?) around the tipping point. We still have further to go in elevating the most marginalized of neurodivergent voices.

In assessing the facilitators and risks to the futures vision given our current positioning…

The results of our SWOT Analysis organized under six themes. The first five ran across all quadrants: (1) Accumulation of Knowledge; (2) Workforce Development; (3) Philosophical Considerations; (4) Infrastructure and Resources; (5) Neurodivergence and Inclusion. The sixth theme (6) Social Pressures was only present in the external Opportunities and Threats, as it involved external contextual forces.

Accumulation of Knowledge. While participatory autism researchers have nearly 20 years of experience and insight working toward the vision with rigorous and impactful research, we can undermine that strength by incompletely or inauthentically implementing what we know, or by reinventing participatory approaches instead of building on existing knowledge. Externally, new domains in related science such as implementation science, as well as growing interest and advances in participatory research and neurodiversity as a paradigm (e.g., (Sonuga-Barke, 2023)), present opportunities. However, 20 years isn’t that long, and we can all be threatened by the sheer force of inertia.

Workforce Development. The growing number of neurodivergent researchers is a tremendous strength, as well as the growing credibility and capacity of researchers of all neurotypes working toward the vision. However, the largest number of neurodivergent researchers is still in the early part of their training and careers, and visionary leaders and senior researchers risk exhaustion and burnout, particularly as a very small number supporting a large number of trainees. The opportunities presented by the growing visibility and respect for researchers who hold the vision externally are threatened by smallness of the field and even smaller numbers working within the field. Additionally, dominant clinical theories of neurodivergent conditions rest on a foundation of ableism which permeates education, training, policy, and professional development at all levels.

Philosophical Considerations. We have strength in the interdisciplinary and transdisciplinary nature of our work and our willingness to tackle complex problems; this gives us access to multiple philosophies of science, including those with subjective, multiple, or interactive epistemologies—and the wide range of qualitative and mixed-methods methodologies available to them. An increasing acceptance of such philosophies and methodologies is also a part of broader opportunities. We need to take care, however, not to develop dogmatic adherence to narrow conceptualizations of neurodiversity or any one paradigm or methodology, or to reject any simply because it was used by someone to marginalize neurodivergence in the past. We also need to be aware of weaknesses in our ability to balance creation and destruction, or to accept inevitable imperfection—particularly in the early, experimental stages of building a vision when perfection is impossible, if only because we are actively still learning. If our internal weakness is going too far in rejecting the philosophies of "normal science," the external threat is in the inertia of normal science itself, especially with the power/knowledge construct resisting change at the center.

Infrastructure and Resources. We are seeing increasing research infrastructure to support our vision (e.g., *Autism in Adulthood* journal, INSAR Autistic Researchers Committee, Facebook group ARRA, AIR-P's neurodiversity-imagined network on health and well-being, textbooks like this), as well as maturing advocacy infrastructure (e.g., ASAN, AWNBN, AANE), and maturing community-campus collaborations (e.g., AASPIRE, PARC, Autism

CRC).[2] As we grow however, we need to protect against the potential for infighting over limited resources and/or innovative ideas instead of generating a culture of sharing. Externally, there are some opportunities in an increased interest in collaborative research by funders, including U.S. federal agencies such as NIDILRR, NIH, and PCORI.[3] However, this remains an area of substantial external threat in that, first, current educational and research systems are not structured to support participatory research, or to support neurodivergent researchers. Second, there remains very limited funding for the types of research the vision most prioritizes.

Neurodivergence and Inclusion. Our neurodivergence is, in itself, one of our greatest strengths. Our neurodivergent creativity, and our culture of creativity, accessibility, playfulness, and justice, is a powerful force for achieving its own infusion into neurodiversity research. We are also strengthened by the growing expansion of the who is included in the neurodiversity movement and consideration for people with greater support needs and intersections of marginalization. Despite that, we currently have uneven development of the vision across those same needs and intersections, and they are insufficiently included. We cannot fully realize the vision until we address these weaknesses. Externally, advances in disability rights, disability justice, and other social justice movements, as well as increased visibility, present opportunity. However, misunderstandings and myths of what neurodiversity means, both in ways that justify opposing it and as a superficial "credentialing" of research that does not use a neurodiversity approach, present significant threats. Additionally, the compulsion to simplify and classify people into binaries or mutually exclusive categories (e.g., high/low functioning, profound autism, visual/verbal thinkers, by diagnostic label) is a substantial threat to inclusion and equity.

Social Pressures. Our current external context provides a number of opportunities. The neurodivergent children diagnosed in the 1990s and early 2000s are now becoming adults, increasing pressure on research to find solutions for the disparities they are experiencing. The neurodiversity paradigm has also permeated the public consciousness through social and other media, particularly for younger generations. However, there are just as many threats. In

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[2] Autism in Adulthood https://home.liebertpub.com/publications/autism-in-adulthood/646; INSAR – International Society of Autism Research https://www.autism-insar.org/page/InsarARC; ARRA - Autistic Researchers Researching Autism FaceBook group; AIR-P – Autism Intervention Research Network on Physical Health https://airpnetwork.ucla.edu; ASAN – Autistic Self Advocacy Network https://autisticadvocacy.org; AWN – Autistic Women and Non-Binary Network https://awnnetwork.org; AANE – Association for Autism and Neurodiversity https://aane.org; AASPIRE – Academic Autism Spectrum Partnership in Research and Education https://aaspire.org; PARC – Participatory Autism Research Collaborative https://participatoryautismresearch.wordpress.com; CRC - Cooperative Research Centre https://www.autismcrc.com.au

[3] NIDILRR – National Institute on Disability, Independent Living, and Rehabilitation Research; NIH – National Institutes of Health; PCORI – Patient Centered Outcomes Research Institute.

particular, there has been an alarming increase in ableist policy and political will, as well as an increasing push back to disability rights. We are living in a highly disruptive time globally, which makes its own opportunities and threats, and our vision may have to quickly adapt.

In taking action to reach the futures we would like to have...

Given our reconciliation of the futures vision with the present and our SWOT Analysis, we developed the following recommendations for reaching the vision we would like to have.

- Continue growing the participation, number, and leadership capacity of neurodivergent scientists and activists in existing systems of research and knowledge production.
- Become conversant with and build on the literature for conducting participatory neurodiversity research that has grown since the 2000s, as well as the substantial literature on participatory and emancipatory science since the 1940s.
- Leverage the creative and cultural strengths of neurodivergent scientists and activists to envision new systems for conducting neurodiversity research and producing knowledge. Locate resources to scaffold and implement them, especially by supporting infrastructures created and maintained by the neurodiversity community.
- Support scholarship by neurodivergent and other allied scientists that challenges “normal science,” both in theory and in application.
- Support policy initiatives that allocate resources toward neurodiversity research, and advocate for neurodiversity framing in broader settings, including education, clinical practice, popular media, community living, employment, and politics.
- Fearlessly explore interdisciplinary and transdisciplinary spaces, collaborations, and approaches to address the complexity of neurodiversity research.
- Be patient, deliberate, and open to change and adaptation in confronting the inertia of the status quo; strive for “best for now” over “perfect forever.”
- Develop strategies to consistently and authentically include people with the most marginalized functional or support needs, or who exist at the most marginalized intersections of identity, in all aspects of neurodiversity research.
- Center neurodivergent epistemologies in all neurodiversity research.
- Recognize that understanding the lived experience of those who oppose neurodiversity paradigms is essential to reconciling past, present, and future and develop strategies for including contradictory opinions and unpopular epistemologies in neurodiversity research.

- Resist the urge to have "winners and losers" in the paradigm shift. Take care not to demonize specific philosophies of science and their methodologies (e.g., positivism and quantitative methods). Take care not to marginalize individuals within the neurodivergent population who do not resonate with the neurodiversity paradigm. Neurodiversity accepts and celebrates all ways of knowing; this is how we bring everyone with us into the kinder, more epistemologically curious, and just future we would love to have.

The Plausible Desired Futures at the Center

In the center of the futures triangle, plausible futures emerge suspended on the tension created by the weight of the past, the push of the present, and the pull of the future. In the specific futures triangle we have envisioned, we focused on futures for neurodiversity research that we felt were desirable to achieve.

The center of our triangle describes an authentically, fully inclusive science, led by the people who best understand neurodivergence through lived experience and balanced by multiple perspectives. It is a fluid and associative science, embracing many ways of knowing simultaneously, or pausing to deeply appreciate the facets of just one without having to extinguish the others. It emerges from neurodivergent culture and is a part of neurodivergent culture. It provides insight into the human experience and strategies for problem solving that would be impossible by neurotypical thinking alone. It legitimizes all neurodivergent epistemologies and disrupts the systems of oppression generated by their marginalization. The world shifts toward justice and greater well-being.

Are these futures plausible? Given the current state of the world and all that the neurodiversity community has achieved in the past two decades, we feel they are, even if they may take time. The current state of the world is, however, fragile, and the pull of the present could easily shift in unpredictable ways to emerge a different center. We hope that whatever centers emerge they include parallel play, gloriously geeky monologues, and all the best stim toys.

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CHAPTER 26

Research Methods and Ethics in Neurodiversity Studies: Looking Back, Moving Forward

Hanna Bertilsdotter Rosqvist and David Jackson-Perry

INTRODUCTION

Editing this volume has been very much a journey of discovery. From the beginning, we knew that we wanted to hear from researchers at various stages of their academic careers and to include both academic and non-academic and variously neurodivergent contributors. This inevitably meant that we were accepting, seeking even, an element of unknowability as to what sort of volume we would end up with, what sorts of lessons we would be learning, and so what sorts of reflections—and thoughts moving forward—would find their ways into this final chapter.

We noted in the introduction that an important barrier to doing neurodiversity research differently has been a relative paucity of detailed descriptions of—and reflections on—collaborative, participatory, or other creative methods in the field: hence this volume. In very different ways, all the chapters in this collection respond to that observation. In this final chapter, we have therefore chosen to keep theoretical musings to a minimum and to stay as close as possible to our ambition of producing an accessible handbook for those looking to use alternative methods in neurodiversity research. What follows is organised around four principal methodological themes that have emerged

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from preceding chapters: 'Saying hello': Befriending Communities from the Start; Navigating Collaborative and Participatory Processes; Facilitating Participation; and 'Saying Goodbye': Final Steps. Each section ends with a brief, hands-on toolbox, drawing on lessons learnt through the contributions of individual chapters. These toolboxes are of course far from definitive, and we encourage the reader to play with, adapt or reject them as they feel fit for their research context and their own functioning/access needs. We conclude with a consideration of the potential and reach of 'unknowing' as a foundational tool for research methods and ethics in Neurodiversity Studies.

'Saying Hello': Befriending Communities from the Start

Befriending Neurodivergent Communities

Several chapters in this volume note the importance of shaping research projects through early community engagement and consultation (Chapters 4,9, 10, 19, 20, this volume; see also Milton & Green, 2024). We refer to this as *befriending communities*. This is an important step even if the project involves neurodivergent researchers or advisors, which may not necessarily be enough to give a broader community view of, for example, research priorities or accessible methods. While this befriending may take various forms, depending on researchers' resources and preferences, the underlying principle is to create a more or less active, and more or less formalised, *early* engagement with communities.

Different approaches may bring researchers a feel for the community and its research priorities, such as familiarising themselves with published community priority literature and informal conversations on social media. Those with more time could carry out formal investigation into community research priorities and accessible methods, such as the online survey Jackson-Perry (Chapter 20, this volume) employed, and as is increasingly being done elsewhere (see, for examples, Davies et al., 2024; Dey et al., 2024). However, various low-hanging fruits exist for those with more limited resources. Thom-Jones and Lowe (chapter 10, this volume) suggest that for students or others with limited resources, simply becoming familiar with the literature describing community priorities or preferred methods (see, for example, Emerson et al., 2023; Chown et al., 2023; Cage et al., 2024), is a good low-cost entry point. Another low-cost/high-benefit approach is to seek out—and cite—neurodivergent theorists regardless of the form of dissemination, for example looking to blogs and forums, which can be referred to as community grey sources. This constitutes what Hillary Zisk (Chapter 19, this volume) refers to as an "ethical engagement with the community," which is about "substantively engaging with work by neurodivergent people at all stages of research." Beyond the advantages of bringing a sense of proximity with community ideas and preoccupations, this also provides the opportunity to reconsider meanings of data and theory, legitimising neurodivergent contributors from beyond academia, who can thus be understood as "sources of theory" and "not only as sources of data" (Zisk, Chapter 19, this volume).

If time and resources permit, more in-depth engagement and collaboration with relevant stakeholders may be invaluable. Jackson-Perry, for example, invested heavily in getting to know autistic communities, initially online and one-to-one, and then through participating in autistic-led spaces that welcome researchers from all neurotypes (Chapter 20, this volume). There exist, for example, autistic-led spaces, such as the Participatory Autism Research Collective (PARC, 2020), which welcome all researchers to their conferences and events. This process of engagement and collaboration is pertinent regardless of one's neurotype. Whether the community being researched is that of your own or another neurotype, engaging with broader communities, to the extent possible within the constraints of your project, will enrich both your research and your researcher journey. While some forms of befriending might be relatively high cost in terms of resources, we have noted here some simple and low-cost options and consider that the benefits of all these processes far outweigh the costs.

Toolbox for befriending neurodivergent communities

- *Get involved*: as much as possible, as early as possible within the constraints of your project, engage with neurodivergent communities. This will be invaluable to your research journey.
- *Tailor it*: if you do not have the time and resources to do this actively (e.g., joining PARC, attending neurodivergent-led conferences, etc.), then do it theoretically, through familiarising yourself with published community priority literature.
- *Cite community resources*: search for neurodivergent blogs and other grey sources (see, for example, Zisk, 2023 for an annotated list in the field of autism). In this case, try to contact neurodivergent creators to ask if they are happy for their work to be used in research, and if so in what way they prefer credit and citation. Allow sufficient time for creators to think about this question and respond ahead of any deadlines.
- *Proactively seek community input*: if you have the resources, and to be as pertinent as possible to your specific project, carry out your own investigation through an online survey, for example.

Befriending, Navigating, and Resisting Academic Norms

Befriending communities can also be seen in terms of another relationship: befriending—in this case meaning becoming familiar with, navigating, and resisting—a largely neuronormative academia as a neurodivergent researcher. Sometimes this starts with a deconstruction of academic normativity, what

Raymaker and Nicolaidis (Chapter 25, this volume) following Kuhn, refer to as "normal science," and how it may clash with researchers' own neurodivergence (see Chapters 5, 17, 18, this volume). Working to change existing systems and paradigms is time and energy consuming. It requires becoming what Ahmed (2023) calls a "killjoy," being willing and able to be perceived as the problem, when in fact you are simply pointing out that a problem exists (see Chapter 5, this volume). Goetz and Adams (Chapter 17) note the "toll" of "trying to live up to the pressure of being the voice in those rooms, advocating for those who are not." The work of changing academic codes, be they concerned with ethics applications or disciplinary codes that pathologise neurodivergence, is all the more complex given that these codes may generally be invisible to neurotypical academics. However, resolving and navigating this clash offers the potential to make academia work better for all researchers, regardless of neurotype. Remember, this should not be left to neurodivergent academics or students to do: making academia a more inclusive and user-friendly environment is everyone's responsibility.

Research ethics applications are one example of this, including formal expectations of filling out research ethics applications, often with little or no guidance (see Chapter 18, this volume). Researchers may be expected to complete applications in unfamiliar or unwelcome language. There may, for example, be an expectation that neurodivergence be described through deficit (when presenting risks and benefits of research in relation to ethics committee assumptions of neurodivergence) rather than describing neurodivergent experiences in line with one's intended research project (Limburg, 2022; c.f. Chapter 10, this volume). Commonly, (neurotypical) ethics committee members, based on their assumptions of neurodivergence, may expect clarifying answers to questions such as "Does your research include anyone who is intellectually, mentally or physically impaired?" or whether research includes "People who may be vulnerable or unable to give fully informed consent." Jones and Lowe (Chapter 10, this volume) use a proactive approach to preemptively address the concerns raised by ethics committees. They suggest creating a proforma statement outlining their position on the ethical conduct of autism research using national or international research ethics guidelines. Adopting a similarly pragmatic approach, Munday (Chapter 18, this volume) deconstructs the UK ethical application process. The author suggests recommendations to improve ethical assessment processes, including making them more accessible to all students and researchers by creating comprehensible guidelines, offering individualised support, and providing access to examples of past ethics applications and forms. These two chapters not only suggest solutions to problems, but also illustrate what Hume (Chapter 13, this volume) refers to as "cripping methodology" or "a neurodiversity-affirming methodology." What all these chapters suggest is to be pragmatic and proactive; where you find a problem, suggest a solution to mitigate the problem for future researchers. This befriending, cripping, or making academia more neurodiversity-affirming is perhaps a pillar of what Raymaker and Nicolaidis (chapter 25, this volume) refer to as neurodiversity science, which they suggest may "infuse neurodiversity principles into the 'normal science' of autism and public health research to generate a paradigm shift both in science and in society more broadly." This is a pleasing reversal of "epistemic infection," whereby neurodivergent individuals might become "infected" by dominant discourses positioning them and their experience as deficitary (Bertilsdotter Rosqvist & Jackson-Perry, 2021). Here, the tables are turned, and neurodivergent researchers are resisting and influencing (neurotypical) modes of functioning rather than submitting to them. We think of befriending academia, or "taking up space," as Munday (Chapter 18, this volume) puts it, as a way of troubling neurotypical "business as usual" from within academia (c.f. Bertilsdotter Rosqvist et al., 2019, p. 1082).

Toolbox for 'befriending academia'

- *Take up space:* to the extent that you feel it is possible for you, be willing to take up space. This might mean asking for support, asking for examples (in the case of ethics applications), or even pointing out to supervisors and colleagues ways in which existing systems and codes might operate to disable you or others. This is the job of all researchers, not just neurodivergent ones.
- *Prioritise time management:* all parts of your research will probably take more time than you think (see Chapters 5, 8 20, this volume). Familiarise yourself with ethics processes as early as possible, leaving you time to take up space without also having to worry about running out of time.
- *Look after yourself:* sometimes we feel able to be the killjoy, sometimes it just takes too much energy and can even be traumatising. Do what you can when you can and feel no guilt when you can't.

Navigating Collaborative and Participatory Processes

We think of collaboration and participatory methods (for example, having an advisory group, or a community advisor) as having much in common, often involving—as they frequently do in this volume—working across neurotypes and academic/non-academic actors. Both therefore require actively navigating "varying and variable needs" (Chapter 8, this volume), and an awareness—and, where possible, correction—of potential power inequalities (see Chapters 4,7,8,9,12,17, this volume). Co-creation, collaboration, and supportive groups of researchers may loosen and unsettle dominant and traditional notions of research processes and expertise, pointing to new directions for research. They may also be a challenge when working within academic institutions and with external funding. In these cases, funders or institutional constraints (such as those for a master's or PhD thesis) largely decide the rules of the game, stressing research outcome deliveries, "fast science" (Alleva, 2006), and limiting the extent to which outside advisors or collaborators are permitted to intervene (c.f. Bertilsdotter Rosqvist et al, 2019, Chapters 5,6,8,20, this volume).

Several chapters focus on relationships between academic researchers and community researchers, or academic researcher/community member dynamics conditioned by academic institutions (see chapters 5, 6, 8, this volume). Academic researchers may be paid as part of their position, or have built-in benefits associated with this type of work (such as funding their own positions), which may not be the case for non-academic community members (see Chapters 6, 19, this volume). Sometimes, as in the case of Grant and co-authors (Chapter 4, this volume), it is possible to include non-academic community members in the development of a funding application. We feel strongly that payment of non-academic community members is necessary in research processes, given that making funding applications and carrying out and writing up research are expected tasks of researchers (along with peer-reviewing and editing and contributing to volumes such as this). However, it can be complex to arrange funding for non-academic community members at this stage, as budgets are not yet assigned. It will be useful when completing funding proposals to lean on published guidance stating the importance of offering "payment at a level that is commensurate with the nature and demands of the activity and is fair when compared to other members of the research team, to acknowledge the value placed on public involvement" (NIHR, 2023).

Collaborative challenges are not limited to tensions implicit in academic researcher/community member dynamics. The question of varying and variable needs, for example, amongst researchers with both different *and* similar neurological positionings is recurrent in chapters here. The co-creation process described by Hultman and co-authors (Chapter 8 see also chaptEr 12, this volume) required navigating between varied and variable needs, particularly around notions of time and energy. Informed by Kafer's (2013) notion of crip time, they stress the importance of "'a reorientation to time' that: requires reimagining our notions of what can and should happen in time or recognizing how expectations of 'how long things take' are based on very particular minds and bodies" (for a similar discussion see Chapters 5,6,7, this volume).

Hume (Chapter 13, this volume) draws on the disability justice movement to address the question of differing needs through the notion of "access intimacy" which, for Mingus (2017, para 21):

> recognizes and understands the relational and human quality of access, while simultaneously deepening the relationships involved. It moves the work of access out of the realm of only logistics and into the realm of relationships.

Recognising the relational nature of navigating needs has, says Hume (Chapter 13, this volume), "the power to bridge the emotional distance between two people, transforming both of them rather than merely adding a ramp one of them can climb while the other takes the stairs." A prerequisite for access intimacy, then, is relationship building for all members of a group to feel at ease and enable the others to express themselves authentically. In the duoethnography of Goetz and Adams (Chapter 17, this volume), the authors explore and reflect upon their positions as differently neurodivergent researchers and their resultantly different experiences of academia. At the same time, their duoethnography forms a caring and supportive space for their reflections and co-writing, in which they explore and mirror each other's experiences in a friendly and curious way. We see this type of process as holding powerful "epistemic healing" (Khan & Naguib, 2019) potential for neurodivergent researchers faced with an often ableist and hostile research environment, however unconscious.

However, as Pearson et al. (Chapter 7, this volume) note, "being nice" to each other is not sufficient to bring about change of practice: rather, as Hultman and Hultman (chapter12, this volume) found, it requires hard, ongoing work throughout the research process, as to accommodate varying and variable needs over a sustained period. Désormeaux-Moreau and Courcy (chapter 9, this volume) refer to this as "navigating *together.*" The authors complicate binary assumptions of sharing or not the same neurological positioning, rather stressing the importance of dialogue and reflection to be able to meet at the crossroads of different experiences. They refer to this as "cross-fertilizing knowledge" valuing the diversity and plurality of knowledge and standpoints and developing a joint political engagement, which can also be seen as a form of access intimacy. Désormeaux-Moreau and Courcy also stress the importance of rebalancing power relations in the collective, where researchers from a dominating neurotype need to consciously practice "self-disempowerment," giving up space and power in order to make space for researchers of a minority neurotype. Something similar may be useful when navigating inequalities in power informing the research collaboration more generally, for example due to age, different disciplinary backgrounds, and different levels of previous academic experience (see Chapters 7, 12, this volume). Given scholarship that increasingly notes interest-based motivation as a powerful resource for both autistic and ADHD folk (Dodson, 2022; Hallowell & Ratey, 2021; Murray, 2019; Murray et al., 2005), what Jones and Lowe (Chapter 10, this volume) refer to as engaging in one's "passion projects," it is perhaps unsurprising that high levels of interest in both research topics and different parts of research processes can overcome or mitigate access difficulties (see Chapters 7, 12, 17, this volume). Indeed, some empirical research suggests that high levels of interest in a given subject may largely bypass both sensory and social challenges (Jackson-Perry, 2023, p.223). Where collaborators have high levels of interest in either a topic or a part of the research process, this plays to strength. However when or if interest wanes, it becomes something of a barrier to the whole project (see

Chapter 12, this volume). As a way to counter the challenges of interest-based research, Hultman and Hultman (Chapter 12, this volume) stress the importance of a pragmatic collective approach in research: "utilizing the group members' collective strengths to create individualized working processes within a collective writing process."

Finally, while participatory research has become increasingly prominentin autism research, some contributors to this volume have questioned how meaningful much community engagement may be. Several chapters here critique the extent to which participation or community involvement is necessarily meaningful, as opposed to tokenistic (see Chapters 5, 9, 10, 17, this volume). Jones and Lowe (Chapter 10, this volume), for example, note that:

> Autistic academics are all too familiar with the proposition of an informal zoom meeting to discuss autistic perspectives about a study that is already underway, being later positioned as a participatory approach or autistic community consultation.

This is not specific to neurodiversity research, being apparent in other fields, such as HIV research (Chapter 22, this volume). This is perhaps the cost of success and brings us back to the risk of "neurodiversity lite" discussed in the introductory chapter (Chapter 1, this volume): when participatory and collaborative approaches become a funding requirement, for example, researchers unfamiliar or unengaged with principles and processes of those approaches may be tempted to do what is necessary to tick the boxes. This is perhaps one of the risks Orsini (2022, p.5) refers to when he says that:

> bringing autistic voices or perspectives to the table may reproduce what many have decried in the past: participation or engagement for the sake of crafting a thin veneer of legitimacy.

While Jackson-Perry (Chapter 22, this volume) is a proponent of participatory research, he is also hesitant about expecting it:

> to fix all our problems, to move from deficit to difference, from 'questions important to researchers' to 'questions important to autistic communities,' from individualist medical narratives to more social leaning models.

The author questions how meaningful participation can be in a research environment still largely dominated by deficit readings of, here, autism, whereby "autism's essence," as Yergeau (2013, p.8) reminds us:

> has been clinically defined as a disorder that prevents individuals from exercising free will and precludes them from accessing self-knowledge and knowledge of human others.

If we agree that this is the case, that neurodivergent folk are to varying extents considered to be unreliable witnesses of their own experience, then the impact of the inclusion of their voices in research processes will necessarily remain limited and tokenistic. To change this requires a reconsideration of everything we have been taught to believe about neurodivergence, a point to which we return below.

Collaborative and participatory toolbox

- *Take small steps:* each project has constraints that need to be considered: we are mindful that collaborative and participatory processes can be hard—if enriching—work, particularly for a novice researcher operating within a resource-poor framework. Jackson-Perry (Chapter 20, this volume) recalls an informal conversation with Damian Milton in 2017. His advice, given the constraints of a PhD, was something like this: even if you only do one small thing that is participatory during your study, and you do it well, this is already more than most people are doing and is better than nothing.
- *Avoid collaboration and participation as an add-on:* to avoid tokenism—build collaboration/participation into your project as early as possible, preferably at the planning stage, including considering pertinent research questions, etc.
- *Compensate when possible, make noise when not:* look into funding mechanisms to appropriately and equitably compensate neurodivergent collaborators for whom research is not part of their jobs. Where this is not possible, lean on existing guidelines to make some noise about this, with your project manager, institution, or ethics committees: you might make a change for those coming after you.
- *Be patient with each other and see challenges as a learning process:* different group members may have varying and variable needs. It is important to discuss these before starting up the research process since it affects planning and time management.
- *Practice access intimacy within your research group:* the time you spend building relationships is time well spent.
- *Time is of the essence:* all parts of the research process will take longer than you had expected—expect this! Further, within the project, different actors will have differing approaches to time and energy management—take this into account, discuss it explicitly, and work with it.
- *Play to interest:* as neurodivergent folk, we often have a complex relationship to interest. Whether concerning the actual subject of the research project, or our interest in particular parts of the research process, our engagement is likely to be significantly impacted by our interest levels. Access intimacy will help make this explicit early on in the collaboration—work to the individual strengths of members rather than a normative idea of what each contributor should be doing.
- *Rethink failure:* as this volume has shown, scholars informed by neurodiversity approaches are often trying out new things. This requires

risk-taking, and not everything will work the first time—if ever! Be willing to embrace failure as a learning process.

Facilitating Participation

Similar tensions as those noted above can be found when it comes to facilitating access for those who have volunteered to be participants in your research project. Access intimacy, an acknowledgement that researcher and participant are inter-dependent, that they create a relationship that needs looking after, is also central here (see Chapter 13, this volume). Indeed, in ethnography, as Taneja-Johansson (Chapter 11, this volume) reminds us, "access to lives and places has been shown to be determined by the time invested in developing trust." The author cites Tavory (2019, p. 727), who describes ethnography as a discipline "made of relationships." We can think of this relationship as starting before a meeting with participants (in whatever form that might take) has even taken place. Indeed, even before the research project has formally started, a broader community relationship can be worked on, through participating in neurodivergent spaces (providing this is allowed: see 'Befriending communities' above and Chapter 20, this volume). This is all the more important given as the distrust that may exist "from autistic persons towards researchers" (Woods and Waltz, 2019, p. 2) and the broader "history of distrusting researchers" amongst "minority communities" (Raymaker & Nicolaidis, 2013, p. 169). This early process of building community relationships will help steer you away from unconscious stereotyping and enrichen your reflections as you move through the entire research process. Further, investing time in these early stages of befriending will be of help when you seek participants for your research, as there is a chance that people will be familiar with your name and approach.

When navigating participation itself, a first step is to identify and adapt the level and type of participation that are appropriate and possible given the expectations and limits of a specific research project. To participate in research can be an opportunity for participants to have a voice, something which in itself can be valuable for people who may not be used to being heard, being listened to (see Chapter 11, this volume). For this to be as emancipatory and meaningful as possible, what can be described as an "*ethics of choice*" may be a valuable tool (see Chapter 4, this volume). An ethics of choice includes choices in terms of individually adapted ways of participation, for which Humes' (Chapter 13, this volume) discussion of access intimacy will also be valuable, including the suggestion to be proactive with proposing accommodation for everyone rather than leaving the burden of requesting accessibility on the participants' shoulders: the onus for providing accessible and comfortable forms of participation is the researchers' responsibility.

Indeed, in inclusive research literature, accessible research opportunities and "maximizing participation" (Harrington et al., 2014; see also Chapters 5, 14, 15, this volume) are commonly referred to when it comes to enabling participant's participation through offering participants a flexible palette of data collection possibilities adapted to the participant's sensory modalities and ways of communication. This can be summed up by the imperative of Jones and Lowe (Chapter 10, this volume) to "Minimise barriers, maximise flexibility" as well as to "Accept autistic participants' personal preferences to engage." Chapman (Chapter 21, this volume) suggests email interviewing, a form of asynchronous communication between a researcher and participant where text-based information is repeatedly exchanged without strict temporal and spatial limitations, as an accessible research method enabling participation of participants who may better express themselves in writing. Participation through written communication may give neurodivergent people time to think, provide structure and predictability, and reduce both feelings of anxiety and negative sensory experiences. However, when choosing tools for data collection, the most important thing is not to assume that a single method will work for all people sharing a neurotype. Rather, as Jones (2022) has suggested in the context of autism research, researchers should: "start from scratch and develop measures that accurately assess the topic of interest, developing appropriate tools in collaboration with autistic people" (Jones, 2022, p 108). Informed by Jones' thinking, Chapman stresses the importance of the role of the researcher in making sure that each interview is tailored to the individual, or "mirroring" the participants, ensuring that the researcher is not responding generically, but to their distinct experiences and in relation to their way of expressing themselves. However, accessibility and access intimacy are also a matter of relationality, of interdependence between participant and researcher; as Hume (Chapter 13, this volume) puts it, "We navigated our, at times divergent, access needs together." Following several chapters (Chapters 11, 13, 21, this volume), this can be summed up as the responsibility of the researcher to build a trusting relationship and provide a space where participants feel at ease and able to share their experiences in the most appropriate way for them.

However, as the challenges of collaboration above illustrated, this is not a task without challenges when the participant's accessibility needs might clash with the accessibility needs of the researcher. For example, in some of the encounters with participants, Jackson-Perry (Chapter 20, this volume) notes that, "in our interaction, what was accessible for Susan was inaccessible for me…access for one person is 'access denied' for another" (c.f. also Chapters 7, 13, this volume). An ethics of choice also therefore requires taking into consideration the energy costs and benefits for participants and weighing those up with what is possible for the researcher, from both the perspective of their own access capabilities and the constraints of the individual project.

Facilitating participation toolbox

- *Invest in your relationship with participants and participant communities:* here, as with collaboration, engage in access intimacy. Think about building both individual and community relationships, before you engage in fieldwork or even plan your project. This will prove invaluable both to inform your substantive and methodological approach and when you seek participants. Remember too that for many people participating in research is a profound and novel experience: recognise and value this.
- *Proactively propose access possibilities to all participants:* do not wait for participants to ask for adaptations—provide a variety of choices and leave yourself open to other possibilities suggested by participants.
- *Think of participant payback and costs/benefits:* seek methods that are accessible, comfortable, and enjoyable for the participants whilst generating the information required to inform the overall research project. Ensure flexibility and choice in timing, location, structure, and modality of interviews.
- *Provide as much clarity as possible:* give participants clear guidance on how the method works in practice, and expectations for them as a participant to help manage any anxieties possible when engaging in research.
- (Here too) *accept and embrace failure:* navigating individual access needs is a process. You won't always get it right. Don't bet yourself up about this. See it as a sign that you are trying something new…and try something new!
- *Crip it up!* Work with crip time in interviews. Follow the participant's flow in conversations. Leave room for circumambulatory conversations rather than pushing for immediate, direct answers. This will enable you to elicit rich storied experiences of participants and avoid gathering only basic demographic information. It will also leave you freer to be surprised, creating space for your participants to tell you something about their experience beyond echoing what you already know, one risk if your questions are too directive.

'Saying Goodbye': Final Steps

She gave me a hug when she left. That was the end. (Taneja-Johansson, Chapter 11, this volume).

As researchers, we spend a great deal of time reading pertinent literature, working on a theoretical framework, and planning out the recruitment of participants and the gathering and analysis of data. As we start our research projects, these are immediate and sometimes urgent requirements for funders, ethics committees, and supervisors (for students), and we give them corresponding levels of attention. At this stage, our levels of energy and motivation are high. However, two or three years down the line, sometimes longer, there is another step that is often completely ignored. This step is not the subject of an institutional requirement and comes when we may be exhausted and at the end of our research tether: saying goodbye to participants. This is not helped by the fact that guidance on this is remarkably sparse in existing literature (Delamont & Smith, 2023), perhaps for the very reason that it is often not on institutional radars and, not being a formal requirement, the researcher concentrates their energy elsewhere. You may have spent considerable time and energy setting up your research tent, you have befriended the community and your participants, but at a certain point your research time and energy runs out and you need—perhaps hastily—to grab your things and leave the field.

And yet, while we have previously discussed an ethics of choice, which is of course as pertinent for this section as for the previous one, we must also consider the "*ethics of care*" in research (Ellis, 2016). Your participants have given their time, their energy, and often their intimacy to your research project. If you have engaged in access intimacy, if you acknowledge and experience the often-intense inter-personal relationship between yourself and your participants, even those you may never have met in person, saying goodbye with care is as important for the researcher as for participants. But "How does one withdraw from the relationships one has so carefully shaped together?", asks Taneja-Johansson (Chapter 11, this volume).

This is perhaps all the truer for long-term studies. Taneja-Johansson, who had numerous in-person meetings with participants over a three-year period, notes that for some participants she "had become a 'friend' and 'confidant,' a person with whom they openly shared what they were struggling with now." In turn, she found herself "looking forward to these regular meetings, engaged in what was happening in their lives." The author wondered "whether a clean break signaling the end was really the most caring way of ending the study for the participants" and decided on a "gradual withdrawal" approach. This involved increasingly mentioning her role as a researcher during meetings and gradually spacing meetings at longer intervals, "timing this to periods when participants were transitioning into a different life phase."

Time management difficulties were an ongoing concern for Jackson-Perry (Chapter20, this volume) throughout the participatory process of his PhD. His data collection and analysis took two years rather than the nine months he had expected, making him extremely uncomfortable about expecting the Research Advisory Group to stay engaged for such a long period. Finally, he sent a final email to advisors thanking them, stating that he would no longer be contacting them but inviting them to contact him if they had any comments, and directing them to the research website for updates. Similarly, he followed up with participants, also leaving the possibility for future communications and saying that the website would contain links to any publications based on the research and give results in an accessible fashion. In this way, just as his website had functioned as a space where potential participants could get information about him and his study and approach *prior* to participating, so it potentially prolonged the relationship beyond the duration of the study. This said, his feeling at the time was one of defeat: he had not anticipated the importance or the difficulty of this stage, not planned for it, and not built in the question of saying goodbye when he was saying hello.

Saying goodbye toolbox

- *Build 'saying goodbye' into your initial planning:* when the moment comes, you will likely be up against an institutional, energetic, and motivational deadline—not the best time to be taking care of this stage of the research process! Again, take into account that all parts of your process will likely take longer than expected.
- *Create a research website:* this can be a valuable way of presenting yourself to participants and the broader community and may function as a point of maintaining contact when the process is over.
- *Lay out the process:* when communicating what will be expected of participants include how and when the process will end as well as the usual 'you will be asked to respond to an interview that should last about one hour.'
- *Consider gradual withdrawal:* if your project involves multiple meetings, think about how to leave the field gradually with the same care you gave to entering it.

(In)Conclusion

> The transition from a paradigm in crisis to a new one from which a new tradition of normal science can emerge is far from a cumulative process, one achieved by an articulation or extension of the old paradigm. Rather it is a reconstruction of the field from new fundamentals, a reconstruction that changes some of the field's most elementary theoretical generalizations as well as many of its paradigm methods and applications. During the transition period, there will be a large but never complete overlap between the problems that can be solved by the old and by the new paradigm. But there will also be a decisive difference in the modes of solution. When the transition is complete, the profession will have changed its view of the field, its methods, and its goals (Kuhn, 1997, p 84-85).

Informed by Kuhn's (1997) thinking, Pellicano and den Houting (2022, p.381) describe current autism research as in a transition period; an ongoing shift from "normal science" to "neurodiversity in autism science" (see also Sonuga-Barke, 2023, for a similar discussion in ADHD research). Also following Kuhn (1997), Raymaker and Nicolaidis (Chapter 25, this volume) envision a future in which "Epistemology is multiple, simultaneous, and fluid. Science celebrates all ways of knowing." As we come to an end of working with this volume, we think of our current time concerning research on all neurodivergencies as one of transition; marked by instability, of disruption. Our hope is that this volume and Neurodiversity Studies more broadly contribute both to the disruption and to the settling process; to a new tradition of normal, neurodiversity science in line with the imagined future of Raymaker and Nicolaidis.

Much has been written here and elsewhere in neurodiversity informed approaches about different forms of knowledge and different types of knowers; of scientific, professional, or experience-based knowledge. These are important debates, doing their invaluable job of disrupting academic business as usual. However, as we have gone through our own process of editing this book, unknowing has come to the fore for us: it is with unknowing that we have decided to conclude this volume. Following Jackson-Perry (Chapter 22, this volume), unknowing of the type we are thinking "is not a lack of knowledge, but rather an intentional, creative, curious, and playful act rejecting a priori premises (notably of deficit) with the aim of coming to new understandings rather than confirming and contributing to existing assumptions." Jackson-Perry leans on queer theorist Halberstam's (2011) work on failure, as well as notions from Ignorance Studies and Epistemic Injustice, to propose unknowing as a way of approaching research, a process of unlearning and rereading, of going back to the sources with a new eye and reinterpreting findings while choosing to remain strategically ignorant of what is assumed to be known about autism.

However, as we consider themes that have emerged in this volume, we have come to think that unknowing is a useful framework beyond individual research processes. There have been, for example, long-standing and ongoing calls for—and recognition of the importance of—the inclusion of neurodivergent voices in neurodiversity research. This is largely framed as seeking ways "to support including neurodivergent perspectives in knowledge production" (Hens & van Goidsenhoven, 2023, p.10), and several chapters in this volume engage, rightly so, with that question (see Chapters 5, 8, 14, 15, this volume). Some critical autism studies scholars push back on this idea, with Elmadagli (2023, p.75), for example, suggesting that rather than seeking inclusion we should consider "limiting the influence of non-autistic scholars within CAS" (see Chapter 2, this volume, for discussion). It seems that the notion of inclusion—as meaning 'assumed to be neurotypical academics including neurodivergent knowers' in their research processes—has come to be so fixed that it is difficult to go beyond either maintaining or rejecting the notion outright. And, as Orsini (2022, p. 5) points out, the current logic of inclusion risks promoting "participation or engagement for the sake of crafting a thin veneer of legitimacy."

We do not believe that neurodivergent folk have a monopoly in understanding all aspects of neurodivergence that they hold a magic connection to the truth (or even that such a thing exists). Indeed, Shildrick (2009, p. 9) reminds us of the importance of "non-disabled people" working in the field of disability studies, of their being well-positioned "to interrogate their own culture and psycho-social location as non-disabled." Further, as Orsini (2022,

p. 11) notes, unknowing "is not a matter of lining up 'for' or 'against' expertise, per se." As Brown (Chapter 23, this volume) points out, unknowing may at times take us to uncomfortable places. The author suggests that we "may have to unlearn much of what the individual 'experts' have told us, even if some of those 'experts' are ADHDers themselves." However, for meaningful change to be brought about in fields so dominated by pathology and deficit, it may be useful in this time of disruption to re-imagine inclusion as conditional inclusion *of* neurotypical researchers rather than *by* them (which, as Struyf et al. (Chapter 5, this volume) point out, brings us to the question of the "'thinness' of neurotypical-led conditionality"), and the parallel elevation of neurodivergent voices. Here, then, we would like to redefine inclusion, unknow its long-accepted sense, and re-read it: we can then conceive of inclusion within Neurodiversity Studies as meaning the inclusion of neurotypical scholars within neurodiversity research.

We can also think of troubling and resisting neurotypical academic norms from the perspective of unknowing. Several chapters (see ex Chapters 5, 16, 17, 18, this volume) have engaged (although not necessarily in these terms) with the complexities of navigating (neurotypical) academic norms. What they describe could be cast as a process of unknowing: first, learn to read and understand existing norms, and then, re-imagine those norms in ways that are a better fit with neurodivergent ways of being. Finally, communicate these re-imaginings to academic hierarchies—help them, in effect, to unknow what they had assumed to be fixed, immutable processes to see them as they could be rather than what they are. The winners, as those authors point out, are not just neurodivergent, but all students—this then becomes a form of institutional unknowing. Troubling neurotypicality is of course in synergy with a diverse range of fellow killjoys and troublemakers. For example, Goodley proposes the "common goal of disturbing those normative homelands that all of us are forced to populate" (Goodley, 2017, p. 194), an invitation to join forces, to share tools and frameworks. Neuro-queering, which "uncovers, upsets, and unsettles power structures in normative spaces" (Yergeau, 2013, p. 205), is also an ally here. Unknowing seems to us to hold powerful potential as we become aware of—and correct for—the risk of the "neurotypical gaze" (McDermott, 2022) in research processes.

Some methods described in this volume seem to intrinsically lend themselves to unknowing. Pearson and co-authors (Chapter 7, this volume) suggest that "the experience of collective knowledge production can lead us to unknow what we had 'known': we started to question our own biases, grow our knowledge and build bridges between different standpoints." This underlines the importance given to working across neurotypes, but also, importantly, across disciplines that has been a hallmark of both Neurodiversity Studies and Critical Autism Studies (and for the future directions of Critical ADHD Studies): "disciplinary silos," as Gross and McGoey (2023, p.3) point out, "can compound ignorance." This is not the creative ignorance of unknowing, but that ignorance which "confirms what is already known according to approved methods of knowing" within disciplinary silos (Halberstam, 2011, p. 6).

Phenomenology too offers much unknowing potential. Autistic feminist Joanne Limburg (2022, p.3) seeks to "try and find a language for all kinds of moments that make up human existence," considering "the accumulation of moments, however trivial they were in themselves, that can determine the course of a life." Finding a language for all kinds of moments also implies changing the questions asked (c,f. also Jones, 2022). Limburg suggests a move from "'How might we recognize you in our [neurotypical world]?' (In what way are you [neurodivergent]? How did they diagnose you? You don´t seem [neurodivergent] at all.)" into "How do you experience your world?" (Limburg, 2022, p 63). Shaughnessy et al. (Chapter 14, this volume) and Redmore (Chapter 15, this volume) align themselves with the field of phenomenological inquiries into neurodivergence (see Murray et al., 2023). They suggest both a systematic phenomenological approach to neurodivergence and a flexible approach, allowing for a range of ways for researchers to explore neurodivergence from the perspective of "inner experiences" rather than the "expressive signs" proposed and reproduced through research drawing on traditional diagnostic criteria.

We feel, then, that unknowing has the potential to be an integral part of a palette of foundational methodological approaches when working within Neurodiversity Studies. This necessarily implies a level of comfort with discomfort: trying to do new things comes with the risks of failure—indeed, in this volume we have encouraged contributors to describe their failures as well as their successes. But here too, we could think about unknowing: unknowing the very notion of failure. Autistic people, for example, have long been described through deficit, through failure to understand, to empathise, to fit into widely accepted system-level norms: the autistic person as "the disordered and damaged other" (Milton & Moon., 2012, p. 5). However, we could also turn this around, to think not of the failure of autistic (or otherwise neurodivergent) person, but of neurotypical, dominant norms as representing 'imperfect systems' that require challenging (Jackson-Perry, 2020). Halberstam (2011, p. 2) reminds us that:

> under certain circumstances failing, losing, forgetting, unmaking, undoing, unbecoming, not knowing may in fact offer more creative, more cooperative, more surprising ways of being in the world.

Finding surprising ways of being in the (research) world is one way of working towards the paradigm shift with which we started this section. While we have only sketched out, in this volume, some of the potential of unknowing for the field of Neurodiversity studies, we encourage you to set out to fail, to forget, to unlearn and relearn, as we move together towards a more epistemologically and ethically robust body of neurodiversity research.

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