CANADIAN JOURNAL OF

Disability Studies

Published by the Canadian Disability Studies Association · Association Canadienne des Études sur l'Incapacité

Canadian Journal of Disability Studies

Published by the Canadian Disability Studies Association Association canadienne d'études sur le handicap

Hosted by The University of Waterloo

www.cjds.uwaterloo.ca

ADHD in higher education and academia Le trouble déficitaire de l'attention avec hyperactivité dans l'enseignement supérieur et universitaire

Hanna Bertilsdotter Rosqvist, Ph.D. in Sociology
Assistant Professor in Sociology and senior lecturer in Social work
Södertörn university
hanna.bertilsdotterrosqvist@sh.se

Lill Hultman, Ph.D. in Social work
Senior lecturer in Social work
Södertörn university
lill.hultman@sh.se

Sofia Österborg Wiklund, Ph.D. in Education Postdoc in Education history Umeå university sofia.osterborg-wiklund@umu.se

Anna Nygren, Ph.D. candidate in Literary criticism
Adjunct in Literary composition
Åbo Akademi University and University of Gothenburg

Palle Storm, Ph.D. in Social work Senior lecturer in Social work Stockholm university

> Greta Sandberg Adjunct in Social work Södertörn university greta.sandberg@sh.se

Abstract

In this paper we explore our own experiences of barriers to learning and academic knowledge production in academia and higher education. Our analyses are based on our collective autoethnographical accounts from our own experiences of ADHD and higher education, with a particular focus on post graduate education and our experiences of ADHD peer support in academic knowledge production. In our analysis, we have distinguished between three different dimensions of academia for ADHD graduate students and faculty: as a place of structural violence and vulnerability; as enabling or disabling, and as a place for neurodivergent community formation. There are few ADHD-centered traditions of learning within education. By ADHD-centered we refer to perspectives within education and support informed by an ADHD insider-perspective. We therefore stress the possibilities of ADHD learning informed by the emerging field of critical ADHD studies.

Résumé

Dans cet article, nous explorons nos propres expériences face aux obstacles à l'apprentissage et à la production de savoirs académiques au sein des universités et de l'enseignement supérieur. Notre analyse repose sur des récits autoethnographiques collectifs issus de nos expériences universitaires en tant que personnes ayant un trouble déficitaire de l'attention avec hyperactivité (TDAH). Nous portons une attention particulière à nos expériences de production de savoirs académiques avec le soutien de pairs ayant un TDAH. Notre analyse a distingué trois dimensions du monde universitaire propres à la communauté étudiante et au personnel enseignant ayant un TDAH: le monde universitaire comme lieu de violence structurelle et de vulnérabilité; le monde universitaire comme espace habilitant ou handicapant; et le monde universitaire comme lieu de création de communautés neurodivergentes. L'apprentissage centré sur le TDAH est peu représenté traditionnellement dans le domaine de l'éducation. Le terme « apprentissage centré sur le TDAH » renvoie à des perspectives de l'enseignement et du soutien orientées par le point de vue de personnes ayant un TDAH. Nous insistons donc sur les possibilités qu'offre l'apprentissage orienté par le TDAH au sein du domaine émergent des études critiques sur le TDAH.

Keywords

ADHD peer support, ADHD learning, ADHD graduate students, ADHD faculty, neurodivergence, knowledge production, critical ADHD studies

Mots-clés

Soutien par les pairs pour le TDAH, apprentissage et TDAH, communauté étudiante aux niveaux supérieurs ayant un TDAH, corps enseignant ayant un TDAH, neurodivergence, production de savoirs, études critiques sur le TDAH

Introduction

This paper aims to shed light on some barriers to ADHD learning in higher education and ADHD academic knowledge production. We will explore and reflect upon the possibilities of finding alternative ways for ADHD learning and performing in academia and higher education. With this paper, we want to call for a renewed focus on ADHD in higher educational contexts, which do not focus on adapting ADHD students to neurotypical norms but enable and support ADHD learners and learning on their terms. This implies moving away from a deficit model of ADHD, which focuses on ADHD as a cluster of cognitive deficits, to embrace a formulation of ADHD within a neurodiversity paradigm, which focuses on ADHD as a cognitive difference (c.f.

Bertilsdotter Rosqvist et al, 2023), including strength-based and solution-focused approaches (c.f. Schrevel et al, 2016).

The level of education is significantly lower among people with disabilities compared to the rest of the population which is due to the fact that support is introduced too late and that students with disabilities feel more insecure than their non-disabled peers (Myndigheten för delaktighet, 2022). Access to accommodations in the form of disability support services can be critical to academic persistence and success in higher education for students with ADHD, among them postgraduate students with ADHD (O'Shea & Thurman, 2017). In accordance with the Swedish School Act (2010:800), medical diagnosis is not required to be entitled to adaptations or special support in primary school, but according to the Higher Education Act (1992:1434) and the Higher Education Ordinance (1993:100), a medical diagnosis is required to have access to special support and relevant adaptations at universities. According to the Swedish higher education institutions' annual reporting, the proportion of students who, due to their neurodivergence, were granted pedagogical support has increased every year. In 2019 there were a total of 20150 students with disabilities, among these 5491 were neurodivergent. In 2020 the corresponding numbers were 22912 and 6917 students respectively. In 2021 the total number of students with disabilities had risen to 26926, among which 21542 had been granted support as a result of their neurodivergence (Årsredovisning 2021). However, exploring the attitudes of university faculty in US universities, concerning ADHD, Buchanan et al (2010) note that irrespective of the age of faculty members in their study, ADHD had the lowest acceptance as a condition deserving special accommodations. Some faculty members attributed difficulties experienced by a student exhibiting ADHD symptoms to "bad character, a lack of discipline or a lack of motivation." (Buchanan et al, 2010). From the results, Buchanan et al (2010), stress that

more emphasis should be placed on disability-related education and training for faculty members, especially during the early stages of their careers.

Our analyses are based on our collective autoethnographic accounts from our own experiences of higher education, with a particular focus on learning as postgraduate students and our experiences of ADHD peer support in academic knowledge production. A large part of our autoethnography writing revolves around experiences of vulnerability, and the urge to mask, pass and fit into the surrounding environment, to protect ourselves from structural violence. We invoke the concept of structural violence, which can illustrate and question the role that structural, systematic, and organizational factors play in enabling structural violence in a particular environment, in our case the academic space (Galtung, 1969). Structural violence can include institutional, organizational, material, and symbolic means of social exclusion, and does not necessarily mean interpersonal discrimination. For example, this could include being pushed out of a workplace, being mocked or given the silent treatment, falling physically and/or mentally ill from minority stress, not accessing certain academic spaces, or having one's way of writing, learning, socializing, or working unjustifiably deemed as problematic. We understand structural violence as a factor for neurodivergent people to be subjected to minority stress to varying extents (Botha and Frost, 2020), requiring continuous masking of neurodivergent traits, and passing as neurotypical (Pearson & Rose, 2021) to navigate in academic spaces dominated by neurotypicals. Here, we use those concepts to illustrate e.g., the difficulty of "appropriately" regulating one's emotions, sharing of information, activity, or focus, or the stress of "getting caught" being unfocused, too talkative, and over-sharing, having too uneven knowledge and abilities, or appearing too messy for academic work.

The process of undermining a person's epistemic legitimacy as a "knower" can be understood as epistemic injustice, which can be divided into two distinct but interrelated forms of injustice: testimonial injustice and hermeneutic injustice that combined or separately contribute to undermining a person's credibility as an epistemic subject. Testimonial unfairness occurs when prejudice causes an audience to give a person's word low credibility; hermeneutic injustice occurs at an earlier stage when a gap in collective interpretive resources puts a person at a disadvantage when it comes to understanding and being able to express their social experiences (Fricker, 2007, p.1).

Theoretical background

Theorizing the neurotypical gaze, McDermott (2022) has invoked the term "neuroconventional". By this, she refers to "the norms and conventions of neurotypicality". McDermott shows how the neurotypical gaze "works to naturalize neuroconventional ideas" of ways of relating to other people, and by this "misses or altogether discounts the non-normative ways", such as neurodivergent ways of relating. Importing the ideas of the workings of the neurotypical gaze in educational and vocational support contexts, we argue that the neurotypical gaze in educational and vocational support contexts similarly "misses or altogether discounts the non-normative ways" of learning in postgraduate education and ways of doing research in academia but also is at risk of formulating support which altogether misses the target. Missing the target without a critical perspective of neurotypical epistemic authority, risk producing ADHD and the ADHD way of functioning as the problem, not the way support and teaching are formulated.

Peers in educational contexts are expected to give each other social support to support mutual learning processes (Kayama & Haight, 2012; Saline, 2021). In the case of ADHD students, neurotypical peers have been used as assisting teachers in the school environment (DuPaul et al, 1998). These neurotypical peers are commonly similarly aged, gendered, and neurologically differently disposed, where differences in neurological disposition (Milton, 2012) are expected and used as a way of trying to make ADHD students conform to neurotypical ways of being. For example, neurotypical siblings and peers are expected to support neurotypically desired social behaviours (Daffner et al, 2020) including teamwork skills (Watkins & Wentzel, 2008; Malik & Sime, 2020). Similarly, coaching in vocational contexts is commonly provided by a neurotypical coach. For example, Swartz et al (2005) illustrate how a neurotypical ADHD coach is expected to:

Empowers individuals to organize and execute their responsibilities in academia and everyday life. With the assistance of a coach, individuals with ADHD can create structure and execute change by identifying strategies that circumvent their deficits in executive functioning. (Swartz et al., 2005, abstract)

However, with neurotypical ADHD coaching comes neurotypical norms which are expressed through interpretative privilege and epistemic authority. Epistemic authority is defined by Oikkonen (2013, p. 284) as 'the belief that the proposed account is the most accurate one'. In a condition as highly medicalized as ADHD, whose symptoms are defined and explained in diagnostic manuals, it follows that the testimony that most likely is assumed to be the most accurate one and holds the highest level of credibility when talking about ADHD, and publishing texts derive from medical science and a neurotypical perspective (c.f. Fricker, 2007). For example, Versteeg & te Molder (2016) have shown how neurotypical ADHD coaches "present their own bodily sensations as indicative of their client's inner state". From the coaches'

perspective, difficulties associated with ADHD are viewed as a "result of unproductive routines or thought processes" (Versteeg & te Molder, 2016). Exploring experiences of coaching from the perspective of ADHD clients, Schrevel et al (2016), stress both the importance of a "strength-based and solution-focused approach", but also coaching as a "joint venture" between coach and client. (Schrevel et al, 2016).

Coaching from a strength-based and solution-focused approach may be viewed as more helpful than deficit and behavioural symptom-centred approaches. However, when the coach's neurotypicality is given the epistemic privilege, i.e., taken as a for-granted perspective when trying to interpret their ADHD clients' experiences, transforms into epistemic injustice in which outsider- rather than insider perspective/experience-based knowledge of ADHD is given epistemic authority. Instead of validating ADHDers' own experiences, the neurotypical gaze (Mc Dermott, 2022) could permeate a situation in which ADHD difficulties as experienced by ADHDers themselves are being belittled, and ADHD is viewed as a cluster of (visible) behaviours or set of impairments, where interventions aim at adapting ADHDers to neurotypical norms, rather than validating ADHD as a different way of functioning.

In the contexts of psychoeducation (Lantz et al, 2021) or group therapy (Meyer et al, 2020) aimed at children and adolescents with ADHD, the importance of peer support between neurologically similarly disposed (ADHD) peers has been stressed. In these settings children and young people with ADHD can meet other ADHDers, share experiences, support each other in the development of self-help skills, and not feel alone (Lantz et al, 2021; Meyer et al. 2020). But outside of these contexts, teaching and support from an ADHD insider perspective are lacking in research. The knowledge and needs of people with an insider perspective are often ignored because people with their own experience are discredited in the role of being an epistemic

subject/"knower", resulting in a lack of recognition of being experts in their own lives and ways of functioning (Fricker, 2007; Botha, 2021).

Work process

We started this project departing from a shared experience of ADHD, albeit in different ways. Some of us have a formal ADHD diagnosis. Some of us are formally diagnosed with ADHD but also acknowledge our autistic traits. Some of us are autists but also acknowledge our ADHD traits. Some are predominantly inattentive, some hyperactive, and some both. For some of us, ADHD is an integral part of our identity. Some of us are late diagnosed, where neurotypicality and neuronormativity have left wounds on our physical and mental health. Some of us have been subjected to bullying, ostracism and ridicule in work life. Some of us have had to fight for regaining health and the ability to remain in work life. Some of us have a history of explicitly targeting structures of power regarding neuronormativity, dis/ability, and the promises of neurodiversity. For others, these experiences have not been as obvious, or un-reflected. Some of us have experiences of forming alliances and support from other neurodivergent teachers and peers, some also from neurotypicals.

We came to this project with different identities and positionalities concerning gender, sexuality, race, and class backgrounds, and with different research focuses/interests. We are located within academia across disciplines and different academic positions (Literary Criticism/Literary Composition, Education, Social work, and Sociology) and geographical contexts within Sweden. Likewise, our academic positions differ, from adjunct, Ph.D. student, postdoc, and senior lecturer. This implies that we have different experiences of oppression from different levels and times in our careers – different positions might experience different versions

of academia, as well as different forms of oppression. Albeit in this paper we have chosen to focus on our experiences as learners during research education. Coming from different positions might, of course, also influence our relationship within the group and what we feel is possible to share, however; working primarily text-based has made it possible to maintain a certain kind of safe space and anonymity within the group — while also being aware of us having different academic positions and statuses. We all have in common, albeit to a different extent, an emancipatory commitment to academic activism for social justice, e.g., through feminist, anti-racist, postcolonial, queer, or other approaches. Some of us are well versed in the concepts and theories this article is based on, but to some, the perspectives were new. We are professionally and/or socially connected in different ways — some of us know each other, and some are new acquaintances. This is the first time we work together as a group.

Throughout, we mingle our collective autoethnographic accounts with research accounts and theories, as a way of illustrating the work with the text as thinking about ADHD with each other in itself. We have chosen to refer to our autoethnographic voices in the text with a collective "One of us". This is a way of stressing the text as written in a collective space, the collective "I" as "One of us". "One of us" is also used as an expression of a "joint action" which feminist researchers Francis and Hey (2009), have stressed as a "core to feminist action over the years" but in particular within academia" where "joint action counter-narrate the position as "individual experts". The use of a collective I, is a way to counter-narrate the image of "the sole", individualized neurodivergent, and rather stress the presence of a neurodivergent togetherness but also to protect ourselves against structural violence and position ourselves—as a neurological minority (stigmatized) selves.

The project arose out of discussions between three of the authors of their interest in coming together and developing the emerging field of critical ADHD studies, responding to calls for ADHD-led research on ADHD (Meadows, 2021, Dieuwertje Huijg, 2021). The initial discussion around this text and during the ongoing co-working with the text made it visible to us how we all have had different experiences of working not only with concepts and theories within the broader fields of critical autism studies or neurodiversity studies (ed Bertilsdotter Rosqvist et al, 2020) but also different experiences of working with our lived experiences and acknowledge them as a source for creating knowledge and/or as a tool to do research and to generate new knowledge.

We use a collective autoethnographic method, which we refer to as ADHD collective storytelling (c.f Jackson Perry et al, 2020), or our "ADHD stories", to restory ADHD.

Throughout our collective autoethnographic we explore ADHD both from an individual and collective point of view and in relation to research accounts and representations of ADHD we have encountered in the Swedish context. Our data include our autoethnographic writings, but importantly, firstly, we stress the importance of the context of writing (c.f. Bertilsdotter Rosqvist & Jackson Perry, 2021); we are writing to and being read by each one another; another person with personal experiences of ADHD albeit in both similar and different ways. Secondly, our autoethnographic writings are being produced in an iterative writing process (c.f. Jackson Perry et al, 2020); we have written our autoethnographic writings in a continuous response to each other's writing. As an add-on to the writing, we also met up a few times in the online meeting space Zoom and discussed our experiences of ADHD and the writing process. Through this collective storying, we have explored our experiences of the world from our different situated

knowledges (Harding, 1991) of ADHD, our different ADHD perspectives, encountering each other's storying, a gradual re-storying of our experiences emerged.

Results

In our analysis, we have distinguished between three different dimensions of academia for ADHD graduate students and researchers: as a place of structural violence and vulnerability; as enabling or disabling, and as a place for neurodivergent community formation.

Vulnerability and structural violence in Academia

Among the risks of structural violence in psychosocial aspects of higher education are risks of involuntary unmasking. Coming to higher education with an ADHD way of functioning means an increased vulnerability including being at risk of involuntary unmasking (when you don't choose for yourself whether to unmask, i.e., display your ADHD or not). This is illustrated by the two of us below with narratives of being at risk of "having the mask torn off in front of everyone else" and the sense of being cautious, to be constantly on your guard in order not to unmask involuntarily.

Despite the fantastic intellectual world that has become mine, and which I loved from the very first moment, I still live with a deep sense of anxiety and worry. The "neurodivergent imposter syndrome" follows me like a shadow and makes me question everything I take for real. If this fantastic world is really mine, or if I belong to it. The threat of being exposed, of having the mask torn off in front of everyone else, eats up large holes in the otherwise hyper-fragmented world which I simultaneously feverishly try to piece together to understand. (One of us)

I both love and hate the academic space. I love it because it allows me to enter the world of analysis and because it gives me the opportunity to meet both students and other researchers who fill me with energy. But at the same time, I am constantly on my guard, what can I say, how can I say something, and how is what I have said perceived? For several days I can linger on something I said in a seminar context — a bit like an open wound that you always have to touch, even though you know it does not heal, the

unspoken can never be left unsaid, and I cannot be responsible for others' interpretations of what I have said. I know it but do it anyway. (One of us)

Another expression of structural violence is the experience of being objects of undergraduate teaching where our way of functioning is constantly described and taught from an outsider's perspective.

I think that both [another one of us] and I read about ADHD/neuropsychiatric diagnosis as part of our undergraduate training, and it wasn't directly that nuanced, but rather stereotypical images of what it means to live with a neuropsychiatric diagnosis (One of us)

However, choosing to voluntarily disclose our ADHD put us in another vulnerability due to the same stereotypical images of what it means to live with ADHD. To get the necessary accommodations, one's way of functioning must be framed within the deficit model of ADHD, rather than within a neurodiversity paradigm. But it also creates the need to repeatedly prove one's epistemic legitimacy, despite one's assumed deficits due to ADHD. This is illustrated in the following extracts.

From my time as a doctoral student, I sometimes got the feeling that any shortcomings (e.g., regarding texts, something you missed, etc., etc.) were interpreted as depending on my ADHD diagnosis, and not as depending on events that had nothing to do with it at all. For me, it meant that the room for action to "dare" to fail was severely limited. (One of us)

I've been mocked. Sitting there in the seminar rooms at the university and in front of a general audience get to know how bad I write, how bad I spell, and that I probably also have dyscalculia. I have tried to say to myself that I will not be sad. But probably I'm the perfect person to push to, or I have let others do it to me. I've been thinking a lot about why I let it happen. This is how I realize after my doctoral studies how much I allowed myself to endure - and why I became a target for certain comments that were unthinkable to say to other doctoral students. I think I took on the role as a way to survive, if you are used to always coming last, always being the one to pep everyone else, then you get locked up. (One of us)

I felt pushed out of a previous workplace. I felt important in the beginning. Then everything started to crack, and I fell. When I got my diagnosis, I could finally get

adequate help. But by then it was too late. I wasn't invited to participate in projects, meetings, social events, or pretty much anything anymore. It didn't help I finally performed flawlessly. They were ignoring and out-phasing me. Then my employment silently ended. (One of us)

In a similar vein, students with ADHD can also be exposed to epistemic injustice on a structural level. Hookway (2010) argues, that if someone fails to be taken seriously in their contributions to joint epistemic inquiry due to forces of oppression (i.e., such as through mechanisms of stereotypes or prejudice), an epistemic injustice occurs. When one is not taken seriously as a participant in inquiry, one can lose self-trust and hesitate to contribute to collective epistemic resources. When one's questions are ignored, one may even develop a habit of silencing oneself, not asking relevant questions to forward scientific knowledge production and scientific ways of knowing (Grasswick, 2017).

Informed by autistic scholar Damian Miltons (2012) notion of the "double empathy problem", Meadows (2021) notes in a critical ADHD studies context "...where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum [of dispositional diversity]". Concerning this, one of us writes to an imagined neurotypical audience:

It's not that we're incapable or deficient, but that your linear ways, your love of stillness and restraint, just don't work for us. It's not that our brains are wrong, but that you are in a position to call yourself right. (One of us)

From our experiences unmasking takes both courage and energy and places the responsibility primarily on the ADHDer rather than the environment. In the worst case, it may result in losing one's epistemic legitimacy as an emerging scholar. One of us refers to their experiences of their needs of adaptations not being taken seriously, being met by statements such as: "We all have a

whiff of ADHD" or "Yes, this is hard for me too", because they have not fitted into the "rather stereotypical images" of ADHDers.

To get support, the ADHDer has to describe the lived experience of ADHD with an emphasis on problematic situations, those descriptions can easily be ignored by the hearer when the co-worker with ADHD has not caused "any problem" in relation to professional performance at work. In situations like these, it becomes nearly impossible to ask for adaptations without having to "talk about" private life, since coping at work without proper adaptations can negatively affect tasks that need to be performed at home in everyday life, such as household chores. This preconception of what ADHD is like rather tends to reinforce the polarized positions of what can be referred to as "the superpower narrative" and "the deficit narrative", which also contribute to difficulties in unmasking at an individual level. This situation exemplifies a double-bind situation (c.f. Watzlawick, 1963) since the student or researcher in a subordinate position is unable to leave the situation and also put themselves in a position where they risk failing a course or being labelled as difficult to cooperate with.

¹ In Sweden ADHD as a "super power" was populized 2017 when the Swedish, white, young "super blogger and artist", Viktor Frisk, published his authobiography *Min superkraft! : så har jag lärt mig älska min struliga adhd* (Eng: *My super power! : that's how I've learned to love my messy ADHD*). In its wake followed a whole wave of bloggers and podcasts that reinforced the image of ADHD as a superpower. While positively received by several ADHDers in Swedish social media, the most dominating Swedish NGO within the ADHD advocacy movement *Riksförbundet Attention* (Eng: The National Association for People with Neuropsychiatric Disabilities) has stressed that "ADHD is far from a superpower for everyone". Riksförbundet Attention. "ADHD långt ifrån en superkraft för alla". Aktuellt, Debatt / Administratören Published 2019-11-05. https://attention.se/2019/11/05/adhd-langt-ifran-en-superkraft-for-alla/ Downloaded 221011

In addition, ADHDers and neurotypical co-workers may communicate differently. For example, when the neurotypical co-worker, says, "We all have a whiff of ADHD", it could be interpreted as validating the relationship, (i.e., we are similar, I can relate to what you say), which becomes a problem when the ADHDer wants to address the issue of having difficulties due to person - environment misfits. This power imbalance between trying to convey one's lived experience of ADHD and not being heard (testimonial injustice) contributes to maintaining structures that may hinder ADHD academics to get proper adaptations due to the discomfort of making themselves vulnerable by exposing themselves.

Attempting to propose a shared experience has the potential for both harm (erasure), on the other hand, it can offer liberation, recognition of disability, and access needs, i.e., accepting that ADHD is on a spectrum can contribute to questioning the binary dis/abled category scheme.

Dis/abling Academia

Being asked to participate in a research project could be a "fast track" into an academic career. Nevertheless, it can become complicated when the protegee (a neurodivergent Ph.D. student) does not follow the expected path due to an uneven talent, where some parts of the research process can become hard to do due to lack of motivation or an inability to regulate focus and concentration when certain tasks become tedious - what can be referred to as challenges of boredom (c.f. Hallowell and Ratey, 2021). Unlucky enough, this could also happen to tasks and texts that are interesting or important, depending on the daily form, amount of sleep, food intake, excitement, anxiety, depression, or other intervening circumstances.

I thought that the academy was a closed chapter for me because I did not want to finish writing my master's thesis. Initially, it felt like a meaningful project, and I set about constructing a survey which, to my supervisor's delight, received a very high response rate. While he was happy, I started to get bored. When I understood that the analysis

consisted of giving an account of various statistical relationships, the resistance became too great. It was so boring! All my energy disappeared. My supervisor tried to motivate me in every way. Unfortunately, this made me even more unmotivated, and I never finished writing the essay. But when I was accepted as a PhD student, it was a different story. The difference this time was that it was for a project and topic that I chose myself, a topic that I am passionate about. (One of us)

One thing that bothers me is the idea of ADHD as laziness or as being spoiled. I remember once, I was handed a task and told that "This will be a good opportunity for you to practice not only doing things you enjoy." I felt so blamed and shamed. Nobody had a clue how much I practised doing things I didn't enjoy, how hard I tried to regulate my focus and concentration to understand what I was reading or hearing, and how hard I tried to hide my difficulties. (One of us)

Sometimes it is not the actual task itself that is hard to do – it is the process of getting started (and also the ability to finish and not fly away in an endless hyper-focused flow, resulting in a crash). However, it can also be the task itself, e.g., an administration that many people can experience as boring, but which for ADHDers can be difficult to do due to difficulties to focus and understanding what one is reading or hearing. Having an uneven ability can be concealed in the research process, and in the end, it is the final product that counts, e.g., a completed PhD thesis, or a publication in an international peer-reviewed scientific journal:

During thesis time, I could wallow in my bubble – bad days didn't matter much, because I knew that soon the good days would come. In the world of articles and writing, I could go inside myself and shut off what was outside. I knew that as long as I met the deadlines, I would be kept (One of us).

Closely associated with the uncertainty of good and bad days, some of us write about the uncertainty of expectations, what a 'normal capacity' could be, or what would be reasonable to perform in terms of productivity. In contrast to the challenges of boredom, some of us experience an ability to speed up the pace at certain tasks and at certain times. At the same time, one may not know or find it difficult to set limits for oneself. Here an uncertainty of what others may wish that you should perform puts you in a vulnerable position.

I don't know if it was really like that, but I could feel that my co-workers said other things to me than they said to other PhD. students. I could also feel that they put more pressure on me, precisely because they knew that I rarely if ever objected in the way that I think the others [PhD. students] did (One of us).

An experience that differed significantly among us, was our participation in synchronous meetings, seminars, and other interactive, academic forums. We both found it as facilitating (matching our abilities, building upon our strengths) and as disabling experiences, although for different reasons. For example, they could be exciting for allowing an opportunity to discuss important topics which we found engaging, but they could also provoke anxiety and frustration:

Meetings and seminars have for me sometimes been a championship in masking and guessing. Several threads of discussion flow at the same time, and I perceive detached fragments that flow freely, and that I have to try to put together. When it's my turn to speak, I have to, with the pressure of fluorescent lights and everyone's eyes on me, try to formulate a stringent contribution, while simultaneously hiding if I potentially haven't understood everything. A lot of thoughts, questions, associations, and arguments come out all at once, which I then have to try to tie together into some kind of understandable conclusion. Working memory and central coherence are stretched to their limits. When younger, I often ended up just dropping all pieces to the ground and falling silent, while the others stared at me uncomprehendingly. It has taken me years to master this ability. (One of us)

My experience is almost the exact opposite. When I am at meetings, I am hyper-focused and perceive all threads and quickly tie them together in my head. My feeling is that most others are unfocused, repeating themselves and others without referring to the person who already said it, etc. I take it as no one can hold the common thread, the wheels are constantly replenished, etc. It's extremely tiring for me but if I say something I'm afraid of sounding arrogant. (One of us)

For me, it's the "easy" that is complicated and the "complicated" is easy. For example, different kinds of job meetings. (...) I see patterns, the holistic when others don't. But when it comes to getting to the meeting in time I fail while everyone else is there. (One of us)

Thus, experiences of structural violence are different and contextual. In the example of meetings and seminars, such interactive and unstructured academic forums can be dis/abling: enabling for some of us and disabling for some of us.

Creating neurodivergent communities

A central drive in our writing process has been the longing for leaving the loneliness of the sole ADHD, similar to the sole autist (c.f. Sinclair, 2010), or what one of us has referred to as the individual "broken neurotypical", and instead form a collective, neurodivergent togetherness. Within this togetherness we have sought to explore our ways of learning, focusing on our learning during our research education. Wenger (1998) points out, key components of learning entail community building that draws on different but interrelated aspects such as a joint enterprise, a mutual engagement, and a shared repertoire. In our joint process of learning as a neurodivergent collective, we have explored our sometimes competing ideas of "what matters in this particular group", while at the same time, we have sought to enable collective learning. One of us writes:

I'm terrified and I don't know why. That's what I'm most afraid of. When I saw the recording of the meeting, I felt love. (...) But I'm home, I thought. Finally, home. I started reading your texts. Felt even more of that; warmth, recognition, laughter, and sadness (always a sadness too). The response was immediate and self-evident. I just wanted to answer you. Your texts want answers. No right or wrong answers. Just answers from others who know. Then other voices came to me, and as always; the demanding. It is the worst. Worse than the doubting, arguing, ambivalent. The one who demands. That's when I start to protest. (One of us)

Creating a neurodivergent community also means creating new forms of beings: an unlearning of previous knowledge about sociality, self, and community:

[One of us] wrote to us before that first meeting "Hopefully none of us will have to deal with any masking". I was completely taken aback. Never has anyone asked me or anyone else to unmask. I don't think I even had any idea that there were people who actively examined and dismantled their neurotypical mask and built neurodivergent sociality. I had no idea at all what something like that could mean. "How did that feel?" my psychologist wondered. Then I almost started to cry, because there were such ambivalent feelings. Relief at not expecting neurotypicality. The grief of not knowing who you are beyond the mask. Fear that there isn't even anyone behind the mask. Or that they are too

much, too little, or too difficult to deal with. Frustration because it was so much to ask, so intimate and so unmanageable, to unmask for the first time with people I hadn't gotten to know yet. (One of us)

Hence, the working process has for many of us been a realization of one's self-restrictions and internalized ableism, expressed through e.g., masking, and the actual possibilities of creating something beyond deficit definitions of ADHD ways of being.

Conclusion

The academic interest in ADHD in higher education has focused on ADHDers as undergraduate learners. Research focusing on peer support to ADHDers has foremost taken place in the context of work outside of academia, directed at children and young people and from the perspective of peer support from similarly aged, but differently neurological disposed peers. In the findings, we have discussed our experiences of research education and learning to become researchers processes that might, in this and other contexts, have different implications. Being a researcher traditionally means producing knowledge, while learning means absorbing it. There are several questions to be posed here, for future research to further explore: What is the object of learning – what are we meant to learn or know? We have touched upon both the impact of the specific knowledge about ADHD and the diminished position of the neurodivergent as an epistemic subject (c.f. Fricker, 2007; Botha, 2021). Academia, however, also includes other kinds of knowledge and learning. This includes knowledge about academia and academic structures and processes. From our experience, ADHD influences the perception also of these not specifically ADHD-related knowledge. That means; ADHD learning might be informed by ADHD research since there are few ADHD-centred traditions of learning within academia. By ADHD-centred we refer to perspectives within education and support informed by an ADHD insider perspective.

We have in this paper sought to both map out barriers and start to carve out alternative ways for ADHD being, learning, and performing in research educational contexts.

Some of us have experienced ambivalent feelings about our collective and individual identity formation as ADHDers. Partly this ambivalence stems from our experiences of being schooled within academic traditions such as Sociology and Education, which in the Swedish context are commonly framed by diagnose critical perspectives on ADHD (c.f. Lassinantti, 2014), stressing ADHD as a mere medicalization of societies and individuals (see e.g., Conrad, 1976; 2017). However, in contrast to these perspectives, Versteeg et al (2018) have stressed the importance of acknowledging the role of and relation between experiential knowledge ("lay expertise" and "activists") and professional knowledge (or "scientific" or "professional expertise"), but also how different speakers and recipients compete for the right to own meanings of ADHD. Similarly, Rapp (2016) has pointed out an "epistemological gap among medico-scientific, familial and advocacy visions of human brains" in the context of ADHD, which, however, "provides a mobile space of creativity as well as misunderstanding" (Rapp, 2016). Following Versteeg et al (2018) we stress the importance of acknowledging ADHDers (not ADHD) as agents, enabling ADHD standpoints and epistemic agency, and the importance of a community talking back. However, we also, in line with recent debates within autism studies (Botha, 2021), want to blur the distinction between experiential knowledge and professional knowledge. Within our academic and experienced-based collective, we explored ways of reframing our experiences of ADHD in its very different forms, from both experiential and expert knowledge perspectives, as well as from the perspective of recognition, not othering.

The formulation of the group has had its challenges. We live with different temporalities, workload expectations, and needs for (non-)structure. This has also created a special kind of textbased collectivity. Seeing our approaches to reading and writing reflected and recognized in each other has had an affirmative and empowering effect. It has made us emotionally involved in this project, which is something we want and need to be open with. We do not consider ourselves as neutral but personally engaged, writing from a position where we suggest that the knowledge about us should come from within – "nothing about us without us". We are a research group, and a support group, of ADHD peers. Part of our working together is to support each other's ways of learning and researching, from an ADHD-affirmative perspective. This means we share experiences of living with ADHD in a neurotypical world. We come from different academic fields – but we share the experience of academic environments dominated by neurotypicals. This group is not constituted as a neurotypical-coaching relationship. The support thus does not mean teaching/learning to adapt to neurotypical ways of learning, instead, it sets out a route for sharing, and in the sharing process, finding how we have been experiencing different forms of epistemic and structural violence. Knowing when one has been experiencing epistemic violence is not always evident. The violence is often subtle (though sometimes not) and often masked as a kind of neurotypical caring. As ADHDers, we have also internalized this violence, learned to take it for granted, and accepted it. The research process has therefore also become an empowering process in itself; where we have learnt from and recognized ourselves in each other, but also acknowledging both our similarities and differences in strengths and difficulties. Sharing our experiences and recognizing ourselves in each other has made it a bit clearer how we function in the academic world and when and how the academic world (doesn't) function for us,

Bertilsdotter Rosqvist et al, ADHD in higher education and academia *CJDS* 12.3 (November 2023)

as well as findings ways of handling that, and forming alliances. Sharing has also meant discovering academic strengths in ADHD ways of functioning.

References

- Bertilsdotter Rosqvist, H., Chown, N. & Stenning, A. (Eds.). 2020. *Neurodiversity Studies. A New Critical Paradigm*. London: Routledge.
- Bertilsdotter Rosqvist H., Jackson-Perry D. (2021). Not Doing it Properly? (Re)producing and Resisting Knowledge Through Narratives of Autistic Sexualities. *Sexuality and Disability*, 39(2), 327 344
- Bertilsdotter Rosqvist, H., Hultman, L., Österborg Wiklund, S., Nygren, A., Storm, P. & Sandberg, G. (2023). Intensity and variable attention: Counter narrating ADHD, from ADHD deficits to ADHD difference. *British journal of social work*.
- Botha M. (2021). Academic, Activist, or Advocate? Angry, Entangled, and Emerging: A Critical Reflection on Autism Knowledge Production. *Front Psychol*, 12(4), 196.
- Botha, M., & Frost, D. M. (2020). Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population. *Society and Mental Health*, 10(1), 20–34.
- Buchanan, T., Matt, S., Rigler, M. & Hart, C. (2010). Why are older faculty members more accepting of students with attention-deficit hyperactivity disorder? A life-course interpretation. *International Journal of Disability, Development and Education*, 57(4), 351-369.
- Daffner, M.S., DuPaul, G.J., Kern, L., Cole, C.L. & Cleminshaw, C.L. (2020). Enhancing Social Skills of Young Children With ADHD: Effects of a Sibling-Mediated Intervention. *Behavior Modification*, 44 (5), 698-726.
- Dieuwertje Huijg, D. (2021). ADHD whiteness: An exploration of the (absent) role of race in adult ADHD research. Panel 4: "ADHD & Race" Flipped webinar (9/Jul/21): *Intersectional Approaches to Disability and Race*. https://intersect-nd-disrg.wixsite.com/rg-site/huijg-adhd-whiteness. Downloaded Jul 28, 2022
- DuPaul, G.J., Ervin, R.A., Hook, C.L. & McGoey, K.E. (1998). Peer tutoring for children with attention deficit hyperactivity disorder: Effects on classroom behavior and academic performance. *Journal of Applied Behavior Analysis*, 31(4), 579-592.
- Francis, B. & Hey, V. (2009). Talking back to power: snowballs in hell and the imperative of insisting on structural explanations. *Gender and Education*, 21(2), 225-232
- Fricker, M. (2007). *Epistemic Injustice: Power & the Ethics of Knowing*. Oxford University Press, Oxford
- Frisk, V. & Gahne, M. (2017). *Min superkraft!* : så har jag lärt mig älska min struliga adhd [eng: My super power! : that's how I've learned to love my messy ADHD]. Stockholm: Forum.

- Galtung, J. (1969). Violence, Peace and Peace Research. *Journal of Peace Research*, 6(3), 167-191.
- Grasswick, H. (2017). Epistemic injustice in science. In Ian James Kidd, José Medina, and Gaile Polhaus, Jr, (Eds). *The Routledge Handbook of Epistemic injustice* (pp. 313–323). London and New York: Routledge.
- Hallowell, E.M. & Ratey, J.J. (2021). ADHD 2.0: new science and essential strategies for thriving with distraction-from childhood through adulthood. New York: Ballantine Books.
- Hookway, C. (2010). Some variations of epistemic injustice: Reflections on Fricker. *Episteme*, 7, 151–163.
- Harding S. (1991). Whose Science? Whose Knowledge?: Thinking from Women's Lives. Ithaca, N.Y. Cornell Univ. Press.
- Jackson-Perry, D., Bertilsdotter Rosqvist, H., Kourti, M. & Layton Annable, J. (2020). Sensory strangers: travels in normate sensory worlds. In *Neurodiversity Studies*. *A New Critical Paradigm*, Bertilsdotter Rosqvist, H., Chown, N., Stenning, A. (Eds.). London: Routledge.
- Kayama, M. & Haight, W. (2012). Cultural sensitivity in the delivery of disability services to children: A case study of Japanese education and socialization. *Children and Youth Services Review*, 34(1), 266-275.
- Lantz, S., Fornwall, C., Lööf, M. & Isaksson, J. (2021). SKILLS A psychoeducational group programme for children with ADHD. *Scandinavian Journal of Psychology*, 62(4), 460-467.
- Lassinantti, K. (2014). *Diagnosens dilemman: Identitet, anpassning och motstånd hos kvinnor med ADHD* (eng: The Dilemmas of Diagnosis: Identity, Adaptation and Resistance among Women with ADHD), unpublished Ph.D. Thesis, Department of Sociology, Uppsala university.
- Malik, M. & Sime, J. (2020). Preparing teams of neuro-typical and neuro-atypical students with a computer orchestrated group learning environment for collaborative work: A multi case study. *SEFI 48th Annual Conference Engaging Engineering Education*, Proceedings, 962-973.
- McDermott, C. (2022). Theorising the neurotypical gaze: autistic love and relationships in The Bridge (Bron/Broen 2011-2018). *Medical humanities*, 48, 51-62.
- Meadows, J. (2021). We Need Critical ADHD Studies Now.

 https://jessemeadows.medium.com/we-need-critical-adhd-studies-now-52d4267edd54.

 Jul 5, 2021. Downloaded Jul 28, 2022

- Meyer, J., Öster, C., Ramklint, M. & Isaksson, J. (2020). You are not alone adolescents' experiences of participation in a structured skills training group for ADHD. *Scandinavian Journal of Psychology*, 61(5), 671-678.
- Milton, D.E.M. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society*, 27(6), 883-887.
- Myndigheten för Delaktighet (MFD) (2022). Utbildning. <a href="https://www.mfd.se/resultat-och-uppfoljning/kunskapsunderlag/utbildning/#:~:text=Bland%2030%E2%80%9364-%C3%A5ringar%20med%20funktionsneds%C3%A4ttning%20har%2033%20procent%20eftergymnasial,vanligare%20att%20unga%20med%20funktionsneds%C3%A4ttning%20hoppar%20av%20gymnasiestudierna. Retrieved: 2023-05-18.
- O'Shea, A. & Thurman, S.K. (2017). Perceptions of How Doctoral Students with Learning Disabilities and ADHD Use Disability Services. *Advances in Neurodevelopmental Disorders*, 1(3), 149-157.
- Oikkonen, V. (2013). Competing truths. Eur. J. Engl. Stud. 17, 283–294.
- Pearson, A. & Rose, K. (2021). A Conceptual Analysis of Autistic Masking: understanding the narrative of stigma and the illusion of Choice. *Autism in Adulthood*. 3(1), 52-60.
- Rapp, R. (2016). Big data, small kids: Medico-scientific, familial and advocacy visions of human brains. *BioSocieties*, 11 (3), 296-316.
- Saline, S. (2021). Thriving in the New Normal: How COVID-19 has Affected Alternative Learners and Their Families and Implementing Effective, Creative Therapeutic Interventions. *Smith College Studies in Social Work*, 91 (1), 1-28.
- Schrevel, S.J.C., Dedding, C. & Broerse, J.E.W. (2016). Why Do Adults With ADHD Choose Strength-Based Coaching Over Public Mental Health Care? A Qualitative Case Study From the Netherlands. *SAGE Open*, 6 (3).
- Sinclair, J. (2010). Cultural commentary: Being autistic together. *Disability Studies Quarterly*, 30.
- Skollag [Swedish School Act] 2010:800.
- Swartz, S.L., Prevatt, F., Proctor, B.E. (2005). A coaching intervention for college students with attention deficit/hyperactivity disorder. *Psychology in the Schools*, 42 (6), 647-656.
- Versteeg, W. & te Molder, H. (2016). What my body tells me about your experience: 'My side' empathy formulations in ADHD coaching sessions. *Journal of Pragmatics*, 105, 74-86.
- Versteeg, W., te Molder, H. & Sneijder, P. (2018). "Listen to your body": Participants'

Bertilsdotter Rosqvist et al, ADHD in higher education and academia *CJDS* 12.3 (November 2023)

alternative to science in online health discussions. *Health (United Kingdom)*, 22(5), 432-450.

Watkins, D.E. & Wentzel, K.R. (2008). Training boys with ADHD to work collaboratively: Social and learning outcomes. *Contemporary Educational Psychology*, 33(4), 625-646.

Watzlawick, P. (1963). A review of the double bind theory. Family Process, 2(1), 132–153.

Wenger, E. (1998). *Communities of Practice. Learning, Meaning and Identity*. Cambridge: Cambridge University Press.

Årsredovisning pedagogiskt stöd. 2021. https://www.su.se/om-universitetet/universitetsfakta/%C3%A5rsredovisningar