

Including the Voices of Children with ADHD: An Invitation to Disrupt Normalcy

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Abstract

This paper shares knowledge of ADHD gathered from children's experiences and uses it to inform others. To do the supporting study, I leaned on the New Sociology of Childhood and on Critical Disability Studies and used a qualitative approach with an ethnographic lens. The findings show: (a) the knowledge children have of ADHD is connected to how it manifests in their lives; (b) lack of understanding from others may impact children with ADHD's self-concept; (c) making friends is difficult for children with ADHD; and (d) children with ADHD can offer valuable information on how others can understand them better.

Key words

children with ADHD, children describing ADHD, Critical Disability Studies, Disability Justice, the New Sociology of Childhood, research with children

Author Biography

Rory Vale has been working in the Early Childhood Education Sector for over ten years. She has had direct classroom experience with preschoolers and taken on leadership roles. She holds a bachelor's degree in psychology and a Master of Arts in Early Childhood Studies. Having ADHD herself and having a child with ADHD have motivated her to write her Master's Research Paper on (and for) children with ADHD, in hopes of amplifying their voices and facilitating their understanding by others.

Including the Voices of Children with ADHD: An Invitation to Disrupt Normalcy

Attention-Deficit/Hyperactivity Disorder (ADHD) has been extensively described over the years from a medical standpoint. Medical research defines it as a *neurodevelopmental* disorder that starts during childhood and characterises it as an “imperfection” of the brain that leads to various levels of “impairments” on executive functions, including attention and emotional regulation (Barkley, 2020). Research shows that an average of 7.6% of children have a diagnosis of ADHD globally and that this number is increasing (Salari et al., 2023). In Canada, data from 2018 shows the general prevalence of ADHD is estimated at between 5–9% for children and adolescents (CADDRA, 2018).

The high number of diagnoses and the scientific evidence for the benefit of early intervention (Miller et al., 2023) inspires researchers from all around the world to pursue studies about children and ADHD. Despite the multitude of publications that are available (see for example Barkley, 2005, 2014, 2016, 2020, 2022; Hallowell & Ratey, 2021) and the medical knowledge that is disseminated (for example, American Psychiatry Association, 2013; Wilens & Spencer, 2013), there is a key element to understanding this “disorder” that has been given little attention: what children with ADHD know about it based on their lived experiences. This knowledge and these experiences could play an important role in reframing the way ADHD is collectively perceived and decreasing the negative labels commonly placed on it.

The purpose of this study is to capture an understanding of ADHD from the perspective of children who identify as having ADHD. After listening to these children and gathering their challenges, feelings, and thoughts, I share their voices to demonstrate that being familiar with the ADHD jargon is not enough to fully comprehend children with ADHD.

Acknowledging the perspective of these children provides a model for how teachers, parents, and peers can listen to and understand the social experiences of those with ADHD that cannot be found in medical books. Reflecting

the documented lived experiences and knowledge can help improve the lives of other children with ADHD by recognizing them as reliable sources of information about their lives and by fostering attitudes of appreciation, empathy, and support from others towards them.

Being a person with ADHD myself, I wish that when I was younger the people who were closer to me, particularly my parents and teachers, had known that it was *necessary* for me to constantly get up for bathroom breaks during lessons. This was in fact a way to help me focus, not an attempt to skip a class. Years later, after my son received the same diagnosis and was going through similar challenges, I wondered what he and other children who received labels of “unfocused,” “restless,” or “impulsive” would have to say if they were given the opportunity to voice their own thoughts. This paper presents this opportunity.

As I write this paper, I lean on the New Sociology of Childhood as a framework and place children’s voices at the heart of this research. I also draw on Critical Disability Studies (CDS) and challenge the notion of able-body and -mind that sets normative expectations for people (see Campbell, 2009; Goodley, Liddiard, & Runswick-Cole, 2018) especially those with a “disorder” like ADHD. For this reason, I purposefully use quotes on all the words that are used to describe ADHD from a medical perspective that have a negative connotation and open the doors to new words that, as cited by Castrodale (2017), inform of different bodies, minds, and human attributes. One example of these new words is *neurodiversity*, which reflects the many different ways people think, learn, and behave. The term carries the concept that differences should not be seen from a deficit perspective and is commonly used to refer to disorders such as ADHD, autism, or dyslexia (Baumer & Frueh, 2021). Neurodiversity, as well as the frameworks proposed, are aligned with the Disability Justice movement, which focuses on each person’s value for who they are and advocates that all bodies are seen for their uniqueness and strength (Berne, 2018).

In order to engage in an application of concepts from The New Sociology of Childhood and CDS, I used a qualitative methodology to capture experiences and knowledge from children with ADHD. I outline elements of this process in five sections that follow. The first section is the theoretical framework, which explains how the New Sociology of Childhood and CDS underpin this study. Next, in the literature review, I present other authors who engaged in similar endeavours. In the methodology section I go over my design, which was built with an ethnographic lens and used a focus group as the data collection method. The findings from the focus group are presented next. Finally, this paper concludes by setting the stage for discussion around the importance of listening to children with ADHD's voices and using these voices to promote awareness of the children's value, uniqueness, and strength.

The relevance of studies of this type for children with ADHD is unequivocal. It is time the world gained some perspective of ADHD according to how children see it and to what they want others to see. It is time to let the real experts talk.

Theoretical Framework

The New Sociology of Childhood and CDS are the essential elements that directed my decision-making process throughout the study. The first element places children as an active group in society, whose ideas are worthy of being listened to. Such a position has inspired a growing number of research subjects and methods that are child-centered and oriented (Swauger, Castro, & Harger, 2017). With that in mind, this study was designed to give participants the opportunity to play an active role in producing knowledge about ADHD. The second element, CDS, foregrounds a reflection on how the social value placed on "normal" bodies and minds excludes disabled people from society. Encouraging this type of reflection (amongst others) through this paper is one of the ways in which I can use my role as an educator to promote disability justice.

The choice of the New Sociology of Childhood as one of the theoretical frameworks does not come without challenges. It is not always easy to open space for children's expertise. While the concept of young people's agency and capabilities is generally recognized within early childhood studies, it conflicts with an old, and yet persistent, view of children as a vulnerable group in need of protection (Swauger, Castro, & Harger, 2017), where protection often comes in the form of control and exclusion.

To genuinely have children be the social actors they are capable of being, research needs to address their needs and ensure their participation is "truly emancipatory" (Swauger, Castro, & Harger, 2017, p. 6). Researchers need to see them not as adults in progress, but "to focus on children for the fact that they are children" (Kurt, 2021, p. 733). Listening to children's voices means abdicating control, facilitating comfortable expression, and honouring their wishes. In this study, I acknowledge the position of children as social actors and see their knowledge of ADHD as worthy of investigation and dissemination.

Seeing the participants in this study as the experts on their lives is particularly relevant when considering the intersectional identities they hold: being children and having ADHD, which is traditionally treated as a disability, which brings me to the second theoretical framework used in this study—Critical Disability Studies (CDS).

CDS blurs the boundaries between ability and disability and investigates how context, power, privilege, and oppression define historical physical and mental norms (Schalk, 2017). CDS emerged as a theoretical framework and a form of activism in the context of the culture of ableism: the "discrimination on the basis of ability, perceived or actual" (Campbell, 2009, p. 5). Goodley, Liddiard, and Runswick-Cole (2018) talk about how ableism imposes the collective expectation that happiness and success are intimately related to being autonomous, self-sufficient, and independent.

Abberley (1987) said: "Disabled people are often only relevant as problems" (p. 93). To that point, too often, children with ADHD are treated as problems, which reflects how society responds to perceived impairment. As pointed out by Titchkosky (2000), it is not bodies or minds that cause these problems, but the interactions with society in its physical and social environment. Such interactions, determined by ableist standards, categorize many behaviours presented by children with ADHD as not desirable. Some examples of these behaviours are struggling to sit still, interrupting other people's conversations, or keeping their belongings organized. Because society dictates that a child should be able to sit still, wait for their turn to speak (especially when speaking with adults), and keep their items organized, many children with ADHD are considered to fall outside of expectations around autonomy, self-sufficiency, and independence. Adult guidance and interference are often needed to direct them to conform to these expectations, which may lead to feelings of invalidation and dismissal.

Using the CDS framework as a guide, I pose the following questions: What if sitting still is not an expectation? What if there is an understanding that children with ADHD can find other ways to focus, and there is no attempt to “fix” behaviours that do not necessarily need fixing (such as not being able to sit still)? What if, instead, the current repertoire of what is socially accepted is expanded? This last thought aligns with Minich (2016), who proposes a differentiation between medical studies of disability and studies of disability from the CDS perspective, with the latter suggesting that social norms should be questioned. Such a transformative concept invites a level of introspection around normativity and challenges a status quo “that assigns more value to some bodies and minds than to others” (Minich, 2016, para. 11).

For children with ADHD (and with other disabilities), the rewriting of social norms is imperative and should begin with a reflection on what actions can be taken to ensure the environments these children inhabit (such as their homes and schools) do not exclude them from fully participating in society. Castrodale (2017) speaks of “enabling pedagogies” (p. 51) as pedagogical practices that give space to disabled subjectivities through understanding how information is “accessed, (re)interpreted, and communicated and the ways this may (dis)advantage particular individuals on the basis of difference” (p. 52). For a student with ADHD, for example, the way that knowledge is communicated in most school classrooms (a teacher giving a traditional lecture while students sit and watch) may put them at a disadvantage in comparison to their peers who are considered to be neurotypical, since many children with ADHD are likely to be distracted by external stimuli or have challenges staying in the same position for long periods of time. Reframing the social norm that dictates good learning behaviour could benefit many neurodiverse learners, whose experiences should be considered when determining what constitutes “the right way to learn.”

CDS guided this study, which aims to inform families, educators, and other children of the important knowledge, feelings, and experiences of children with ADHD and inspire necessary changes. Alongside the New Sociology of Childhood and its transformative call to value the capacity of children, including those with ADHD, these two theoretical frameworks underpin this study. Both frameworks support the vision of children with ADHD occupying an important place in society and being valued for their contributions to the understanding of ADHD. This vision is also encouraged by the undertakings of other authors who used their work to allow children to express themselves freely.

Literature Review

When I looked up ADHD on any scientific database, I encountered a large number of papers that were written from a medical perspective. Thus, to situate the reader, I considered it important to briefly describe these views, which are summarized in the subsection “Through a Medical Lens.” When I narrowed my search to include elements of my theoretical framework and other work that had been done with children with ADHD, I was glad to have found other studies that, similarly to this one, focused on children, their feelings, and how to better listen to them. These studies are presented in the other subsections: “A Paradigm Shift,” “Stigma and Identity,” “Many Ways to ‘Speak,’” “Every Voice Tells a Story. And More,” and “Moving Forwards Towards More.” Through these subsections, I recognize the work of authors who have come before me and whose work supported my thought process when designing this study.

Through a Medical Lens

For many years, ADHD has been thoroughly studied and described through a medical lens. The Centre for ADHD Awareness, Canada (CADDAC) defines ADHD as a chronic *neurodevelopmental disorder* that impacts all ethnicities and socioeconomic statuses (CADDAC, 2022). According to the CADDAC (2022), ADHD causes symptoms in the executive functions of the brain, potentially leading to inattention; difficulties in organization, time management, self-regulation, and emotional regulation; impulsivity; poor working memory and processing speed; and problems with mental flexibility/rigidity. Spencer et al. (2022) place ADHD “amongst the most common mental health ‘disorders’ in childhood” (p. 4), and Barkley (2020) defines ADHD as a “disorder” of self-control, with consequences in an individual’s ability to regulate their actions relative to the passage of time and to understand the consequences of their actions. The Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) classifies it as a *neurodevelopmental disorder* and defines it as a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development (American Psychiatric Association, 2013). All of these definitions carry one thing in common: they frame ADHD as a pathology, a “condition” that impairs those who have it.

A Paradigm Shift

As evidenced above, the medical-psychiatric model of ADHD sees it as a pathology, as a condition that is outside of the norm, and as a problem. From my experience

with ADHD, being framed inside such categories invites a multiplicity of feelings that deserves its own space in research, such as feelings of inadequacy and lack. This study does not aim to shy away from medical knowledge or to deny its importance, but rather to expand the understanding of ADHD by including the perspective of children who live with it. To do so, I rely on the CDS call for “alternatives to deficit and medical views” (Balter et al., 2023, p. 49).

With that in mind, I steer away from relying on a paradigm that aims exclusively to “fix” what is outside of the accepted “norm” and open a dialogue to investigate what else there is to know about ADHD from a standpoint of children with ADHD. Honkasilta (2016) states that the uncritical reproduction of medical-psychiatric discourse in educational practices should be questioned, “as it is oversimplified and insufficient to understand the experiences of ‘life with ADHD’” (para. 1). Likewise, I believe that to comprehend the lives of children with ADHD better, it is necessary to listen to them instead of exclusively looking through a medical lens. By opening space for teenagers in Finland to express their views around the label ADHD, Honkasilta (2016) found that their difficulties in building an identity detached from ADHD may be related to the excessive use of medical discourses in their homes and schools, with little attention being given to their thoughts. These findings warrant further undertakings that aim to listen to people with ADHD, such as this study, which focuses on presenting the experiences of children with ADHD and the knowledge they have of it.

Stigma and Identity

The literature on ADHD includes studies of children’s views of ADHD in research and produces knowledge that is relevant to their lives and that can be applied to improve them. Many of these studies conclude that stigma is an important topic. One example is Moldavsky et al. (2013), who write on young people’s experiences with ADHD and advocates for their perspectives to be accounted for. By describing their feelings of stigmatisation and discrimination, she opens doors to further investigation on what causes such feelings and what can be done to prevent them.

Similarly, Petry et al. (2018) use a student voice method to investigate the experiences of adolescents with ADHD in Spain. In this study, it was observed that participants mirrored a psychiatric discourse in their descriptions of ADHD while also mentioning their “experiences, feelings, distress, and coping strategies” (p. 5). The difficulties

they experience, according to Petry et al. (2018) can be particularly noticed in the school environment, where the lack of support both from families and educators once diagnosis is confirmed suggest that the social variables that interfere with people who have ADHD are not taken seriously. Peddigrew (2023) uses a CDS framework to reflect on the feelings of inadequacy and stigmatisation people with Learning Disabilities (LDs) and/or mental “illnesses” and calls for further research to identify how stigma is internalised. She concludes by proposing that difference should be understood as natural, as opposed to “other than normal” (p. 154).

The three studies above show how the different experiences that children and young people with ADHD go through impact their self-image and identity. Through my research, I strive to give space for participants to share such experiences and feelings involved with them, so they feel their perspective matters.

Many Ways to ‘Speak’

Amplifying children’s voices through research is an initiative that requires understanding the multiple forms children can use to communicate. Pezzica, Vezzani, and Pinto (2018) use children’s drawings to investigate the metacognitive knowledge of attention among children with ADHD. Children’s drawings communicated “their emotional difficulties associated with the school environment” (Pezzica, Vezzani, & Pinto, 2018, p. 150). Such findings can be useful to inform children’s parents and teachers of their difficulties and thus promote further conversations with children on what they think might help them thrive in their daily lives. A photo elicitation study done in Belgium by Coussens et al. (2020) gathers the perception of children with developmental disabilities (among whom were children with ADHD) about participation. This study suggests that children find their participation in life events to be more satisfying when they feel included by a mediator, such as their mothers. Coussens et al. (2020) show how other people can adopt attitudes to improve the lives of children with ADHD and other disabilities. Stafford (2017) questions ableism and adultism and how these constructs leave children with disability out of research, proposing that participant-centered methods like activity-based interviews be used to share the narratives of children with physical or neurological impairments.

The studies described above centre on the child as the main source of data and provide insights on how researchers can adapt themselves to children’s unique

ways of communicating. The children's perspectives are elicited in an inclusive, encouraging, and age-appropriate manner. To this point, Einarsdottir (2007) emphasizes that children and adults have fundamental differences in how they see the world and communicate. Therefore, research that aims to understand children's lives should not only reflect such differences, but propose methods that suit children's interests, contexts, and individual ways of communicating (including non-verbal ways). By proposing a dialogue with children with ADHD that embraces how they wish to communicate, I hope to grant them the freedom to express themselves as they wish.

Every Voice Tells a Story. And More

As important as giving children their voices is understanding that these voices are shaped by a variety of circumstances and influences. In the study "Can They Speak?", Witeska-Młynarczyk (2020) describes her experiences doing ethnographic research in Poland with children with ADHD and the tensions in her pursuit to enable children's voices. She highlights that the voices of children are not always well articulated and can be "inconclusive, entangled and interdependent" (p. 47).

Witeska-Młynarczyk's paper concludes that children's voices should be studied in a relational and contextual manner and adds that "the way children's voices will be approached and represented is an issue requiring careful consideration and deserving an honest discussion" (p. 57). This view is particularly inspirational for my study, where children's words (or their silence) may speak of more than what their words are saying. Their communication may reveal the societal influences they are under, which must be considered in the analysis and discussion.

Moving Forward Towards More

Aside from the medical studies, the literature that has been presented and discussed here has one common element: it portrays different scenarios where the lived experiences of people with ADHD are looked at as the centerpiece of the investigation. As a result, the studies bring knowledge that is not limited to a medical perspective and that is essential to truly understanding what living with ADHD is like. The stories observed and told through a variety of methods share multiple ways in which individuals with ADHD internalize their experiences. Moreover, these experiences reflect the understanding individuals with ADHD are exposed to, as well as the discourses behind such information.

By addressing the gap in the literature that seeks to capture young children's understanding of ADHD in my research, I hope to foster a genuine sense of interest, appreciation, and empathy for these children, whose attitudes and behaviours are commonly misunderstood and frowned upon. Part of my inspiration comes from Muller and Kenney (2021). In their fieldwork with juvenile correction actors, they found that educators working with "at-risk" youth learned how to reframe "difficult behaviors—such as swearing, yelling, fighting, breaking classroom rules, etc." (p. 1243) after relating them to trauma experiences lived by youth. By doing so, they no longer took youth's behaviour as a "personal attack," and "new forms of attention and response to familiar and challenging behaviors" (p. 1243) were created.

Similarly, I hope to contribute to promoting a shift on how others relate to children with ADHD by disseminating information pertaining to the experiences lived by these children and the knowledge acquired from them that they would like to share with others.

Methodology

To answer my questions about the lived experiences of children with ADHD, I applied an ethnographic lens to "research with" children with ADHD, using a focus group as a data collection method. The choice of ethnography reflects the main research question: "What is ADHD for children with ADHD?" This question invited a thorough exploration of a phenomenon (ADHD) within a particular group (children with ADHD) through observing them in their natural setting. A focus group as the data collection method was the means to ask children the questions proposed and to expand on the data derived from observing children while they were engaged in the discussion. For the purpose of data analysis, I took into consideration participants' behaviours and interactions with each other and the investigator as much as their answers to the questions.

I acknowledge that ethnography is also linked to the lived experience of the ethnographer (Berry, 2011), and I allowed my subjectivity and my identity of someone who has ADHD to flow into the process. Guided by the ethical responsibility of benefitting the participants of this study, I followed a shift from plain ethnography to critical ethnography, which goes beyond simply collecting data and proposes to solve problems raised by participants (Naidoo, 2012).

An important note is that under ideal circumstances this study would have included the observation of participants in their environments (in their schools, for example), so that their activities could be captured as they naturally occur (Elliott & Jankel-Elliott, 2003). However, due to time and logistical constraints, the focus group happened on Zoom. Although my initial feeling on using Zoom in this study was hesitation, I was encouraged by cases where this platform was used successfully in ethnographic research.

For this focus group, participants were selected using purposive sampling through advertisement on social media (Instagram, LinkedIn, and Facebook). Inclusion criteria were children of either sex, self-identifying as someone with ADHD, between the ages of 8 and 12 (grades 3 to 5), and able to understand instructions in English. The questions that initiated the discussion were built to elicit children's understanding of ADHD and what they considered important for others to know about it. Because of the sensitive nature of the subject, participants were informed they were not under any obligation to answer a question if they did not want to. After ensuring participants were comfortable enough, the discussion was initiated with this opening question:

- "What is ADHD for you?"

This question was followed by:

- "What would you like your parents to know about ADHD?"
- "What would you like your teachers to know about ADHD?"
- "How about friends? What do you think is important for them to know about ADHD?"

When the discussion ended, children were asked if they wanted to add anything else.

Findings

To analyze the data, I used a combination of thematic analysis and observation of children's behaviour. As pointed out by Braun and Clarke (2006), thematic analysis involves an active process of reflexivity, where a researcher's subjectivity influences how data is sorted into themes and interpreted. Therefore, my experiences as an individual with ADHD played a role in how I identified patterns, codes, and themes.

How Children Describe ADHD

This theme encompasses how ADHD manifests in participants' lives, such as impulsivity, lack of focus or distraction, hyperactivity, and hyperfocus. The descriptions of each of these aspects reflected children's experiences that posed either a challenge or simply an aspect that was a part of their daily experiences. When B. says, "You get distracted easily," he is describing a challenge. Further, B. adds that his distractibility relates to things he does not enjoy doing, such as cleaning: "If you're cleaning with ADHD, since you don't like it, you're just gonna look around and when you see a single spark in the sky, you're gonna run, drop the broom, run everywhere, and then look for that spark." Another challenge described by B. is the impulsivity, which he illustrates by telling a story about the day he ran from his teachers: "I ran out of the school all the way home with teachers chasing me." Further, B. talks about hyperactivity and exemplifies how it keeps him awake at night: "I can't fall asleep 'cause I'm, I'm always too hot, too cold or I'm just wiggly or drawing (...) and whenever I try and lie down, boom (...) I'm just like a wide awake."

When B. speaks about his hyperfocus, on the other hand, it seems as though he is only narrating an aspect of his personality that comes through when he is doing an activity he likes: "Since I like researching, like, computer stuff, I can hyperfocus, or I like coding, so I can code, so I can hyperfocus on coding." Along the same lines, J1. adds: "It's like, you're super, like, if you actually like something you're doing, you'd be in your room, like, the whole day doing it, if you don't have anything to do." J2. added that basketball was an activity that would get him really involved.

An important reflection here is to understand what determines whether each behaviour described by participant constitutes a challenge. CDS shows how the world is built around an idea of "normal" (see for example Balter et al., 2023; Campbell, 2009; Goodley et al., 2018). Therefore, being easily distracted, which falls out of the "normalcy" zone, certainly becomes a challenge for many individuals with ADHD. Were the expectations around "normalcy" redefined, perhaps this particular aspect of participants' lives would not pose a challenge for them.

Regardless of whether each description by participants constitutes a challenge or an aspect of themselves that might even be helpful for some tasks, it was clear that their representations had similarities, but also differences, which were also observed in their behaviour during the focus group. These differences both in speech and behavior

mirror Witeska-Młynarczyk's (2020) findings that point to how children's voices should be studied in a relational and contextual manner. B.'s articulate speech seems to be the result of open conversations about ADHD with his parents. J2.'s silence, on the other hand, can reflect a variety of influences, from timidity to not being actively engaged in discussions about ADHD. Furthermore, these differences show that each individual having ADHD has a unique experience that cannot be generalized. Understanding these differences is important so that others do not make assumptions about what a person will be like just because they have ADHD.

Self-Concept

When asked about what ADHD was for them, it became clear to me that the repertoire of words that the participants associated with it carried a strong association of ADHD with problems. It seems that the medical-psychiatric discourse is still very prevalent among other people's representations of ADHD. To expand on that, I refer to Titchkosky (2000), who speaks about how medical and therapeutic disciplines produce knowledge on and about disabled people and how such knowledge influences the representations society has of disability.

The first word I heard upon my first question was "stupid," which was used by J1. to define ADHD. When I asked J1., "Why stupid?" he said that it was the first thing that came to his mind, and explained that actually, he was called "retarded" by the eighth graders: "Instead of stupid, I get called 'retarded' a lot by the 8th graders." The use of the "R slur," as described by B., sparked a very rich discussion between J1., and B. around the inappropriateness of the word, which resulted in the consensus that this word should not be used to refer to neurodiverse people. However, this is the word that, according to J1., was used to refer to him many times. The impact such a strong, offensive word may have caused on J1.'s self concept is something I would very much like to have understood better had I had the time. It was clear though, that the words—either "stupid" or "retarded"—were there in the back of his mind, as he showed no hesitation in answering the first question, what ADHD was for them, with the statement, "Being stupid and doing bad stuff."

Listening to J1.'s words makes me recall Peddigrew (2023) and reflections on the feelings of inadequacy and stigmatisation amongst people with LDs, as well as Moldavsky et al. (2013) and their reports on young

people's feelings of stigmatisation and discrimination. Another aspect of having ADHD mentioned by J1. with potential to impact his self-concept negatively was the lack of understanding from other people: "Another thing that I feel like ADHD is, is that a lot of people don't really understand you. And they think you're just like a lot different." This lack of understanding, combined with the inappropriate words J1. heard about himself, indicates the urgency to spread more awareness of ADHD amongst the general population and in schools, as well as more advocacy actions towards the well-being of children with ADHD.

What They Want the World to Know

When asked what they would like their parents, teachers, and peers to know about ADHD, the participants had very clear ideas of what they wanted to say. They want their teachers to know that teachers need to "explain things over and over again in, like, a very easy way for somebody to understand" (J1.); that they (the children) "get distracted way easier than anybody else in the universe" (B.); and that they (the teachers) should refrain from giving them too much homework: "Stop giving us a lot of homework, 'cause we're probably not gonna do it." (J2.). As for their parents, J1. asks: "Be more easy on me because I get mad really fast." Finally, in regard to other children, they wish that they were not seen as "a lot different." Perhaps this would make it easier for them to make friends with others.

All of these statements have one common element: they are a call for change. For these changes to happen, all the actors involved in the participants' lives need to do one thing: understand them. This request for understanding is summarized by B. in a very well articulated appeal: "Just understand us for once. Just understand us (...). They just don't understand. Eventually they finally understand, but it takes, I have to educate them." B. is an elementary school boy who feels responsible for educating other people about ADHD. His profound level of agency transports me to Tuck's (2009) open letter in which she calls for a change from damage-based research to desire-based research. Tuck explains the need to move from research that is based on people's pains and that sees them as "defeated and broken" (p. 412) to one that captures people's desires and hopes and that "understands complexity, contradiction, and the self-determination of lived lives" (p. 416). In this sense, B. does not speak of himself as someone who needs fixing. He expresses the desire to be understood for who he is.

To create more access to the findings, I compiled the themes identified in the focus group into a short video¹.

The language used in the video is accessible (available in captions and audio) and easy to understand, so that the knowledge contained in this study and the messages that participants want to communicate can reach those who need to be reached: the parents, teachers, and peers of children with ADHD.

Discussion and Conclusion

Expanding the traditional understanding of ADHD by incorporating children's knowledge and experiences is an important step in enabling these children (and many more) to see themselves as full participants in society and in their lives, an important premise of the New Sociology of Childhood and of CDS. The knowledge gathered from participants also teaches an important lesson: that every individual with ADHD is unique and, as such, cannot be only defined by a diagnosis, especially when such diagnosis carries so much stigma and negativity. Furthermore, listening to what these children want to communicate to others is a way to encourage the re-thinking of norms that prevent these children from thriving in their environments (for example, the norm that children must have their bodies still while learning when it would be beneficial to many learners to be allowed to move while in class). By doing so, this research suggests that the perceived idea of "normal" must be confronted so that every child lives and learns in the way that best works for them and serves as an act of disability justice, inviting the reader to listen to children with ADHD's unique experiences and recognize in them strengths, desires, and wholeness.

I acknowledge there are a few limitations to this study. One of them is the small number of participants. The challenges with recruitment call for further studies that investigate the obstacles that prevent more families from engaging with research with their children. Another limitation was the use of a digital platform as the study location as opposed to a more natural setting. Although Zoom has been used with success for ethnographic research (Podjet, 2021), I believe meeting children in person would have given me the opportunity to have more meaningful interactions with them, as well as to observe their behaviours better. Finally, had I had the time, and had the logistical constraints imposed by the families' schedules been lesser, I would have held more focus group sessions, ideally until the content discussed amongst participants reached saturation.

Nonetheless, this study reflects the importance of amplifying the voices of children (with or without ADHD) and invites those engaged with these children to take the time to listen to them. Moreover, it disrupts the traditional developmental discourses and expectations by making the public aware of how children perceive ADHD in their own words. By providing an avenue for participants to tell their stories, this research challenges developmental and medical-psychiatric discourses and positions itself to be the beginning of a counter-story told by children with ADHD. I also believe a systematic change is necessary so that children with ADHD can be seen for everything they are, which is so much more than a collection of "symptoms" that make others deem them as "broken."

My hope is that we can recognize children with ADHD for their wholeness and uniqueness. My larger hope is that common attitudes towards them such as impatience, frustration, and prejudice turn into interest, understanding, compassion, and support. Finally, I want to inspire further research that allows many other children with ADHD to share their voices and life stories.

Using research as a means for participants to share their knowledge is enabling them to have agency over their lives, an important foundation in the New Sociology of Childhood and something I believe to be indispensable to truly understanding children's worlds. Opening the doors to these worlds is, at the same time, a way to learn about them and a tool to empower these children in environments that often exclude them. As argued by Goodley & Runswick-Cole (2010), it is important to consider the need to work with numerous forms of educational intervention that address the exclusion of disabled children. For children with ADHD (and with other disabilities), one of these interventions is exactly what this study proposes: giving them the stage and the spotlight. Being a curious audience that listens attentively to their stories and makes sense of them. To the audience, it is a bit of an adjustment, a necessary one. To the children, it is their whole world.

The stories shown here are more than data for a paper. They serve as an advocacy tool for the participants and for other children with ADHD. They show what it is like for children when they have a chance to be heard: it is liberating. But who am I to speak for them? Perhaps it is best to let another expert talk about that.

A Child With ADHD

*Let me tell you about me
 I am a child with ADHD
 Sometimes it's hard for others to see
 How the world is different for me
 I have a thousand stories to tell
 I bet you would love to hear them all
 But some people who don't know me well
 Make me feel so incredibly small
 You see, some people treat me differently
 And I think that's not good
 'Coz I should be treated as everybody else should
 I sometimes lose my temper
 When I don't mean to
 Then I regret and surrender
 But my heart still feels blue
 I love my Nintendo, VR, and TV
 The problem is I forget about time
 And see only right in front of me
 Letting other things slide
 But if you ask me about ADHD
 I will say what's in my mind
 That it makes me exactly me
 Someone who is brave and kind
 ADHD may come with a few "buts"
 That some people like to judge
 But then you know what?
 I make the world more diverse
 I am so glad you took the time to listen to me
 You see, not everyone is willing
 To pay attention to a child with ADHD
 Who sometimes struggles fitting
 So, thank you, it means a lot to me
 And to all other children
 Who live with ADHD
 We just want to be happy
 We just want to thrive
 To be loved and respected
 And to live... with Pride!*

Vale, O. (2023), based on the poem by Chesterman-Smith, A (Vale, O. is a child with ADHD).

¹ <https://youtu.be/qNQXz4GnHH0?si=uisf5SblJ99r9ctB>

References

- Abberley, P. (1987). The concept of oppression and the development of a social theory of disability. *Disability, Handicap & Society*, 2(1), 5–19. <https://doi.org/10.1080/02674648766780021>
- American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders* (5th ed.).
- Balter, A-S., Feltham., L.E., Parekh, G., Douglas, P., Underwood, K. & van Rhijn, T. (2023). Reimagining inclusion through the lens of disabled childhoods. *Social Inclusion*, 11(1), 48–59. <https://doi.org/10.17645/si.v11i1.5722>
- Barkley, R.A. (2005). *ADHD and the nature of self-control*. New York, NY: Guilford Press.
- Barkley, R.A. (2014). *Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment* (4th ed.). New York, NY: Guilford Press.
- Barkley, R.A. (2016). *Managing ADHD in school: The best evidence-based methods for teachers*. Eau Claire, WI: PESI Publishing & Media.
- Barkley, R.A. (2020). *12 principles for raising a child with ADHD*. New York, NY: Guilford Press.
- Barkley, R.A. (2022). *Taking charge of ADHD: The complete, authoritative guide for parents* (4th ed.). New York, NY: Guilford Press.
- Baumer, N., & Frueh, J. (2021, November 23). "What is neurodiversity?" Harvard Health Publishing. Retrieved from <https://www.health.harvard.edu/blog/what-is-neurodiversity-202111232645>
- Berne, P., Morales, A.L., Langstaff, D., & Invalid, S. (2018). Ten Principles of Disability Justice. *WSQ: Women's Studies Quarterly*, 46(1), 227–230. <https://doi.org/10.1353/wsqr.2018.0003>
- Berry, K. (2011). The ethnographic choice: Why ethnographers do ethnography. *Cultural Studies ↔ Critical Methodologies*, 11(2), 165–177. DOI: 10.1177/1532708611401335
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Campbell, F.K. (2009). Disability matters: Embodiment, teaching and standpoint. In F.K. Campbell, *Contours of Ableism: The Production of Disability and Abledness* (pp. 115–129). London: Palgrave Macmillan. <https://doi.org/10.1057/978023024>
- Canadian ADHD Resource Alliance (CADDRA). (2018). *Canadian ADHD practice guidelines* (4th ed.). Toronto, ON: CADDRA.
- Castrodale, M.A. (2017). Critical disability studies and mad studies: Enabling new pedagogies in practice. *The Canadian Journal for the Study of Adult Education*, 29(1), 49–55. <https://cjsae.library.dal.ca/index.php/cjsae/article/view/5357>
- Centre for ADHD Awareness, Canada (CADDAC). (2023). What is ADHD. <https://caddac.ca/about-adhd/in-general/>
- Coussens, M., Destoop, B., De Baets, S., Desoete, A., Oostra, A., Vandestraeten, G., Van Waelvelde, H., & Van de Velde, D. (2020). A qualitative photo elicitation research study to elicit the perception of young children with developmental disabilities such as ADHD and/or DCD and/or ASD on their participation. *PLoS One*, 15(3), 1–20. <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0229538>
- Einarsdottir, J. (2007). Research with children: Methodological and ethical challenges. *European Early Childhood Education Research Journal*, 15(2), 197–211. <https://doi.org/10.1080/13502930701321477>
- Elliott, R., & Jankel-Elliott, N. (2003). Using ethnography in strategic consumer research. *Qualitative Market Research*, 6(4), 215–223. <https://doi.org/10.1108/13522750310495300>
- Goodley, D., Liddiard, K., & Runswick-Cole, K. (2018). Feeling disability: Theories of affect and critical disability studies. *Disability & Society*, 33(2), 197–217. <https://doi.org/10.1080/09687599.2017.1402752>
- Goodley, D. & Runswick-Cole, K. (2010). Len Barton, inclusion and critical disability studies: theorising disabled childhoods. *International Studies in Sociology Education*, 20(4), 273–290. DOI: 10.1080/09620214.2010.530851
- Hallowell, E.M., & Ratey, J.J. (2021). *ADHD 2.0: New science and essential strategies for thriving with distraction: From childhood to adulthood*. New York, NY: Ballantine Books.
- Honkasilta, J. (2016). Voices behind and beyond the label: The master narrative of ADHD (de)constructed by diagnosed children and their parents. *Jyväskylä Studies in Education, Psychology, and Social Research*, 553, 1–86.
- Kurt, S.H. (2021). Perceptions of children and childhood in the context of new childhood sociology. *Child Indicators Research*, 15(3), 731–746.
- Miller, M., Arnett, A.B., Shepard, E., Charman, T., Gustafsson, H.C., Joseph, H.M., Karalunas, S., Nigg, J.T., Polanczyk, G.V., Sullivan, E.L., & Jones, E.J.H. (2023). Delineating early developmental pathways to ADHD: Setting an international research agenda. *The Association for Child and Adolescent Mental Health*, 3(2), 1–14. <https://doi.org/10.1002/jcv2.12144>

- Minich, J.A. (2016). Enabling whom? Critical disability studies now. *Lateral: Journal of the Cultural Studies Association. Emergent Critical Analysis for Alternative Humanities*, 5.1. <https://csalateral.org/issue/5-1/forum-alt-humanities-critical-disability-studies-now-minich/>
- Moldavsky, M., & Sayal, K. (2013). Knowledge and attitudes about Attention Deficit/Hyperactivity Disorder (ADHD) and its treatment: The views of children, adolescents, parents, teachers and healthcare professionals. *Current Psychiatry Reports*, 15, 1–7. DOI: 10.1007/s11920-013-0377-0
- Muller, R., & Kenney, M. (2021). A science of hope? Tracing emergent entanglements between the biology of early life adversity, trauma-informed care, and restorative justice. *SAGE Journals*, 46(6), 1230–1260. <https://doi.org/10.1177/0162243920974095>
- Naidoo, L. (2012). *Ethnography: An introduction to definition and method. An ethnography of global landscapes and corridors*. London, UK: IntechOpen. DOI: 10.5772/39248
- Peddigrew, E. (2023). Stigma, self-hatred, and stereotypes: Using a critical disability studies framework to understand learning disabilities and mental illness. *Canadian Journal of Disability Studies*, 12(1), 141–160.
- Petry, P.P., Soria-Albert, C., & Vadeboncoeur, J. (2018). Experiencing disability in the school context: Voices of young people diagnosed with ADHD in Spain. *International Education Studies*, 11(8), 79–90. DOI:10.5539/ies.v11n8p79
- Pezzica, A., Vezzani, C., & Pinto, G. (2018). Metacognitive knowledge of attention in children with and without ADHD symptoms. *Research in Developmental Disabilities*, 83, 142–152. <https://doi.org/10.1016/j.ridd.2018.08.005>
- Podjet, D. (2021). Renewal of ethnography in the time of the COVID-19 crisis. *Sociologija i prostor*, 59 (219), 267–284. DOI: 10.5673/sip.59.0.10
- Salari, N., Ghasemi, H., Abdoli, N., Rahmani, A., Shiri, M.H., Hashemian, A.H., Akbari, H., & Mohammadi, M. (2023). The global prevalence of ADHD in children and adolescents: A systematic review and meta-analysis. *Italian Journal of Paediatrics*, 49, 48. <https://doi.org/10.1186/s13052-023-01456-1>
- Shalk, S. (2017). Critical disability studies as a methodology. *Lateral: Journal of the Cultural Studies Association. Emergent Critical Analytics for Alternative Humanities, Responses*, 6.1. DOI: 10.25158/l6.1.1
- Spencer, N.J., Ludvigsson, J., Bai, G., Gauvin, L., Clifford, S.A., Awad, Y.A., Goldhaber-Fiebert, J.D., Markham, W., Faresjo, A., White, P.A., Raat, H., Jansen, P., Nikiema, B., Mensah, F.K., McGrath, J.J. (2022). Social gradients in ADHD by household income and maternal education exposure during early childhood: Findings from birth cohort studies across six countries. *PLoS One*, 17(3). <https://doi.org/10.1371/journal.pone.0264709>
- Stafford, L. (2017). “What about my voice”: Emancipating the voices of children with disabilities through participant-centred methods. *Children’s Geographies*, 15(5), 600–613. <https://doi.org/10.1080/14733285.2017.1295134>
- Swauger, M., Castro, I.E., & Harger, B. (2017). The continued importance of research with children and youth: The “new” sociology of childhood 40 years later, *Sociological Studies of Children and Youth*, 22, 1–7. <https://doi.org/10.1108/S1537-466120180000022001>
- Titchkosky, T. (2000). Disability studies: The old and the new. *The Canadian Journal of Sociology*, 25(2), 197–224. <https://doi.org/10.2307/3341823>
- Tuck, E. (2009). *Suspending damage: A letter to communities*. Harvard Educational Review, 79(3), 409–427. [TuckHedR79-3.pdf \(ucsd.edu\)](https://www.tuckhedge.org/79-3.pdf)
- Wilens, T.E., & Spencer, T.J. (2013). Understanding Attention-Deficit/Hyperactivity Disorder from childhood to adulthood. *Postgrad Med*, 122(5), 97–109. DOI:10.3810/pgm.2010.09.2206
- Witeska-Mlynarczyk, A. (2020). Can the children speak? Voice, children and an ADHD diagnosis in an ethnographic research. *Revue des Sciences Sociales*, 63, 46–57. <https://doi.org/10.4000/revss.4902>