Unheard Voices:

Adults with ADHD in Aotearoa New Zealand

A thesis

submitted in partial fulfilment of the requirements for the degree

of

Master of Disability and Inclusion Studies

in Te Kura Toi Tangata Faculty of Education

at

The University of Waikato

by

Amy Jo Murray

KO TE TANGATA

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

2021

Abstract

Attention-deficit/hyperactivity disorder (ADHD) is a well-researched condition within multiple editions of the *Diagnostic and statistical manual of mental disorders (DSM)*. Historically, ADHD was believed to be a childhood condition that typically diminished in adolescence. However, current research confirms that not only does ADHD often continue into adulthood, but its impact also has a cumulative effect over the lifespan. Consequently, adults not diagnosed in childhood are a growing demographic of ADHD diagnoses. Within this growing demographic, there is little research on the lived experiences of adults with ADHD, and none were found in Aotearoa New Zealand. The purpose of this study was to explore the similar and differing lived and ableist experiences between groups of adults who were diagnosed with ADHD in childhood, adolescence, adulthood, and those who suspect they have ADHD. Data were collected from eight participants (two from each diagnosis group) using online survey software and online one-to-one interviews. The study used a mixed-method design, and data were interpreted using hermeneutic phenomenology and critical disability theory frameworks to explore participants' lived experiences with ADHD. Findings revealed some differences in life trajectories and between-group experiences of participants with diagnosed or suspected ADHD. However, most experiences revealed a commonality centred around feelings of frustration, rejection, shame, and the lack of personal agency. These experiences and normative social discourses prompted participants to actively police and mask their behaviours and ADHD characteristics. Participants reported lacking crucial knowledge to navigate life internally and externally with ADHD due to the absence of relevant guidance and support. The impact of these internal and external difficulties was compounded by the ableism they faced related to their ADHD. Early ADHD diagnosis followed by comprehensive ADHD information and support within the broader community, i.e. educators and health professionals, would have facilitated more positive lived experiences according to participants. This study indicates that early information, treatment, and support could mitigate the unseen personal toll associated with having ADHD. Additionally, the results highlight the need for further research to understand better the most needed supports and how they might best be made available.

Keywords: *attention-deficit/hyperactivity disorder, ADHD, ableism, masking*

Acknowledgements

Throughout the journey of this research, I experienced a number of setbacks. These experiences made the support and encouragement I received even more important and meaningful in completing this study.

There are many people to whom I will always be immensely grateful, and the first of these are my loving husband and daughters. They are genuinely my inspiration. They encouraged me and have supported my education at every step along this journey. They helped me find strength when I struggled and was frustrated, encouraged me when I floundered, and celebrated each milestone along the way. Additionally, I had often received encouragement from family and friends when maybe they did not realise I was struggling. Their support and encouragement strengthened me, for which I am thankful.

I am also incredibly grateful for the support and encouragement of my supervisor, Dr Janette Kelly-Ware of Te Kura Toi Tangata - Faculty of Education at the University of Waikato. Learning from a distance produces many challenges. From the beginning, whether helping with my transfer to the University of Waikato or giving encouragement that I needed to continue my studies, Dr Kelly-Ware has been unwavering. Through engaging conversations, questions, feedback, and supportive guidance, she guided the way through both the academic and emotional aspects of completing this thesis. I look forward to her support as I move further with my education.

I also want to express my gratitude to Waikato University support staff for helping me transfer during a challenging period of my education. It was seamless, and the support I received through online tutorials and from library staff, particularly Melanie

Chivers, has been instrumental in my engagement and enjoyment of this part of my educational journey.

Dedication

I want to dedicate this thesis to the eight participants who took part in this study. They opened themselves to a stranger and shared what was often distressing memories and experiences. They have my utmost respect. I hope their experience engaging with this study enhanced their awareness of how resilient they have been in the face of often invisible roadblocks and setbacks related to their ADHD. I heard your voices and hope this thesis does them justice.

Table of Contents

List of Figures

List of Tables

Chapter 1: Introduction

This chapter details the rationale for this study. The relevance of this study in filling the existing research gap regarding the lived experiences of adults in Aotearoa New Zealand, in relation to the age of diagnosed or suspected diagnosis of ADHD is explained. The chapter concludes by justifying the research and stating the research questions.

What is ADHD?

ADHD is primarily viewed as a childhood condition; however current research confirms that as many as 65% of childhood cases continue to experience ADHD characteristics in adulthood (Caci et al., 2015). A neurodevelopmental condition, ADHD is identified by persistent patterns of behaviours - including hyperactivity, impulsivity, inattentiveness - typically present before age twelve (American Psychiatric Association, 2013; Kooij et al., 2019). ADHD can cause distress to individuals and interfere with their typical functioning and development (American Psychiatric Association, 2013). ADHD characteristics must be present in more than one environment (school, home, work) to receive a diagnosis, but their presentation may fluctuate depending on the setting and context (American Psychiatric Association, 2013). ADHD is a relatively common but often unrecognised and under-diagnosed condition that is inheritable and has a lifespan perspective (Asherson et al., 2012; Kooij et al., 2019). Individuals with ADHD often experience academic, social, and emotional consequences resulting from impairments and characteristics associated with ADHD (American Psychiatric Association, 2013; Barkley, 2015; Berberat et al., 2021).

Common ADHD characteristics include drifting off-task, often resulting from distractibility, which may be interpreted as a lack of persistence (American Psychiatric Association, 2013). The behaviours related to ADHD may also manifest as difficulties related to maintaining focus on uninteresting tasks and a lack of organisation, which would not be attributable to defiance or lack of comprehension (American Psychiatric Association, 2013). Equally, hyperactivity can be experienced as an overabundance of physical or mental activity, which may include excessive or repetitive movements or fidgeting, and racing internalised and externalised thoughts (American Psychiatric Association, 2013; Kooij et al., 2012).

Diagnosis prevalence rates of ADHD are estimated to range between 2.5-7.1% of the childhood population worldwide (Caci et al., 2015; Chen et al., 2018; Garcia-Argibay et al., 2021). Although geographic differences exist among prevalence rates, these are thought to result from methodological and cultural variations relating to the diagnostic criteria interpretation of behaviours and the presentations of impairments rather than true differences in actual rates (American Psychiatric Association, 2013; Caci et al., 2015).

There are many misconceptions about ADHD and its related impairments. It is expected that the research that is the focus of this thesis will add to the small body of international research literature that centres on the experiences of individuals who live with ADHD and its interrelated impairments. The research findings may be of interest within Aotearoa New Zealand (and internationally) to people with ADHD and people supporting individuals diagnosed with ADHD. Interested parties may include individuals interested in long-term outcomes relating to early diagnosis, misdiagnosis, and late diagnosis, including teachers and educators in understanding the importance of early support; recognition of impairments and treatments; counsellors*;* psychologists; and medical experts supporting adults with late diagnoses.

Additionally, it is expected that this study may also be the first that explores ableist experiences specifically in relation to ADHD. While disablism produces and devalues disability, ableism prefers and values able-bodiedness and able-mindedness (Campbell, 2008; Dolmage, 2017). Ableism in relation to ADHD would be the requirement to be or interact in line with social norms – to behave in a manner that does not hint that one has ADHD or its related impairments. Internalised ableism is particularly meaningful to this study as it represents the internal burden of coping with ADHD characteristics for the individual with ADHD. As Campbell (2008) explains;

> Internalised ableism can mean the disabled subject is caught 'between a rock and a hard place'; in order to attain the benefit of a 'disabled identity' one must constantly participate in processes of disability disavowal, aspiring towards normativity, a state of near ablebodiedness (sic), or at very least to effect a state of 'passing' (p. 156).

Thus, it is believed that exploring participants' experiences related to ableism is necessary to the overall aim of this study.

Research Rationale

Within the research literature reviewed for this thesis, few authors discussed the daily impact that ADHD generates from the individual's point of view with ADHD. Qualitative studies on ADHD do exist, nevertheless, most ADHD research is quantitative. These studies explore treatments, 'cures', social and educational impacts, and use the lens of 'about, rather than with' in relation to participants. This lens contrasts with the concept of ‘nothing about us without us’ described by Charlton (1998) concerning individuals with impairments and disability and their empowerment. This mantra drives the current study regarding the lived experiences of individuals with ADHD. As I am situated within the community of adults with a late ADHD diagnosis, the rationale for a better understanding of lived experiences is based on the lack of current research as well as my own lived experiences and interaction with other adults with ADHD, diagnosed or suspected. Many of these interactions occur through online blogs and support groups where members ask for ADHD advice and detail the struggles that adults with ADHD face daily. Throughout my academic studies related to ADHD thus far, I have yet to read any research that conveys the struggles expressed in ways that are discussed within such support groups by adults with ADHD or suspected ADHD.

The lack of personal experiences within the research literature is surprising given that ADHD has often been considered one of the most broadly researched disorders in the ***D****iagnostic and statistical manual of mental disorders* (DSM). Therefore, with the growing focus on ‘inclusion’ in society, personal experiences might be expected to guide research. However, within research within Aotearoa New Zealand, no studies could be found that solely communicated ADHD related experiences of adults with ADHD. This information vacuum lays bare the need for research within New Zealand authenticated by the currently unheard voices of individuals with ADHD.

The researcher’s interest was drawn to the possible differences between adults who have been diagnosed with ADHD at different stages of life. The stages of life that will be queried are individuals diagnosed in childhood (aged 12 and under), adolescence (aged 13-17), adulthood (aged 18+) and adults who suspect they have ADHD but are not diagnosed (aged 18+). The logic for these groupings is related to research, which found that early diagnosis and support allows for more positive outcomes (Halmøy et al., 2009). Specific topics of interest in relation to the participants' ADHD will centre around educational experiences, experiences regarding diagnosis or not having a diagnosis, and quality of life. It is expected that the Childhood Group will have had more positive experiences related to their ADHD than participants within the groups diagnosed later and those with no diagnosis due to the opportunity for earlier support. In addition, each group's experiences with ableism will be explored. As previously stated, the interest in ableism in this study is to examine group participants' internal and external experiences in relation to their ADHD or suspected ADHD.

Research Objectives and Questions

The objectives of this research are twofold. First, to investigate the life and ableist experiences of individuals who have received or believe they could receive a diagnosis of ADHD and the personal impact of these experiences. Results are expected to provide a clearer picture of the impact ADHD and ableism have on the lives of individuals with ADHD and highlight any differences between the four groups - adults diagnosed in childhood, adolescence, adulthood, and adults with suspected ADHD. Second, this research is seen as a quasi-exploratory pilot study which will help identify any issues in question and scale clarity, research methodology, data analysis, as well as further develop the researcher's competencies to expand this research at a doctoral level and guide future career paths (Gudmundsdottir & Brock-Utne, 2010). These aims and objectives will be explored through the following research questions:

1. What are the similar and differing experiences of adults in New Zealand diagnosed with attention-deficit/hyperactivity disorder (ADHD) in childhood, adolescence, or adulthood or who suspect they could receive a diagnosis of ADHD?
2. What are the similar or differing experiences of external and internalised ableism for adults in New Zealand diagnosed with attention-deficit/hyperactivity disorder (ADHD) in childhood, adolescence, adulthood or who suspect they could receive a diagnosis of ADHD?

Chapter 2: Literature Review

This chapter will examine a range of literature relating to ADHD to set the background and framework for this research. As a widely researched topic, ADHD has been studied and written about from many perspectives. Thus, much is known about its aetiology, diagnosis, home and educational impacts and interactions, treatments, and outcomes. However, much less is known about the lived experiences of adults with ADHD. Indeed, searches within WorldCat/org, which were expanded to include terms related to ADHD, attention deficit hyperactivity disorder and experiences, returned seventy-two peer-reviewed articles. Of those seventy-two articles, only seven were qualitative and focussed on the voices of individuals with ADHD. A further search for peer-reviewed articles within WorldCat/org was also expanded to include terms related to ADHD, attention deficit hyperactivity disorder and voice and qualitative. Only three of the thirty results were focused on the individual with ADHD rather than parents and educators. The 2017 New Zealand report on youth and families' experiences of living with invisible disabilities touches on childhood and adolescence experiences related to ADHD. However, none of the articles used for the systemic review solely focused on ADHD experiences in the report (Janson, 2017).

Additionally, within the Janson (2017) report, the voices of individuals with impairments are limited to seven pages of experiences shared by members of the Youth Engagement Group (YEG). They "have demonstrated natural leadership abilities and are provided with personal and professional development opportunities and mentoring support" (p. 6). While this is a positive interaction for this small group of YEG members, it is unlikely to represent most individuals with invisible impairments. Therefore, from the researcher's viewpoint, it is important to highlight what ADHD is and its impact to fully understand any insights gained in the experiences conveyed by participants within this study. This viewpoint will shape this chapter and present information and research regarding; what ADHD is, its history, diagnosis, gender differences, comorbidities, historical and current treatments, the impact on quality of life, and ableism.

ADHD Defined

It is important to clarify what attention-deficit/hyperactivity disorder (ADHD) is and is not to understand the impact of having ADHD. Previously ADHD has been described as a moral failing or the result of bad parenting (Barkley, 2015; Horton-Salway, 2018). Sadly, although these descriptions have been discredited through research, they still persist (Tatlow-Golden et al., 2016). Nevertheless, ADHD is currently understood to be a neurodevelopmental condition identified by a persistent pattern of behaviours - including hyperactivity, impulsivity, and inattentiveness - typically present before age twelve (American Psychiatric Association, 2013; Kooij et al., 2019). While the term inattentiveness is used as a key characteristic, inattention is often due to being overly attentive and therefore highly distractible (American Psychiatric Association, 2013). Neurodevelopmental conditions are referred to in the DSM as disorders, while within the ADHD community, they have increasingly been considered a neurologic diversity or as ‘neurodivergent’ as defined by Judy Singer in 1999 when speaking about her autism (Singer, 1999). The neurotypical, referring to those who do not have neurodevelopmental conditions, and neurodivergent terminology underlines the idea of variations in human development and humankind (Singer, 1999).

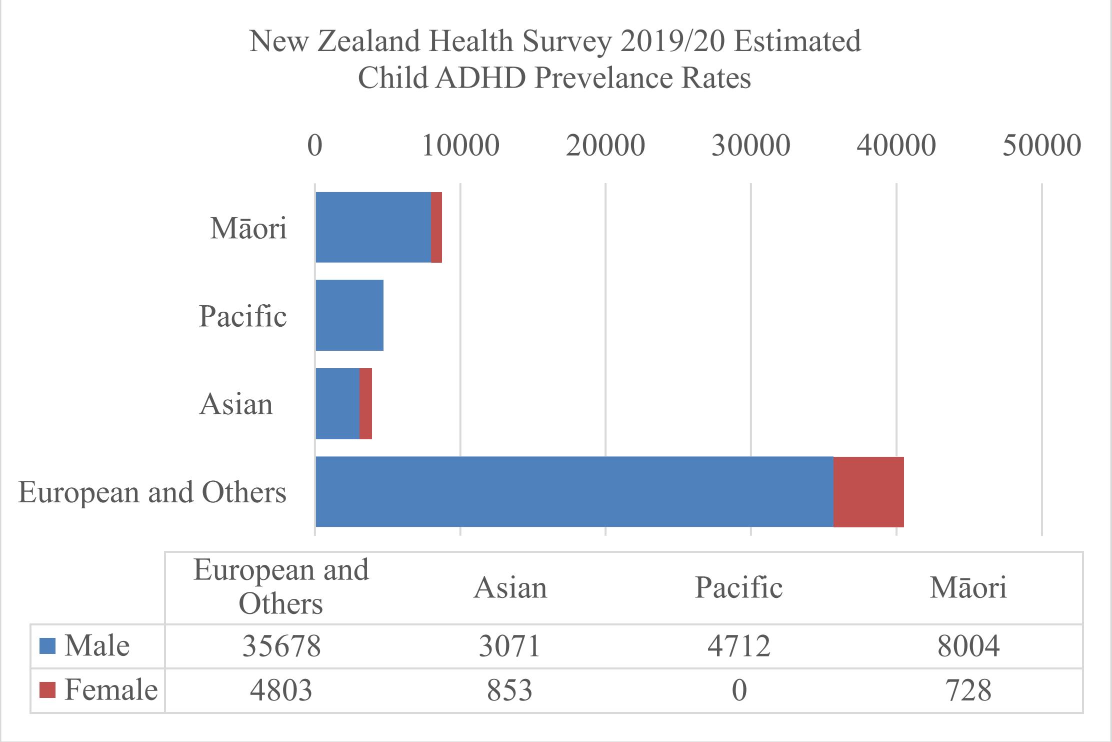
Within this line of thinking, ADHD is considered the result of polymorphic genes - variations in gene presentations (Logue & Gould, 2014). The impact of polymorphic variations decides the colour of our hair or eyes and, in this case, the systems that process certain neurotransmitters, i.e. dopamine, noradrenalin, and serotonin, that help regulate executive functioning (Logue & Gould, 2014). Executive functioning refers to a complex multi-faceted regulation of higher mental operations, including processes such as working memory, cognitive flexibility, planning, inhibition, and attention (Barkley, 2015; Logue & Gould, 2014). Discrepancies in executive functioning create difficulties and sometimes a complete inability to function or meet typically expected cultural norms as the individual might desire (Bjerrum et al., 2017). ADHD is a relatively common, inheritable condition with a lifespan perspective that often goes unrecognised due to its heterogeneous presentation and a history of misinformation and misrepresentation (Barkley, 2015; Kooij et al., 2019). Environmental factors can contribute to difficulties related to ADHD, including maladaptive emotional regulation strategies such as emotional suppression that can be adopted as a response to shame (Velotti et al., 2017).

In the past, ADHD was predominantly viewed as a childhood condition; however current research confirms that as many as 65% of childhood cases continue to struggle with ADHD characteristics in adulthood (Caci et al., 2015). Although geographical differences exist among prevalence rates, these are reported to be the results of methodological and cultural variations relating to the diagnostic criteria, interpretation of behaviours, and the presentations of impairments rather than true differences in actual rates (American Psychiatric Association, 2013; Caci et al., 2015). Worldwide ADHD prevalence rates are estimated to range from 2.5-7.1% in children and 5-7 % in adults

(Barkley, 2015; Caci et al., 2015; Chen et al., 2018; Garcia-Argibay et al., 2021). As detailed in *Figure 1,* the New Zealand Health Survey of 2019/20 reported unadjusted childhood prevalence and means for the total population are estimated at a total rate of 4.2% and predominantly male (Ministry of Health – Manatū Hauora, 2020). However, no questions regarding adult ADHD were included in this survey.

Figure 1

Estimated child ADHD prevalence rates New Zealand 2019/20



	European and Others	Asian	Pacific	Māori
🟦 Male	35678	3071	4712	8004
🟥 Female	4803	853	0	728

Family perceptions regarding ADHD characteristics are frequently unrecognised or dismissed as ‘normal’ behaviours by undiagnosed family members because of the high hereditability (American Psychiatric Association, 2013; Swanson et al., 2007). Therefore, undiagnosed family members are often diagnosed after their child has received a diagnosis. This high occurrence of heritability, in turn, makes genetics an area of interest concerning ADHD. While there are currently fourteen specific genes identified that relate to the presentation of ADHD, they are interactive effects rather than individual effects, which is why we are unlikely to see a genetic test for ADHD any time soon (Liu et al., 2021; Willcutt et al., 2010). In addition to genetic research, the emergence of positron emission tomography (PET) and functional magnetic resonance imaging (fMRI) that detail the brain's activity can help reveal previously hidden details (Abbas et al., 2019; Berberat et al., 2021; Fox et al., 2005; Spencer et al., 2007; Swanson et al., 2007). These details are analysed and compared between individuals with ADHD and their neurotypical counterparts. Findings include PET imaging which revealed significant differences between ADHD and non-ADHD adult dopamine transporter receptors (DAT) within the brain right caudate, which suggest that abnormal binding of DAT plays an essential role in the aetiology of ADHD (Spencer et al., 2007).

Research into the brain's function and organisation has uncovered the brain's default-mode network (DMN) and task-positive network (TPN). The DMN is activated during passive rest or mind-wandering but is deactivated during attention-specific or working memory tasks when the TPN activates (Abbas et al., 2019; Raichle, 2015; Spreng, 2012). Research in this field suggests that the "toggle switch" between these two networks can remain open in individuals with conditions such as ADHD (Hallowell & Ratey, 2021, p. 24). The open toggle switch means that the DMN can derail individuals with ADHD needing to function within the TPN during task-directed activities (Hallowell & Ratey, 2021). With ADHD, the result of this kind of derailment can manifest as distractibility or be seen as a lack of persistence in finishing projects (American Psychiatric Association, 2013). Thus, brain function and genetics reveal the realities behind ADHD and refute the simplistic approach of seeing ADHD as nothing more than a behavioural disorder, although there is an extensive history behind this misconception.

History of ADHD

The history of ADHD is extensive and the discussion that follows builds on the previous section by mapping out the complexity of ADHD's development over time and outlines why there has been much confusion around ADHD. Horton-Salway (2018) explores the discourses around ADHD and states that the concept of identifying a 'disorder' in children did not come about until the development of what they term the "psy disciplines" (p. 41). This sentiment is often used to address what is believed to be an excess of modern medicalisation of childhood behaviours. However, ADHD-like symptoms can be found even within some of the earliest writings. One such example is seen in Hippocrates' writings dated 493 BCE, which referred to adults who were quick to respond but highly distractible, raising the speculation that conditions such as ADHD have always been present (Martinez-Badía & Martinez-Raga, 2015). While this seems to be the earliest mentioning of characteristics resembling today's ADHD diagnosis, more recent examples can be found in Heinrich Hoffmann's writings dated 1856. A psychiatrist, Hoffmann wrote a collection of stories and poems originally for his young son and then for publication (Lange et al., 2010; Martinez-Badía & Martinez-Raga, 2015). Some of his titles include Slovenly Peter, Straw Peter, Johnny look-in-the-Air, and the ever famous - Fidgety Philip which presents boys with ADHD-like characteristics as having flaws of moral character (Lange et al., 2010; Martinez-Badía & Martinez-Raga, 2015). At the same time, other references and related terminology are seen in the medical literature from as early as 1775, as seen in *Table 1* (Barkley & Peters, 2012; Lange et al., 2010; Martinez-Badía & Martinez-Raga, 2015).

Table 1

Past ADHD-like medical terminology and authors

Medical Terminology and its Authors

Year Documented	Terminology Used	Authors
1775	attention deficit	M. A. Weikard
1798	disease of attention	A. Crichton
1812	syndrome involving inability to focus attention	B. Rush
1848	nervous child	C. West
1859	hypermetamorphosis	H. Neumann
1885	mental instability	D-M. Bourneville
1892	unstable nervous system	T. C. Albutt
1899	simple hyperexcitability	T. S. Clouston
1902	defect of moral control	G. F. Still
1932	hyperkinetic disease of infancy	F. Kramer & H. Pollnow
1957	hyperkinetic impulse disorder	M. Laufer, E. Denhoff & G Solomons

Note. Terminology listed was used in medical reports and textbooks to describe ADHD-like characteristics before Still's (1902). This table is a reproduction of data from Martinez-Badía & Martinez-Raga (2015) and Lange et al. (2010)

Sir George F. Still, a British paediatrician, is known as "the father of British paediatrics" (Dunn, 2006, p. 1). Still delivered his now-famous Goulstonian Lectures to the Royal College of Physicians of London in 1902, which he titled "On Some Abnormal Physical Conditions in Children" (Still, 1902). In the lectures, Still described a group of children whose characteristics he defined as having a defect of moral control but not impaired intellectually and not suffering a physical disease. Of the twenty children Still observed, fifteen boys and five girls, which he reportedly felt reflected proportionate ratios of showing deficits of moral control (Lange et al., 2010). Still states that these children showed symptoms of this deficit before the age of seven, the most common being "an abnormal degree of passionateness (sic)", which is described as an outburst of emotion (Still, 1902, p. 1009). Still also stated that these cases showed an "abnormal incapacity for sustained attention" (Still, 1902, p. 1166). While Still's descriptions of children with a 'defect of moral control' do not entirely align with today's ADHD diagnosis, they are nonetheless viewed as historical in the contemporary conceptualisation of ADHD (Horton-Salway, 2018; Lange et al., 2010; Martinez-Badía & Martinez-Raga, 2015).

Additionally, while not directly related to today's ADHD diagnosis, the encephalitis lethargica epidemic is linked to ADHD epistemology. At the beginning of 1917, encephalitis spread worldwide, affecting approximately 20 million people, and subsequently impacted the understanding of previously observed ADHD symptomatology (Lange et al., 2010). The long-term impact of encephalitis, which is referred to as postencephalitic behaviour disorder, created symptoms resembling ADHD, including distractibility and hyperactivity (Lange et al., 2010). The findings supported the concept that childhood behaviour could be related to brain function, which further added to the foundation of the current ADHD diagnosis as biological (Lange et al., 2010).

Time produced multiple concepts about the epistemology of ADHD-like symptoms. As the twentieth century progressed, one of these was the concept of minimal brain dysfunction (MBD). The idea of MBD, either at birth or a functional brain disturbance, was the cause of hyperkinetic syndrome (Lange et al., 2010). Clements

(1966), as part of a national task force established in 1963 by the National Institute of Neurological Diseases and Blindness, defined minimal brain function as:

> The term minimal brain dysfunction refers to children of near average, average or above average general intelligence with certain learning or behavioural disabilities ranging from mild to severe, which are associated with deviations of function of the central nervous system. These deviations may manifest themselves by various combinations of impairment in perception, conceptualisation, language, memory and control of attention, impulse or motor function. (p. 9-10)

This definition also helped shift the focus from environmental and social factors to an emphasis on the neurological. Additionally, the characteristics defined by the task force formally established the three main symptoms of ADHD within the MBD definition (Clements, 1966; Lange et al., 2010).

Despite this advancement, some argued that the diagnosis of MBD was too varied. This issue led to more specific classifications, including; hyperactivity, dyslexia, language disorders, and learning disabilities (Lange et al., 2010). Hyperactivity was viewed as a behavioural condition that could evolve by biological or non-biological means but considered biologically-based rather than environmental (Barkley, 2015). The second edition of the *Diagnostic and statistical manual of mental disorders* (DSM-II) first used the conceptual definition of hyperactivity in 1968, labelled hyperkinetic reaction of children (Barkley, 2015; Lange et al., 2010). The disorder was characterised by distractibility, restlessness, overactivity, and a short attention span, predominantly found in children and typically declining by adolescence (Barkley, 2015). With the publication of the DSM-III in 1980, the hyperkinetic reaction was relabelled as attention deficit disorder (ADD) with or without hyperactivity (Epstein & Loren, 2013). This diagnosis was more about attention, impulsivity, and hyperactivity than previous descriptions. In 1987 ADD without hyperactivity was removed from the DSM-III-R and replaced with attention-deficit/hyperactivity disorder (ADHD) (Epstein & Loren, 2013). The fourth edition (DSM-IV) was published in 1997, retaining the ADHD terminology and adding subtypes; predominantly hyperactive/impulsive, predominantly inattentive, and combined (Epstein & Loren, 2013). ADHD was categorised as a behavioural disorder in early editions of the DSM. This categorisation changed in the most recent version, DSM-V, released in 2013. The category change was the first of numerous minor updates found in the DSM-V, but one of the most meaningful as it acknowledged the previously understood and currently accepted fact that ADHD is a neurodevelopmental condition (American Psychiatric Association, 2013). Other DSM-V diagnosis criteria changes included;

- *evidence of impairment* was changed to *evidence of symptoms*
- *clinically significant impairments* was changed to *reduce the quality of social, academic, or occupational functioning*
- autism spectrum disorder was no longer an exclusionary diagnosis
- *ADHD subtypes* were changed to *ADHD presentations*
- mild, moderate, and severe were added as diagnostic modifiers.
- provisions for an adult diagnosis

These most recent changes represent the constantly evolving research and steered the diagnosis of ADHD into the 21st century. However, the perception of ADHD has not shifted so readily from the concept of being the result of behavioural problems (Horton-Salway, 2018; Tatlow-Golden et al., 2016).

ADHD Diagnosis and Outcomes

The natural progression to build the understanding of experiences that are directly related to ADHD is its diagnosis. In many countries general practitioners diagnose ADHD, however, in this country, the New Zealand Ministry of Health (2001) sets the guidelines for diagnosing and treating ADHD. These guidelines specify that an individual is typically referred to a psychiatrist or paediatrician for diagnosis, and appointments can be attained by self-referral or referrals by school faculty, concerned parents, a general practitioner, or a registered psychologist. An extensive assessment is required that often includes long questionnaires for the individual, family members, teachers, or others with whom the individual interacts. Through the public system, this process can take from three to as long as nine months; that is when the public system considers the case extreme enough. If one can afford to be assessed privately, there is still a three to six-month wait, and it can cost from $400 to $600, and sometimes more.

As previously stated, the current guidelines for diagnosing ADHD are laid out in the ***Diagnostic and statistical manual of mental disorders***. To reflect current research, the DSM-V has updated the ADHD diagnosis criteria to reflect the understanding that ADHD frequently continues into adulthood (American Psychiatric Association, 2013). As presented in *Table 2*, eighteen characteristics, nine in each category, inattention and hyperactivity/impulsivity, make up the diagnostic criteria (American Psychiatric Association, 2013). Meeting the threshold for diagnosis in each category requires

Table 2

ADHD diagnosis criteria

A persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development, as characterised by (1) and/or (2):			
Note:	The symptoms are not solely a manifestation of oppositional behaviour, defiance, hostility, or failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.		
1	**Inattention:** Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:	**2**	**Hyperactivity and Impulsivity:** Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities:
a.	Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities (e.g., overlooks or misses details, work is inaccurate).	**a.**	Often fidgets with or taps hands or feet or squirms in seat.
b.	Often has difficulty sustaining attention in tasks or play activities (e.g., has difficulty remaining focused during lectures, conversations, or lengthy reading).	**b.**	Often leaves seat in situations when remaining seated is expected (e.g., leaves his or her place in the classroom, in the office or other workplace, or in other situations that require remaining in place).
c.	Often does not seem to listen when spoken to directly (e.g., mind seems elsewhere, even in the absence of any obvious distraction).	**c.**	Often runs about or climbs in situations where it is inappropriate. (Note: In adolescents or adults, may be limited to feeling restless.)
d.	Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (e.g., starts tasks but quickly loses focus and is easily side-tracked).	**d.**	Often unable to play or engage in leisure activities quietly.
e.	Often has difficulty organising tasks and activities (e.g., difficulty managing sequential tasks; difficulty keeping materials and belongings in order; messy, disorganised work; has poor time management; fails to meet deadlines).	**e.**	Is often “on the go,” acting as if “driven by a motor” (e.g., is unable to be or uncomfortable being still for extended time, as in restaurants, meetings; may be experienced by others as being restless or difficult to keep up with).

f.	Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g., schoolwork or homework; for older adolescents and adults, preparing reports, completing forms, reviewing lengthy papers).	**f.**	Often talks excessively.
g.	Often loses things necessary for tasks or activities (e.g., school materials, pencils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones).	**g.**	Often blurts out an answer before a question has been completed (e.g., completes people's sentences; cannot wait for turn in conversation).
h.	Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts).	**h.**	Often has difficulty waiting his or her turn (e.g., while waiting in line).
i.	Is often forgetful in daily activities (e.g., doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).	**i.**	Often interrupts or intrudes on others (e.g., butts into conversations, games, or activities; may start using other people's things without asking or receiving permission; for adolescents and adults, may intrude into or take over what others are doing).

(American Psychiatric Association, 2013, pp. 59-60)

individuals aged sixteen and under to display at least six characteristics. Individuals seventeen and over require only five or more characteristics for a diagnosis. However, in both categories, the characteristics would need to have been present for six months or more and be viewed as developmentally inappropriate. Alongside meeting the distinct categorical criteria, the characteristics must be present before age twelve; experienced in two or more settings; clearly interfering with the quality of life; and lack a better explanation, i.e., mood disorder, anxiety disorder, thyroid issues.

ADHD presentations are currently diagnosed as one of three types: predominantly hyperactive/impulsive, predominantly inattentive, or combined presentations. Additionally, the DSM-V stipulates that the presentations can be further defined as mild, moderate, and severe - depending on the level of social and occupational impairment

(American Psychiatric Association, 2013). There also exists a diagnosis of ‘other specified ADHD’. This category is diagnosed when characteristics are subclinical but cause significant distress or impairment and the category is clarified by a defined reason, i.e. “with insufficient inattentive (hyperactive) characteristics” (American Psychiatric Association, 2013).

Individuals with ADHD often experience negative academic, social, and emotional consequences resulting from characteristics and related impairments associated with ADHD (Bjerrum et al., 2017). ADHD characteristics often present as drifting off-task often resulting from distractibility, which may be seen as a lack of persistence (American Psychiatric Association, 2013). The behaviours related to ADHD may also reflect difficulties in maintaining focus on uninteresting tasks, and a lack of organisation which on the whole would not be attributable to defiance or lack of comprehension (American Psychiatric Association, 2013). Equally, hyperactivity can be experienced as an excess of physical or mental activity, which may include excessive or repetitive movement or fidgeting, and racing internalised and externalised thoughts (American Psychiatric Association, 2013; Kooij et al., 2012).

The presentation of ADHD characteristics listed in *Table 2* can lead to many struggles at every stage of life; these can include personal, relational, educational, and occupational difficulties (Ahnemark et al., 2018; Asherson et al., 2012; Eccleston et al., 2019; Holthe & Langvik, 2017; Pawaskar et al., 2020; Rucklidge et al., 2016; Taylor et al., 2014; Young & Cocallis, 2019; Young & Woodhouse, 2020). Research repetitively details the negative impact ADHD can have on families, within educational settings, and its societal burden via higher resource consumption (Asherson et al., 2012; Bjerrum et al., 2017; Young et al., 2020). For the individual, negative experiences exist for both diagnosed and subclinical as well as those who are not recognised or diagnosed (Uneri et al., 2015). These experiences include reduced education engagement and higher peer victimisation (Uneri et al., 2015). Additionally, educational impacts have been shown to occur due to teachers' awareness of an ADHD diagnosis and, in turn, rating those students as under-achieving (Metzger & Hamilton, 2020). Conversely, the research also revealed that teachers were less likely to acknowledge students with ADHD who achieved above their grade level (Metzger & Hamilton, 2020). Females of all ages may be more likely to present with more subtle presentations of ADHD, and experiences may be internalised (Young et al., 2020). Individuals with ADHD are more likely to use nicotine and illegal substances with a higher likelihood to develop substance use disorder than their non-ADHD peers even when moderators such as gender, age and ethnicity were factored in (Lee et al., 2011).

Adolescents with ADHD are an especially 'at-risk' group. This group experiences a higher rate of suicidal ideation, self-harm, and completed suicides related to a higher rejection rate due to being different from their peers (Balazs & Kereszteny, 2017; Bjerrum et al., 2017; Eccleston et al., 2019). In addition, adolescents with ADHD experience significant physical and emotional impacts that can undermine an individual's self-concept (Eccleston et al., 2019). Feelings of frustration can intensify due to a lack of agency, i.e., voicing their feelings and experiences (Eccleston et al., 2019). These frustrations can lead to conflict and the rejection of treatment, medical or otherwise (Eccleston et al., 2019).

As diagnosed adolescents move into adulthood, they can feel the full weight of one of the most stigmatising conditions in the DSM-V (Gwernan-Jones et al., 2016; Kooij et al., 2019). Many of the same presentations exist for adults that children and adolescents experience, however, as a person ages there is less and less understanding around the cause of these behaviours and more overall judgment (Chigome et al., 2018). After all, adults should not have issues with organising themselves, being on time, completing projects or curbing impulsive behaviour, yet these tasks are all connected with impaired executive functions, which are key aspects of ADHD (Chigome et al., 2018; Kessler et al., 2010). Often by adulthood, hyperactivity shifts to extreme restlessness, while impulsive and inattentive behaviours may include hasty actions or decisions made with little or no forethought (Goodman, 2009). Childhood impulsivity that is affected by immediate rewards or an inability to wait for outcomes manifests in adults as social introversion and making critical decisions without considering long-term consequences (American Psychiatric Association, 2013). Inattentive children who cannot keep track of belongings can become unorganised adults who can be late to work due to time blindness, have unsettling repetitive behaviours such as rechecking doors to confirm they are locked, and constant internal rumination (Hansson Halleröd et al., 2015; Holthe & Langvik, 2017).

If this is the case for diagnosed adults, imagine the internal working for the 65% of individuals who never received a diagnosis and therefore lack the internal understanding of why they behave the way they do (Chigome et al., 2018). For these individuals, there is often a greater degree of substance abuse, decreased academic attainment, increased unemployment, accidents, arrests, and higher rates of mortality that even higher intelligence quotient (IQ) did not mitigate when compared to individuals with ADHD and average IQ (Antshel, 2008; Chigome et al., 2018). Many people receive diagnoses for anxiety or depression, among other conditions, instead of a diagnosis of ADHD, especially women (Quinn & Madhoo, 2014).

Gender Differences

There can be gender differences in presentations of ADHD, and these are worth examining to create a broader understanding of ADHD. Currently and for many years, ADHD has been perceived as a predominantly male condition at a ratio anywhere from 2:1 to 3:1, with females reported to be diagnosed more often with the inattentive presentation (American Psychiatric Association, 2013; Lange et al., 2010). However, as research into those gender differences expands, these ratios are questioned as adult women are a growing diagnostic population (Vildalen et al., 2019; Young et al., 2020).

Murray et al. (2019) conducted a seven-year longitudinal study that reported an increased vulnerability and symptoms in early adolescence for females and males with ADHD. The study revealed that there were gender differences in developmental trajectories. Females exhibited increased symptomatology in early adolescence compared to males who presented elevated symptoms from childhood (Murray et al., 2019). Thus, females with predominantly hyperactive/impulsive or combined presentations risk not being diagnosed due to the onset criteria currently set at age twelve. However, Groenewald et al.(2009) found that teachers could recognise ADHD characteristics in female students yet viewed themas emotional or attention difficulties rather than related to ADHD. Other studies suggestthat differences in childhood and adult diagnosis ratios are associated with female symptom presentations and the perceptions of those presentations due to gender biases, e.g. gender-typical behaviours, and compensatory strategies adopted by females (Younget al., 2020). These strategies include coping mechanisms such as 'masking' behaviours,engaging in negative social supports, and self-medicating with alcohol and drugs, all of which can delay referrals for diagnosis of ADHD (Quinn & Madhoo, 2014). In apparentcontrast, other research indicates that females may have higher tolerances to genetic andenvironmental exposures, which have been linked to ADHD; this effect has been termedthe 'female protective effect' (Taylor et al., 2016).

Vildalen et al. (2019) conducted a study that compared the frequency and severity of ADHD characteristics between a large group of ADHD male and female adults (n = 682) compared to non-ADHD male and female adults (n = 882). Contrary to other studies, Vildalen et al. (2019) reported that females with ADHD had more extreme inattentive and hyperactivity and impulsivity characteristics; those presentations were higher than non-ADHD females than those between ADHD and non-ADHD males (Hasson & Fine, 2012). While a population-based study conducted in Norway revealed gender differences in prevalence rates of comorbid conditions were significantly larger in females, related to anxiety, depression, bipolar disorder, and personality disorders by as much as twice that of their male counterparts (Solberg et al., 2018). Conversely, the opposite showed to be accurate for substance use disorders and schizophrenia. No matter the gender, comorbidities, an overlap of conditions clearly complicates the diagnosis and treatment of ADHD.

Comorbidities

ADHD often presents with other comorbid conditions, which have been referred to as the rule rather than the exception. Often the most referred to are oppositional defiance (ODD) and conduct disorder (CD) (American Psychiatric Association, 2013).

The DSM-V states that almost half the individuals with ADHD and ODD are diagnosed with combined and a fourth with inattentive presentations. While CD is comorbid with ADHD in a quarter of combined presentations, this depends on age and situation (American Psychiatric Association, 2013). ADHD is sometimes seen as the principal diagnosis in ODD and CD while others coexist, e.g. disruptive mood dysregulation disorder. In contrast, others are secondary, which include affect disorders such as anxiety and major depressive disorder. Substance use disorder is comorbid with ADHD and is seen at a higher rate than the general population (American Psychiatric Association, 2013). International research identifies other conditions that can coexist with ADHD, including learning disorders (reading – 12-36%, writing (unknown), mathematics – 12-36%); substance use disorder (SUB - unknown); tic disorders (20-30%); obsessive-compulsive disorder (OCD – unknown); affect disorders (10-40%); and up to 50% may have developmental coordination disorder (DCD) (Pitcher et al., 2003; Taurines et al., 2010; Taurines et al., 2012; Willcutt et al., 2010). Solberg et al. (2018) state that many comorbid diagnoses of affect disorders and substance abuse disorders are directly related to underlying ADHD.

Within New Zealand, research among adults with ADHD has revealed that the rate of affect disorders (65%) was twice that of the general population (Rucklidge et al., 2016). The same study found that adult alcohol abuse was two times higher, while social phobias and substance abuse were three times higher than the general population. New Zealand has also reported that 30-61% of those diagnosed with ASD have ADHD (Janson, 2017). These comorbidities are not surprising as the neurobiological aspects of conditions such as ADHD, ASD, and OCD can be remarkably similar, to the point that there is a body of research that proposes that they exist along a continuum rather than in separate categories (Kern et al., 2015; Kushki et al., 2019). This research is further supported as the literature suggests that the probable causes for these comorbidities are genetic, epigenetic, neurobiological, and environmental (Dewey, 2018). No matter the epidemiology, the dire circumstances related to diagnosing ADHD as well as any comorbid conditions is highlighted by the significant association relating severity of ADHD and coexisting affect and substance abuse disorders with self-harm, recurrent suicidal ideation and previous suicide attempts (Barkley, 2015; Taylor et al., 2014). These points clarify the significant importance of early ADHD diagnosis with appropriate follow-up support and treatment.

Treatments – Historical and Current

ADHD treatments and their history are also needed to better understand the overlapping complexities of an ADHD diagnosis. While many options for ADHD treatment exist, the most effective remains stimulant medications. These medications were accidentally found by Charles Bradley, who reported the first trial of stimulant medications to treat ADHD-like symptoms in 1932 (Lange et al., 2010; Martinez-Badía & Martinez-Raga, 2015). Bradley performed pneumoencephalograms as medical director of the Emma Pendleton Bradley Home in Rhode Island, which served neurologically impaired children. The procedure was used on vulnerable patients before disability and children's rights were established by the United Nations (U.N. General Assembly, 1989, 2006). Atropine and codeine were used as premedication, while avertinand ether were given during the procedure in which oxygen or air was injected into the spine via a lumbar puncture (Ishaque et al., 2017). The air was reported to allow for a more precise resolution of intracranial structures and abnormalities when x-raying the skull (Ishaque et al., 2017).

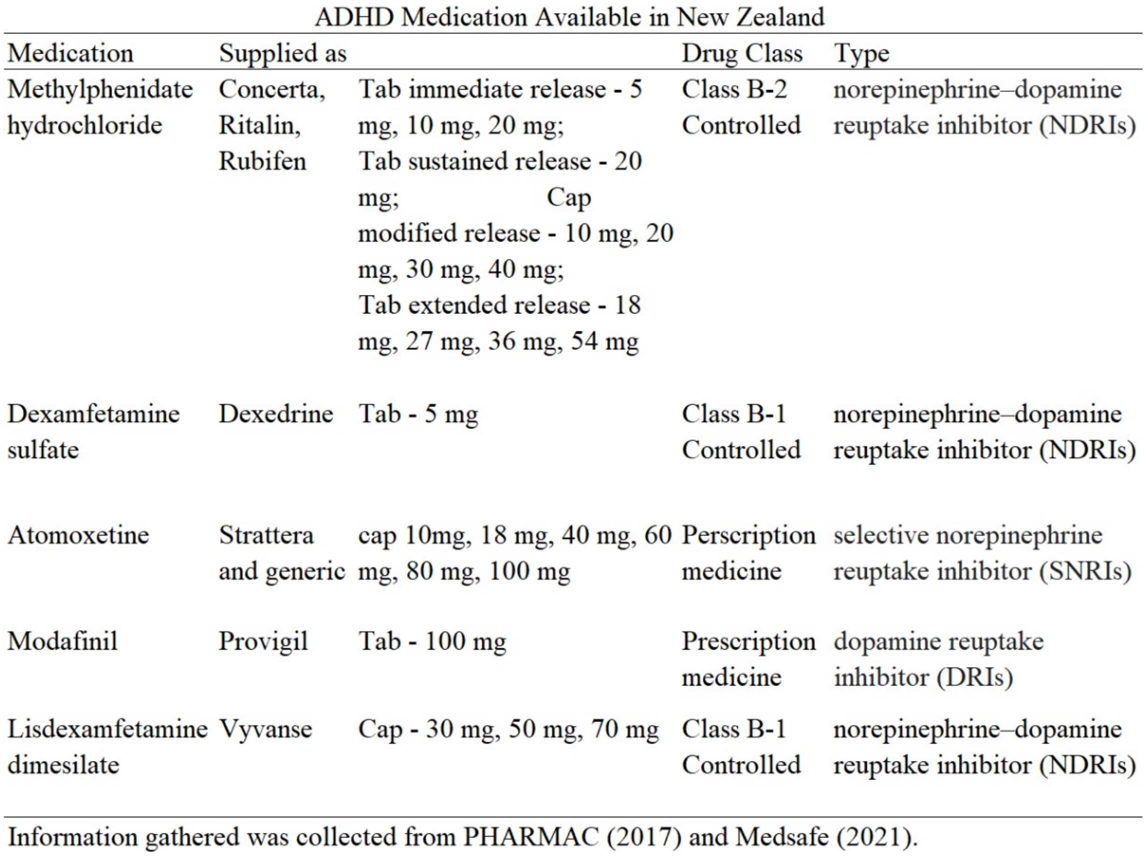
Bradley's goal was to examine the patients for structural brain abnormalities (Lange et al., 2010). However, the invasive procedure was known to cause headaches, vomiting, tachycardia, neck stiffness, and nausea, while some reports documented a 30% mortality rate of the procedure (Ishaque et al., 2017). As a result, Bradley treated the side effects experienced by his young patients with Benzedrine, reported to be the most potent stimulant available in 1932 (Lange et al., 2010). Although the patients experienced no relief from the headaches, there was a substantial improvement in academic performance and behaviour (Lange et al., 2010). After a trial with thirty of his patients, Bradley identified specific characteristics of children who benefitted from the Benzedrine treatment; these characteristics included memory issues, inattentiveness, impulsivity, hyperactivity, emotional dysregulation, and dyscalculia (Lange et al., 2010).

Despite the outcome, from what would be considered by today's standards a cruel procedure and a violation of the United Nations Commission on the Rights of the Child (UNCRC), it would be another twenty-five years before this research had any impact. Eventually, stimulants were again investigated by Laufer et al. in 1957 (as cited in Lange et al., 2010) to treat children diagnosed as hyperkinetic. However, by 1957 the stimulant methylphenidate had already been produced by Leandro Panizzon, which he named for his wife Rita in 1944. Ciba-Geigy Pharmaceutical Company first marketed Ritalin in 1954 and is still known as one of the most successful and frequently prescribed psychostimulants for ADHD (Lange et al., 2010).

Hallowell and Ratey (2021) reported that thirty-four variations of medications are currently available to treat ADHD. However, as seen in *Table 3,* there are currently only eight brand name and generic drugs within New Zealand specifically used to treat ADHD. Hallowell and Ratey (2021) explain that these drugs work by increasing the

Table 3

Current ADHD medications approved in NZ



ADHD Medication Available in New Zealand

Medication	Supplied as		Drug Class	Type
Methylphenidate hydrochloride	Concerta, Ritalin, Rubifen	Tab immediate release - 5 mg, 10 mg, 20 mg; Tab sustained release - 20 mg; Cap modified release - 10 mg, 20 mg, 30 mg, 40 mg; Tab extended release - 18 mg, 27 mg, 36 mg, 54 mg	Class B-2 Controlled	norepinephrine–dopamine reuptake inhibitor (NDRIs)
Dexamfetamine sulfate	Dexedrine	Tab - 5 mg	Class B-1 Controlled	norepinephrine–dopamine reuptake inhibitor (NDRIs)
Atomoxetine	Strattera and generic	cap 10mg, 18 mg, 40 mg, 60 mg, 80 mg, 100 mg	Perscription medicine	selective norepinephrine reuptake inhibitor (SNRIs)
Modafinil	Provigil	Tab - 100 mg	Prescription medicine	dopamine reuptake inhibitor (DRIs)
Lisdexamfetamine dimesilate	Vyvanse	Cap - 30 mg, 50 mg, 70 mg	Class B-1 Controlled	norepinephrine–dopamine reuptake inhibitor (NDRIs)

Information gathered was collected from PHARMAC (2017) and Medsafe (2021).

availability of dopamine and norepinephrine within the brain. Neurotransmitters such as these are used to relay information in the synapsis between nerve cells of the brain. Of these neurotransmitters, dopamine and norepinephrine help regulate the brains' attention system, which explains the paradoxical nature of giving stimulant medication to a hyperactive individual. Thus, the increase in the availability of particular neurotransmitters that support executive functioning can calm the brain's need for movement and promote attention (Barkley, 2015; Hallowell & Ratey, 2021).

Stimulant medications have been proven successful, particularly when coupled with cognitive behavioural therapy (CBT) (Weiss et al., 2012). Concern over the impact of stimulant use in children has centred around worries that the consistent, early and long-term use of stimulants and lower socioeconomic status correlate with reduced height and weight growth compared to non-ADHD cohorts (Yackobovitch-Gavan et al., 2021). However, research also shows the detrimental effect of ADHD when left untreated. Effects include a greater risk of affect disorders, smoking, substance use, serious accidents, and higher rates of comorbidity (Kooij et al., 2012; Rucklidge et al., 2016). Moreover, the use of stimulant medication for ADHD in childhood has shown to be a strong predictor of employment in ADHD adults and reduce substance use disorders in adults by as much as 50% (Halmøy et al., 2009; Huss & Lehmkuhl, 2002). Despite this, there is fear related to the abuse of ADHD stimulant medication (Kooij et al., 2012). Thus, some either do not want to use or allow their children to take these medications or find they cannot take them due to side effects or ineffectiveness. In these cases, the options are typically a collection of other 'tools'. As previously mentioned, CBT is very effective in helping children and adults with ADHD (Weiss et al., 2012). Other measures may include diets, food avoidance, organisational apps, ADHD coaches, meditation, yoga, self-medicating with caffeine, legal and illegal drugs, e.g. marijuana and alcohol (Brod et al., 2012; Kooij et al., 2012; Rucklidge & Blampied, 2011; Schreuer & Dorot, 2017).

Recent research has found that high-grade micronutrients administered by capsule or powder mix have been shown to improve resilience for those with ADHD in adults, for some to subclinical levels (Rucklidge & Blampied, 2011). However, considerable ADHD roadblocks reduce the practicality of micronutrients. These include the high cost of high-grade micronutrients and the number of capsules (or smoothies) required three times daily to maintain results. Another option showing significant positive impact is routine exercise by improving executive functioning and self-regulation as it naturally raises dopamine levels (Hagerman & Ratey, 2014). This measure also has issues for those with ADHD since engagement is interest-based or externally motivated; thus, individuals may have difficulty engaging or remaining engaged with a regular exercise routine if it is not part of their focused interest. What is clear is that awareness and treatment of some kind are imperative.

There is a large body of research that focuses on the social and financial impact of ADHD. The personal financial impacts of untreated ADHD can create short-term difficulties in maintaining jobs or being promoted and difficulties managing budgets (Bjerrum et al., 2017). At the same time, societal impacts have been found in significantly higher medical costs (Asherson et al., 2012), early interaction with the criminal justice systems with a higher occurrence of adult reoffending, and increased driving offences and accidents (Young & Cocallis, 2019). Treatment choices are personal and as varied as individual ADHD presentations. However, finding a personalised, effective, and sustainable treatment is often a long journey of trial-and-error, and rarely do treatments completely alleviate the impact ADHD has on a daily basis in both external and internal lives (Barkley, 2015; Stein & McGough, 2008).

Quality of life and ADHD

The World Health Organization (WHO) defines quality-of-life as an;

> individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (World Health Organization, 1997, p. 1).

This concept is all-encompassing and woven with the threads of an individual's physical and psychological health, personal agency and beliefs, social interactions, and environment (World Health Organization, 1997).

Attention-deficit hyperactivity disorder is typically recognised and diagnosed by externalised behaviour in childhood or adolescence; however, it is now accepted that ADHD is often a lifelong condition. Ahnemark et al. (2018) found that nearly half their patients (49%) had psychiatric comorbidities, most often anxiety and affect disorders among adults diagnosed later in life. Brod et al. (2012) found that despite little difference in the presentation of ADHD across a lifetime, ADHD produces an accumulative burden that affects the social, professional, and financial achievements of older ADHD adults. Although ADHD symptomatology did not seem to increase over the lifetime, the cumulative detrimental impact was emphasised by significantly lower quality of life scores on the Adult ADHD quality of life scale (AAQOL) - than the study's younger ADHD adults (Brod et al., 2012).

Salvi et al. (2019) found that when studying ADHD persisting across the lifespan, contrary to the DSM-V, a significantly higher percentage of females presented with hyperactive presentations than males who presented more often as inattentive (American Psychiatric Association, 2013). Therefore, the female hyperactive presentation of ADHD may be linked to more internalised symptomatology rather than externalised (Salvi et al., 2019). Additionally, the research found that individuals with the hyperactive-impulsive subtype showed a more significant decrease in quality of life and interpersonal relationships and increased anxiety disorders. Overall, research shows that ADHD impacts the quality of life across a lifetime via low self-concept, relationship issues, communication issues impacting parenting skills, academic outcomes, and employment achievement (Barkley, 2015; Brod et al., 2012; Goodman, 2009).

Asherson et al. (2012) focused on the cultural influences involved in diagnosing adult ADHD. They noted that adults with ADHD often underestimate the impact of their

ADHD characteristics because they have learned to compensate. These adults appear externally to function to the norm, i.e., masking, but are inevitably expending excessive amounts of energy to maintain the appearance of normalcy (Asherson et al., 2012; Bjerrum et al., 2017). This expenditure in turn taxes the adult's ability to sustain those compensatory measures across interactions (Chigome et al., 2018; Hinshaw et al., 2021; Kooij et al., 2019; Young et al., 2020). Ultimately, these measures were shown to consistently, but often inconsistently, impact poor time management, procrastination, difficulty retrieving thoughts, organising tasks, distractibility, and self-inhibition. All of which can affect each area of life, i.e., relationships, occupation, education, and overall societal interaction, thus adding to daily stress related to ADHD symptomatology on a day-to-day basis (Bjerrum et al., 2017; Chigome et al., 2018). As stated previously, research has shown that higher ability does not mitigate these outcomes (Antshel et al., 2009).

A population-based study in Sweden with a sixteen-year follow-up found that individuals with ADHD had lower income (17%) and greater unemployment when compared with those with no ADHD with an equal level of education (Jangmo et al., 2021). Fredriksen et al. (2014) found that when inattentive characteristics persist into adulthood, they result in higher occupational impairment, while hyperactive-impulsive characteristics are associated with higher school dropout rates. The impact on social life was most significant for both groups when researching social life, family life, home responsibilities, and occupational interactions with diagnosed or symptomatic ADHD (Pawaskar et al., 2020). However, this research found that those with no ADHD diagnosis experienced more significant functional impairment over the measured quality-of-life categories than those who had been diagnosed.

The importance of diagnosis is counterbalanced by the fear of an ADHD label, i.e., diagnosis, often related to internalised negative discourses of differences and disabilities (Horton-Salway, 2018). Educators, parents, and even individuals with ADHD may often think of a diagnosis, and its subsequent labelling as detrimental, e.g. stigmatising (Metzger & Hamilton, 2020). The stigmatisation of labelling someone with ADHD is a reality that is often perpetuated unknowingly and invisibly (Gwernan-Jones et al., 2016). A logical response would be to forgo labelling to avoid stigmatising. However, as covered earlier, this answer to stigmatisation has the inevitability of leaving the individual with ADHD adrift without the knowledge or tools to traverse daily social interactions and, more importantly, understand themselves (Ohan et al., 2011; Pawaskaret al., 2020).

Additionally, Meza et al. (2019) found that awareness of an ADHD diagnosis mediated negative judgements and social distancing among teachers when presented with vignettes describing students with ADHD characteristics. Thus, the rejection of a perceived stigmatising label may harm more than help the individual with ADHD. The added negative association of defining ADHD as a disorder or a disability may also feed the stigmatism of an ADHD label. This rejection is likely amplified due to cultural and social perceptions regarding ability and disability (Gwernan-Jones et al., 2016).

Disability and Ableism

Thus far, this chapter has focused on the history and realities related to ADHD. Attention will now shift to consider the societal norms concerning living with the impairments of ADHD and its relationship with disability. The social model of disability is embodied in this quote from the United Nations *Convention on the Rights of People with Disabilities Preamble* (UNCRPD);

> … disability is an evolving concept…disability results from the interaction

> between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others (U.N. General Assembly, 2006, p. 1)

This model identifies that the barriers for those with impairments are only those created by the attitudes and environments they exist in (Degener, 2016). However, this heterogeneous concept of impairment fails to recognise the internal impacts of those impairments on the individual. Examples of these impacts could be physical or mentalpain experienced due to a condition or the impact of impairments in executive functioning, as in those who are neurodivergent (Degener, 2016). While the previous quote embodies the social model of disability, the overriding concept laid out in the UNCRPD is more aligned with the human rights model of disability, as detailed by Degener (2016). Stretching beyond the social model, the human rights model identifies impairments as a condition that, despite possibly reducing the quality of life, still embodies humanity and therefore must be respected as variations in humankind (Degener, 2016). This distinction is significant because it is estimated that "almost everyone is likely to experience some form of disability ─ temporary or permanent ─ at some point in life" (World Health Organization, 2020, para. 1). The UNCRPD introduced equality law and laid the groundwork for individuals with disabilities to challenge discrimination (U.N. General Assembly, 2006). Despite measures such as the UNCRPD, stigma against individuals with impairments and disabilities prevails, leaving much work to do to recognise and value varied individual human experiences (Kooij et al., 2019; Metzger & Hamilton, 2020; Meza et al., 2019; Tatlow-Golden et al., 2016; Young et al., 2020).

A beginning to this work can be an understanding of the concepts of ableism and disablism. In order to understand ableism, it is vital first to understand disablism, which is a set of conscious or unconscious assumptions and practices that promote unequal treatment of a person based on actual or supposed disabilities (Campbell, 2008; Campbell, 2009). The premise is that there could be nothing worse than to be disabled (Dolmage, 2017). Ableism skips this outright stigmatisation of disability and focuses solely on uplifting able-bodiedness and able-mindedness (Dolmage, 2017). These concepts are two sides to the same coin ever in tandem, however as stated by Dolmage (2017);

> Ableism renders disability as abject, invisible, disposable, less than human, while able-bodiedness is represented as at once ideal, normal, and the mean or default. (p.7)

These prejudices are the grounding for the 'othering' of individuals with disabilities that create barriers and unequal treatment that subjugates those with actual or perceived disabilities by favouring the 'norm', and the concept behind critical disability theory (Campbell, 2008; Hosking, 2008).

While most people may baulk at the thought of explicit disablism, they might quite freely speak of concepts relating to able-bodiedness and able-mindedness. These conscious and unconscious attitudes on disability exist in a complex dance that hides the impact of internalised disability stereotypes and representations; thus, they are not often recognised as being negative (Friedman & Owen, 2017). The expectation or admiration that an individual overcomes their disability or impairment or the push to cure a disability underlies those implicit ableist beliefs that being disabled is a tragedy (Dolmage, 2017). The 'overcomer' can be seen as an example of what can be achieved despite a disability. More modern terms like "supercrip" and "inspiration porn" refer to the use of an individual with an impairment or disability to inspire those without impairments - ‘if they can do it, what is your excuse’ (Grue, 2015; Young, 2014).

However, it is easy to see that this can also be used to motivate those with impairments as well. For ADHD, this can happen when people, primarily neurotypicals, hold up examples of those with ADHD who have achieved extraordinary success. The tragedy and inspiration tropes are at risk of being externalised by individuals who do not currently have an impairment; however, they also may be internalised by those who do. Campbell (2008) defines internalised ableism as the disabled individual conforming to the dominant norm by assuming “an ‘identity’ other than one’s own” (p. 157). Thus, internalised ableism is fabricated through interactions with oppressive social and economic systems that can produce self-loathing and self-recrimination regarding their disability and rejection of others experiencing those disabilities (Campbell, 2008). This concept of policing one's body is discussed by Kattari et al. (2018) as part of internalised ableism experienced by individuals with invisible impairments. These findings related feelings of shame, frustration, and stigmatisation regarding interactions in every aspect of life. The importance of shame cannot be overlooked as Velotti et al. (2017) found that shame is associated with low self-worth and is thought to increase emotional dysregulation. An additionally critical point explains that different types of impairments may produce different types of ableist discrimination. This point is particularly true when considering the invisible nature of neurodivergent impairments such as ADHD.

Summary

In this chapter, literature relating to ADHD has been reviewed and discussed from a historical and diagnostic perspective to highlight the many transformations ADHD has experienced. These transformations, while progressive, also stand at the heart of multiple levels of misinformation and misrepresentations regarding ADHD. The impact of gender, comorbidities, and treatments has been explained and examined to create a guideline to assess the study results that is the topic of this thesis. In addition, relevant literature concerning quality of life, disability, and ableism as they relate to ADHD has also been presented. These topics form the foundation of questions that were the subject of this research project. Chapter 3 details this study’s research design, methods, and rationale.

Chapter 3: Research Design and Methodology

This chapter presents the researcher's role in this study in conjunction with the research methods, design, and rationale. The aim of this research was to explore the gap identified in current literature regarding the lived and ableist experiences and the perceived impact of those experiences on adults who have been or believe they could be diagnosed with ADHD within the New Zealand context. This chapter describes the research design, including the theories that underpin it and why they are well-matched to this study (See *Table 4*). The participants and their selection, research instruments and procedures are presented and explained. The research questions, practices for collecting, managing, and analysing data, and ethical considerations are also detailed.

Table 4

Research design synopsis

Worldview (paradigm)
Pragmatism is a combination of deductive and inductive reasoning, which the researcher utilises as a project unfolds. This combination draws on various ideas and tactics that respect objective and subjective knowledge - a ‘what works’ approach (Creswell & Plano Clark, 2018). Thus, knowledge or objects of knowledge are constructs. John Dewey viewed this as transactional constructivism - holding knowledge while being constructed and reality (Biesta, 2010). This worldview allows for both interpretivist and transformative approaches to be utilised.

Ontology
Singular and multiple experiences are based on a social ontology that views the world as one of meaning and interpretation (Biesta, 2010).

Epistemology
Subjective epistemology embraces that knowledge is based on the knowers who hold the knowledge and experience the phenomenon (Biesta, 2010).

Theoretical lens
The hermeneutic phenomenological theory focuses on the personal experiences of individuals or groups to understand the essence of a phenomenon.

Critical disability theory focused on shifting the concept of disability away from able-bodied perceptions to focus on the voices and experiences of adults with disabilities as a path to advocacy and social justice.

Axiology
Multiple stances – includes biased and unbiased viewpoints.

Topic: Unheard Voices: Adults with ADHD in Aotearoa New Zealand

Research Question
What are the similar and differing experiences of adults in New Zealand diagnosed with attention-deficit/hyperactivity disorder (ADHD) in childhood, adolescence, or adulthood or who suspect they could receive a diagnosis of ADHD?

What are the similar or differing experiences of external and internalised ableism for adults in New Zealand diagnosed with attention-deficit/hyperactivity disorder (ADHD) in childhood, adolescence, or adulthood or who suspect they could receive a diagnosis of ADHD?

Sample
Eight participants aged 18 and over were sorted two each into four groups: those diagnosed with ADHD in the Childhood Group (aged 1-12), Adolescence Group (aged 13-17) and Adulthood Group (18+), and adults who suspect they have ADHD (aged 18 +).

Methodology
Mixed-method phenomenological research (MMPR) was used to explore participants' in-depth descriptions and meanings of lived experiences (Mayoh & Onwuegbuzie, 2015).

Methods of data collection
Online qualitative surveys through Qualtrics Online Software and one-to-one quantitative semi-structured interviews via online Zoom meetings were used to collect data.

Rhetoric
Descriptive and narrative

Design and Rationale

Philosophical assumptions outline the researcher's worldview or paradigm; these fundamental beliefs are used to process the character of experience and understanding (Creswell & Plano Clark, 2018; Kaushik & Walsh, 2019). Biesta (2010) argues that pragmatism should not be viewed as a paradigm but opens the possibility of challenging different designs and knowledge claims. Thus, the pragmatic worldview was used in this research as a conduit of flexible thought, making available a broad choice of research methods. While not assumed to be the final summation on any topic, pragmatism is determined to pursue ethical treatment for each individual and allows for combining worldviews to meet this study's aim (Creswell & Plano Clark, 2018; Kaushik & Walsh, 2019). Combining worldviews enabled an interpretivist and transformative approach to be used (Creswell & Plano Clark, 2018). This combination permitted participants' perspectives and societal perspectives, multiple ontological and epistemological subjectivities, and researcher and participant collaboration (Creswell & Plano Clark, 2018). Within the pragmatic worldview, it was determined that the best methodological approach would be a mixed-method phenomenological research (MMPR) exploration of the experiences of adults with diagnosed and suspected ADHD (Mayoh & Onwuegbuzie, 2015).

Phenomenology is the essence of how a phenomenon is described within lived experiences and as an object of conscious reflection (Peoples, 2020). As detailed by Peoples (2020), a philosophical phenomenology baseline has two foundational theoretical frameworks - Edmond Husserl's transcendental phenomenology and Martin Heidegger's hermeneutic phenomenology. As with most theoretical frameworks, these increase objectivity and encourage consideration outside of the researcher's thoughts. Heidegger's hermeneutic phenomenological framework moved away from Husserl's original transcendental phenomenology because Heidegger did not believe one could set aside one's biases. Husserl called this process epoché or bracketing and believed that a researcher could suspend all personal judgments and biases when focusing on a phenomenon. Heidegger believed epoché was impossible to achieve within the context of existing, what he called dasein - the German term for 'being there' or 'presence'. The

English translation would be ‘existence’ - the state of being in the world. Each individual is dasein, the self within the context of their existence.

Heidegger suggested that the hermeneutic circle could be used to arrive at the essence of a phenomenon. The hermeneutic circle is a method that uses the researcher's preconceived knowledge, what Heidegger called fore-sight, such as biases, understandings, or judgements, as a process of understanding (Heelan & Schulkin, 1998; Peoples, 2020). For example, this process analyses the whole (a transcript) and then parts (codes and themes) of the data. This information is dissected and integrated, which begins the process again, encouraging new interpretations and understandings. The whole gives insights into the parts, and the parts give insights to the whole. Heidegger's view was that the repeated process of exploring a phenomenon through the researcher's fore-sight and returning to the experiences that participants relate to the phenomenon produced a continual re-evaluation of the new understandings of the phenomenon. Although represented as a circle, this method is often called the 'hermeneutic spiral' as each repetition of inquiry is designed to progressively reveal the essence of the phenomenon being studied (Heelan & Schulkin, 1998; Peoples, 2020).

Besides hermeneutic phenomenological theory (HPT), critical disability theory (CDT) was used as an additional lens within the hermeneutic circle. CDT is part of the critical theory that seeks to pull back the curtain of normativity to expose unjust social processes. Specific critical theories have emerged which focus on class, race, gender, sexuality, and disability. Hosking (2008) states that CDT does not view disability as an "inevitable consequence of impairment but as a complex socially constructed interrelationship between impairment, individual response to impairment, and the social environment"(p. 17). Hosking also notes that the social disadvantages experienced by disabled people result from equity failures within social environments for people who exist outside able-bodied norms. CDT incorporates a variation of the social model, which merges the medical and social models of disability into what the World Health Organization (WHO) calls a 'biopsychosocial model' (Hosking, 2008; World Health Organization, 2011). Furthermore, Hosking (2008) asserted that "this approach balances the contributions of impairment, personal responses to impairment and the barriers imposed by the social environment to the concept of disability" (p. 7). Through this model of disability, CDT shifts the concept of disability away from able-bodied perceptions to focus on the voices and experiences of adults, in this case, with diagnosed and suspected ADHD, as a path to advocacy and social justice.

In deciding on suitable theoretical frameworks for this research, other frameworks were considered. Ethnography was contemplated; however, it would have required focussing more on the cultural aspects of ADHD in adults (Creswell & Plano Clark, 2018). This focus fell short of the desired experiential focus on lived experiences that were to be included in this research. A case study framework was also considered, but it would have limited the objective of documenting the participants’ lived experiences as envisaged (Creswell & Plano Clark, 2018).

Consequently, a phenomenological plus quantitative (Phen + Quan) model of MMPR was deemed the best option to explore in-depth descriptions and personal meaning of participants’ lived experiences (Mayoh & Onwuegbuzie, 2015). This exploration and interpretation of participants' experiences associated with ADHD and ableism, coupled with the researcher's existing fore-sight, provided the opportunity to bring new understandings and advocacy to light. These understandings will be the foundation of future, broader research on ADHD within the Aotearoa New Zealand context that the researcher intends to engage in next. Thus, qualitative data was collected and analysed concurrently using the hermeneutic circle and a CDT lens in this research while incorporating statistical analyses on the quantitative data (Creswell & Plano Clark, 2018; Hosking, 2008; Mayoh & Onwuegbuzie, 2015). Although uncommon in hermeneutic phenomenological research, the use of MMPR design allows for identifying and cross-validation of corresponding quantitative and phenomenological data within one study (Mayoh & Onwuegbuzie, 2015). Additionally, the hermeneutic phenomenological framework permits a detailed analysis of individual and collective experiences as a lived process, while CDT facilitates the troubling of disability perceptions alongside any experienced and internalised ableism.

Researcher's Role

The hermeneutic phenomenological principle of fore-sight is especially critical to my role as the researcher in this study. Being diagnosed with ADHD as an adult and being a member of the ADHD New Zealand Adult Support Facebook Group gave me an intimate perspective on participants' experiences when utilising the hermeneutic circle to analyse data. In addition, this insider's view comes with the immense responsibility to conduct myself with a sense of balance and open-mindedness regarding participants' individual experiences and different perceptions regarding the research topic compared to my own. While not personally acquainted with the participants prior to the study, the possibility of us having similar experiences related to coping with the impact of the impairments associated with ADHD guided my interactions with them. I made every effort to communicate an attitude of acceptance devoid of judgment to create a safe environment where the participants could discuss their experiences in response to the interview/survey questions related to the research questions. Upon reflection, I believe this effort and openness permitted a level of raw vulnerability that most participants displayed in interviews, which some later described as "cathartic".

Participants

The sample for this study were eight participants who were members of the ADHD New Zealand Adult Support Facebook Group. The eight participants volunteered and were randomly selected from four groups based on the stage of life in which the participants received their original ADHD diagnosis (childhood, adolescence, adulthood) or, if they suspected they could receive an ADHD diagnosis.

Research Instruments

Stage 1 of this study was quantitative and included an online expression of interest survey followed by invitation to complete an online consent and research survey. The research survey consisted of questions related to participants' demographics and their ADHD diagnosis and treatment. Additional questions dealt with ableist perceptions relating to the social requirements to behave as ‘normal’ and the participants’ feelings about ADHD. The Adult ADHD Self-Report Screening Scale for DSM-V (ASRS-5) and the ADHD Impact Module for Adults - Adult ADHD Quality of Life survey (AAQoL) were also included (Brod et al., 2006; Brod et al., 2012; Ustun et al., 2017). Stage 2 of this study was the qualitative phase which involved individual semi-structured interviews where participants shared life experiences related to having ADHD.

Stage 1 Instruments

Expression of Interest Survey

An authorised advertisement (Appendix D) that invited an Expression of Interest (Appendix E) was presented to the members of the ADHD New Zealand Adult Support Facebook Group to filter interested participants into study groups based on their age of ADHD diagnosis (Childhood, Adolescence, Adulthood) and those who suspected they could be diagnosed with ADHD.

Demographic Questions

The study's demographic questions in Stage 1 (Appendix F) were specific to participants' age, gender, education, self-assigned ethnicity, New Zealand citizenship, relationship, and employment status. These questions were followed by statements and questions related to participants' ADHD diagnosis, medication taken, the impact of the diagnosis or lack of one. Additionally, other non-medical treatments and any known comorbid conditions were queried. Each demographic inquiry enabled greater transparency regarding any possible similarities or differences between individual participants and study groups, i.e. Childhood, Adolescence, Adulthood, and those who suspected they could be diagnosed with ADHD.

Ableism Questions

Although scales to assess ableism were investigated, only those related to microaggressions of others toward individuals with disabilities were found. Therefore, five statements (Appendix F) were designed to assess the participants' perceptions and feelings about ADHD and its impact on their interactions with others and their self-assessment. Each item was scored using a five-point Likert-like scale from one (Strongly disagree) to five (Strongly agree). These scores were used to calculate the group means for comparison.

The Adult ADHD Quality of Life Scale

The Adult ADHD Quality of Life Scale (AAQoL) was developed and validated by Meryl Brod, Joseph Johnston, Stephen Able, and Ralph Swindle (2006). The purpose of this scale was to assess life-related quality to the individual's perceived place within their existing culture and social norms concerning their goals, hopes, and concerns. Further research conducted outside of the United States of America supported the validation and reliability of the AAQOL for use in European countries (Brod et al., 2015). For these reasons, permission to use the AAQOL in this study was sought and subsequently granted by Meryl Brod via email on 20 September 2020 (Appendix B). Permission was also granted to change specific wording to meet the New Zealand context (apartment for flat, balancing checkbook for tracking spending, and family for whānau).

The questionnaire consists of twenty-nine items that comprise four subscales of eleven Life Productivity items, six Psychological Health items, seven Life Outlook items, and five Relationships items (Appendix F). Brod et al. (2006) presented Cronbach's α was 0.93 for Total score, 0.88 for Life Productivity, 0.83 for Psychological Health, 0.79 for Life Outlook and 0.75 for Relationships indicating strong internal consistency and thus high reliability (Brod et al., 2006). These results were closely replicated in the European study (Brod et al., 2015). Each item was scored using a five-point Likert-like scale from one (Not at all/Never) to five (Extremely/Very Often). The total and subscale scores were attained by first reversing item scores for negatively worded items and converting all item scores to a 0–100-point scale. Once item scores were converted through this process, they were totalled and divided by item count to produce scores for each subscale and an overall total. Higher subscale and total scores indicate an increased quality of life.

Adult ADHD Self-Report Screening Scale

The Adult ADHD Self-Report Screening Scale (ASRS v1.1) is a six-item questionnaire based on an eighteen-item ADHD checklist. Both versions were developed and validated to align ADHD symptoms as detailed in the *Diagnostic and statistical manual of mental disorders IV* (DSM-4) (Kessler et al., 2005). The scale and scoring were a joint venture between the Workgroup on Adult ADHD and the World Health Organization (WHO) to support healthcare providers as an initial screening tool for adult ADHD (Kessler et al., 2005). Later the ASRS-5 (Appendix F), a six-item version of the ASRS v1.1, was developed to meet the updated DSM-V ADHD criteria (Ustun et al., 2017). The ASRS-5 items include four classic ADHD symptoms, but two items were changed from the previous version to reflect co-occurring symptoms of executive dysfunction (Ustun et al., 2017). The ASRS-5 has been assessed to effectively recognise the symptoms of ADHD in individuals aged eighteen years and older with a sensitivity of 91.4% and a specificity of 96.0% in general population samples (Ustun et al., 2017). In the study that is the subject of this thesis, the ASRS-5 was utilised as a predictor of the ADHD related impairment that each participant may be experiencing, which suggests the need for a comprehensive assessment (Anbarasan et al., 2020). The simple scoring method was utilised for this study which did not require permissions (Ustun et al., 2017). Each item was scored using a five-point Likert-like scale from zero (Never) to five (Very

Often) to give a continuous score of 0-24, with a score of 14 or greater suggesting the need for further ADHD screening (Ustun et al., 2017).

Stage 2 Instruments

Interview questions (Appendix L) were developed to scaffold the semi-structured interviews with participants for the qualitative stage of this study. Initially, seven questions were set as code topics and decided based on possible life experiences that ADHD typically impacts. These included education, relationships, ADHD diagnosis or lack of, the impact on participant's quality of life (i.e. relationships, finances), 'passing as normal' and any impact or internalisation that it caused. A follow-up question asked in the first interview was added to each subsequent interview. This question related to the perceived impact earlier intervention and personal understanding of ADHD might have had. Each question was centred around participants’ experiences and their feelings about them. This approach was essential to using hermeneutic phenomenology and critical disability theory as it links participants' lived experiences related to ADHD and ableist interactions and their perceptions of its impact.

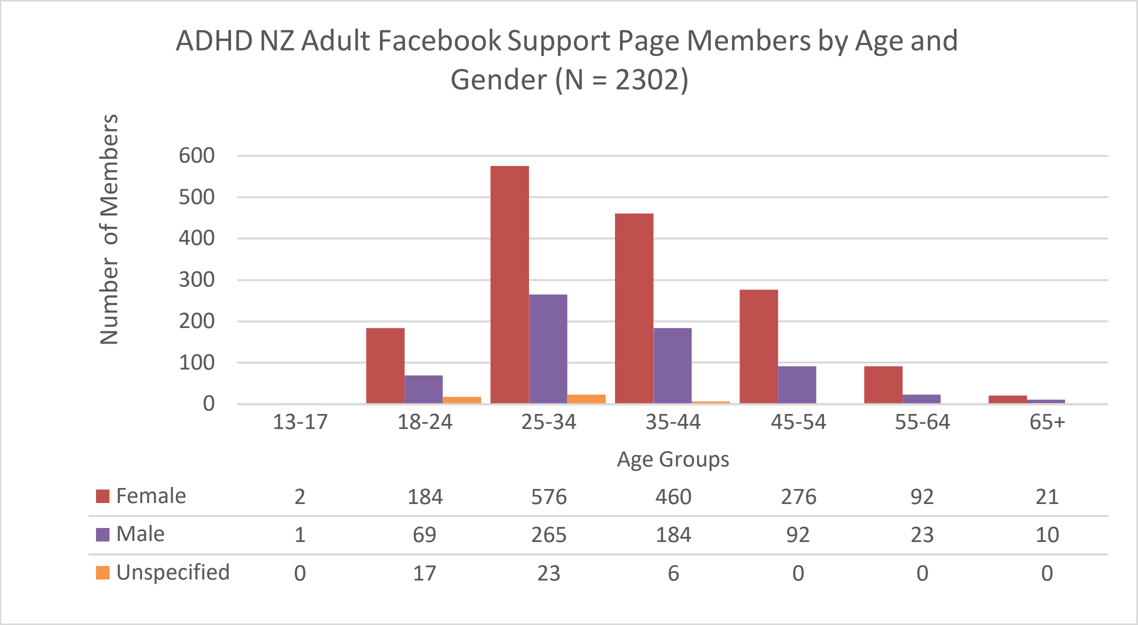
Procedure

Recruiting and Grouping Participants

Permission to post an advertisement for prospective research participants on the internet was made to ADHD New Zealand (ADHD NZ) via email on 22 September 2020 (Appendix A). Prospective participants for this study were members of the ADHD New Zealand Adult Support Group Facebook page (N = 2302). As per data supplied by ADHD NZ and detailed in *Figure 2*, the group’s population covered varied ages and was primarily females (70%), followed by males (28%) and unspecified genders (2%).

Figure 2

NZ Adult Facebook Support Page member demographics



An advertisement was created and submitted to the Adult Facebook Group page's administration for posting on 12 November 2020. The advertisement invited members to register their interest to participate in the research project via a link to the Expression of Interest Survey. A fifty-dollar Visa Prezzy Card was offered as time compensation for chosen participants who completed the interview process. Stratified purposeful sampling was used via a two-minute online survey to sort participants into the four distinct groups (adults diagnosed: at aged twelve or younger – Childhood Group; from aged thirteen to seventeen – Adolescence Group; aged eighteen and over - Adulthood Group; and adults aged eighteen and over with

Table 5

Expression of Interest by groups

Expression of Interest by groups

Adult expression of interest	Number of prospective participants
Childhood Group	9
Adolescence Group	10
Adult Group	131
Suspected Group	11
Total	161

suspected ADHD – Suspected Group). As detailed in *Table 5*, one hundred sixty-one members of the ADHD New Zealand Adult Support Group Facebook page registered an expression of interest to participate in this study by completing the survey or emailing the researcher requesting their details be added manually. The overwhelming response of support group members meant that registration closed on 14 November 2021.

Prospective participants of the three diagnosed groups were numbered in Excel and sorted by the age of diagnosis, while the Suspected Group was numbered and sorted alphabetically by first names. An online number generator was used to pick two participants from each group.

Stage 1 Procedures

Each randomly selected participant was then sent an email (Appendix H) through Qualtrics Online Survey Software, inviting them to participate in the study. The email included a link to the Stage 1 consent and survey created on Qualtrics. The survey was available to the participants from 14 November until 28 November 2020, and reminders were sent via Qualtrics on the 25th (Appendix J) and 27th (Appendix K) of November. Two participants did not complete the survey by 28 November. Randomised participant selection was restarted within the incomplete groups, and two new participants were emailed the Stage 1 consent and survey.

Stage 2 Procedures

Once participants had completed the Stage 1 survey, an automatic follow-up email (Appendix I) was sent via Qualtrics inviting each participant to book an open appointment slot that best suited their schedule in a linked online Google calendar for the Stage 2 interview. A ‘gentle’ reminder email was sent to participants in cases were meetings were not booked or missed. Interviews were conducted and recorded on Zoom video-telephoning software program. Video telephoning supported face-to-face interviews to encourage an increased sense of connection between the researcher and participants during interviews. After their interviews, participants were asked to email their details so that Prezzy Cards could be sent, and these were posted within two days. Interviews were transcribed using the dictate feature on Word and sent for participant approval within two weeks of their individual interviews. Transcripts were approved either by email from the participant or by default after a two-week window of no response, at which point the transcripts were entered into NVivo computer software.

Stage 1 and 2 Objectives

The objectives of Stage 1 of this study were to explore similarities and differences in participants' demographics, ADHD diagnosis, and treatment experiences. A mixture of researcher's questions and proven instruments to assess ADHD characteristics and the impact on the participants quality of life were used to assess quantifiable attributes of ADHD. The objectives of Stage 2 were to focus on the participants' lived experiences and perceptions of the impact ADHD had on their lives. The Stage 1 qualitative data was viewed as independently meaningful while providing more profound insight in combination with data from Stage 2 quantitative semi-structured interviews into the lives of adults living with ADHD. These measures were designed to open a window into the impact and experiences of participants to guide further studies the researcher wishes to complete.

Ethical considerations

All research needs a solid ethical grounding to protect the interests and rights of participants. In this case, participants were human; therefore, ethics approval was sought and received (Health - 2020#77) from the University of Waikato Human Research Ethics Committee (HREC) on 2 November 2020. These measures ensure detailed consideration for the participants' wellbeing and support the project's validity.

Minimising the Risk of Harm

Information was provided regarding support agencies, and participants were encouraged to access these agencies if they felt their participation impacted their emotional or mental wellbeing. Participants were reminded that they could withdraw from the research project at any point up until the final Interview Transcript approval date. At the beginning of Stage 2 interviews, the researcher disclosed their ADHD diagnosis. This interaction was done to present the interview as a safe, non-judgemental space that would not be impacted by typically ADHD characteristics that might be stress-inducing in interviews, i.e. fidgeting and distractibility. Participants were reassured that these characteristics would not be seen as an inconvenience.

Informed Consent

Informed consent was sought at each stage of the research project. (See Appendices F & G). The Expression of Interest advertisement contained a link to the Participant Information Sheet, introducing the researcher and detailing the project procedures. The Stage 1 survey required electronic consent to complete, and verbal consent was asked at the beginning of Stage 2 interviews. Participants were informed that they could withdraw from the research project until the end of the two weeks after receiving their complete transcript, during which participants could approve, edit, amend, or ask that their Interview Transcript be withdrawn.

Confidentiality

Identifiable information about participants and information they provide cannot be disclosed unless there is permission. It was essential to present findings in a way that ensures participants remain unidentifiable. Ethical guidelines indicate that a researcher should anonymise their research participants. Anonymity in this project was protected using pseudonyms chosen by the participants to assure their voices impact each aspect of this study alongside omitting details of specific employers or other personal information (Allen & Wiles, 2016).

Data Management

All participant information was carefully managed to ensure that privacy and confidentiality were maintained. All identifying information was changed or removed. The interview recordings were transcribed using the Word dictate feature and downloaded into NVivo. Recordings, transcriptions, and associated information were securely stored on an external hard drive, with only the researcher and supervisor having access. Upon completion, all data will be stored and protected in a secure hard drive for a total of five years.

Data Analysis and Explication

Analysis is the process of breaking apart the elements of a particular thing. This data analysis definition applied to Stage 1 of this project but was inappropriate in conjunction with the hermeneutic circle in Stage 2. For Stage 2, a process of explication expanded specific experiences by allocating meaning to unravel the underlying meaning overall, in this case, the experience of being an adult with diagnosed or perceived ADHD (Peoples, 2020).

Data Analysis for Stage One: Quantitative Data

Survey responses were transferred from Qualtrics to IBM Statistical Package for Social Sciences (SPSS 27) to conduct the data analysis. There was no missing data in the eight completed surveys. As previously stated, participant names were changed to pseudonyms, and codes for diagnosis groups were added. However, the analysis of the data with a primary focus on the group similarities and differences meant that while each participant was an integral part of this study the participant pseudonyms were not used in the reporting results and discussion. Due to the small sample size, most qualitative data was analysed using case summaries to assess group and participant similarities and differences. All reverse coded variables within the AAQOL were recoded and converted to 0-100 scores to assure accurate data analysis. The ASRS-5 and AAQOL group means were then assessed using a one-way between-group analysis of variance.

Data Explication for Stage Two: Qualitative Data

Interview transcripts were coded in NVivo computer software by question topics. These topics included education, relationships, ADHD diagnosis or lack of, the impact on participants' quality of life, and masking or passing as normal. Additionally, any impact or internalisation that ADHD caused, and the perceived impact of earlier intervention, and personal understanding of ADHD may have had. These coded topics were explicated using the hermeneutic circle to understand the implication of the experiences for the individual. This process was spiral in nature, using the whole transcript to look at explicated coded responses and then returning to the whole transcript. In addition, any similar or different experiences between participants' coded responses were examined using the same procedure. Within the use of the hermeneutic circle, the information was also assessed through the lens of critical disability theory. Coded responses were explored for experiential similarities and differences in participant responses.

Chapter Summary

Chapter 3 details the research study starting with the underpinning of a pragmatic worldview and the use of hermeneutic phenomenology and critical disability theory and how they are suited to this study (*Table 4*). The mixed-method phenomenological research (MMPR) methodology was deemed most appropriate for exploring the lived experiences of adults with diagnosed and suspected ADHD in an Aotearoa New Zealand context. Participants were introduced (*Table 5)* along with the process of their selection. The choice of research instruments and their related procedures was also presented and explained, along with the practices for data collection, management, analysis, and any ethical considerations. These details and processes are the lenses used to interpret the findings reported in Chapter 4.

Chapter 4: Results

With the research methods and design outlined, attention now turns to the results of this study. This chapter starts with a detailed account of the demographic characteristics of study participants. The focus then shifts to the results and findings from the Stage 1 questionnaire and the Stage 2 semi-structured interviews. These findings are detailed separately for each stage and followed by a final chapter summary. All interaction with participants and data collection was conducted online. The registration of interest and Stage 1 survey was presented through Qualtrics, whilst the one-to-one interviews took place through Zoom online.

Stage One Results: Online Survey

Observations

While there were numerous expressions of interest initially, participants were mixed in their approach to completing the survey once randomly selected; some completed the survey immediately, while others revisited it multiple times. Reminders were sent to two of the original eight participants, who were subsequently replaced as one never logged into the survey and the other did not complete the survey. Quantitative analysis from Stage 1 was conducted to explore the participants' similar and differing responses to specific ADHD experiences in the survey. The small sample size limited the statistical analysis of the data. Therefore, case summaries, detailed in tables and figures within this chapter, are mainly used to report findings related to the impact on the group participants’ quality of life and assessment of ADHD.

Demographic data

Members of the ADHD New Zealand Adult Support Facebook Group were invited to participate in this study. Eight participants were randomly chosen from those (n = 161) who registered interest in this study, and they were assigned into one of four groups. Groupings were based on the stage of life in which the participants received their original ADHD diagnosis (childhood, adolescence, adulthood) or if they suspected they could receive an ADHD diagnosis. As detailed in *Table 6*, participants were categorised into

Table 6

Participant demographics by diagnosis group

Study Group	Pseudonym	Age	Age of ADHD Diagnosis	Highest level of Education	Employment Status	Self-Assigned Ethnicities	Relationship Status
Childhood	Koda	20	11	L2 or less	Searching for Employment	NZ Pākehā	Committed relationship
	Lillian	30	6	L2 or less	Paid employment	Māori	Committed relationship
Adolescence	Edith	35	17	Bachelor's degree	Paid employment	Romani Gypsy	Single
	Ray	28	17	Trade degree/diploma	Student	British - NZ Pākehā	Committed relationship
Adulthood	Kirsty	32	31	Some UNI/no degree	Not Employed (health/disability)	Māori - NZ Pākehā	Committed relationship
	Peta	64	64	Master's degree	Self-Employed	Māori - NZ Pākehā	Divorced
Suspected	Raine	43		Some UNI/no degree	Prefer not to say	Māori - NZ Pākehā	Separated
	Sarah	37		Some UNI/no degree	Paid employment & student	NZ Pākehā	Committed relationship

the Childhood Group participants were age 20 (diagnosis age 11) and age 30 (diagnosis age 6). The Adolescence Group participants were aged 28 and 35, and both were diagnosed at age 17. The Adulthood Group participants were age 32 and 64 (and diagnosed at age 31and age 64, respectively). The Suspected Group participants were aged 37 and 43. Seven of the eight participants classified themselves as female and one as female/ish.

This gender data is somewhat surprising considering the 3:1 male to female ratio reported in the DSM-V and an 8:1 male to female childhood ratio reported in the NZ Health Survey 2019/20 (American Psychiatric Association, 2013; Ministry of Health – Manatū Hauora, 2020). However, this is not surprising when the ADHD NZ Facebook Support Group male to female ratios (2:5) are considered alongside the growing demographic of adult females diagnosed (Murray et al., 2019). This growing demographic of females who are diagnosed as adults may be more likely to search out support and connections to help them understand the full impact that ADHD has had on their lives. Additionally, support within ADHD communities is typically non-judgemental, and members are happy to share strategies and tools to cope with the impact of ADHD characteristics and its diagnosis.

The participants were ethnically diverse, identifying themselves as; Māori (n = 1), Māori and NZ Pākehā (n = 3), NZ Pākehā (n = 2), British and NZ Pākehā (n = 1), Romani Gypsy (n = 1). Seven participants identified that they were New Zealand citizens, and the eighth was a New Zealand resident. Participants were geographically spread throughout Aotearoa New Zealand, as detailed in *Figure 3*. Educational levels ranged from Level 2, the National Certificate of Educational Achievement (NCEA) or less to a master’s degree. Participants' employment status varied as well from job seeking to self-employed. Five participants reported that they were in committed relationships, one was single, one was separated, and one was divorced.

Figure 3

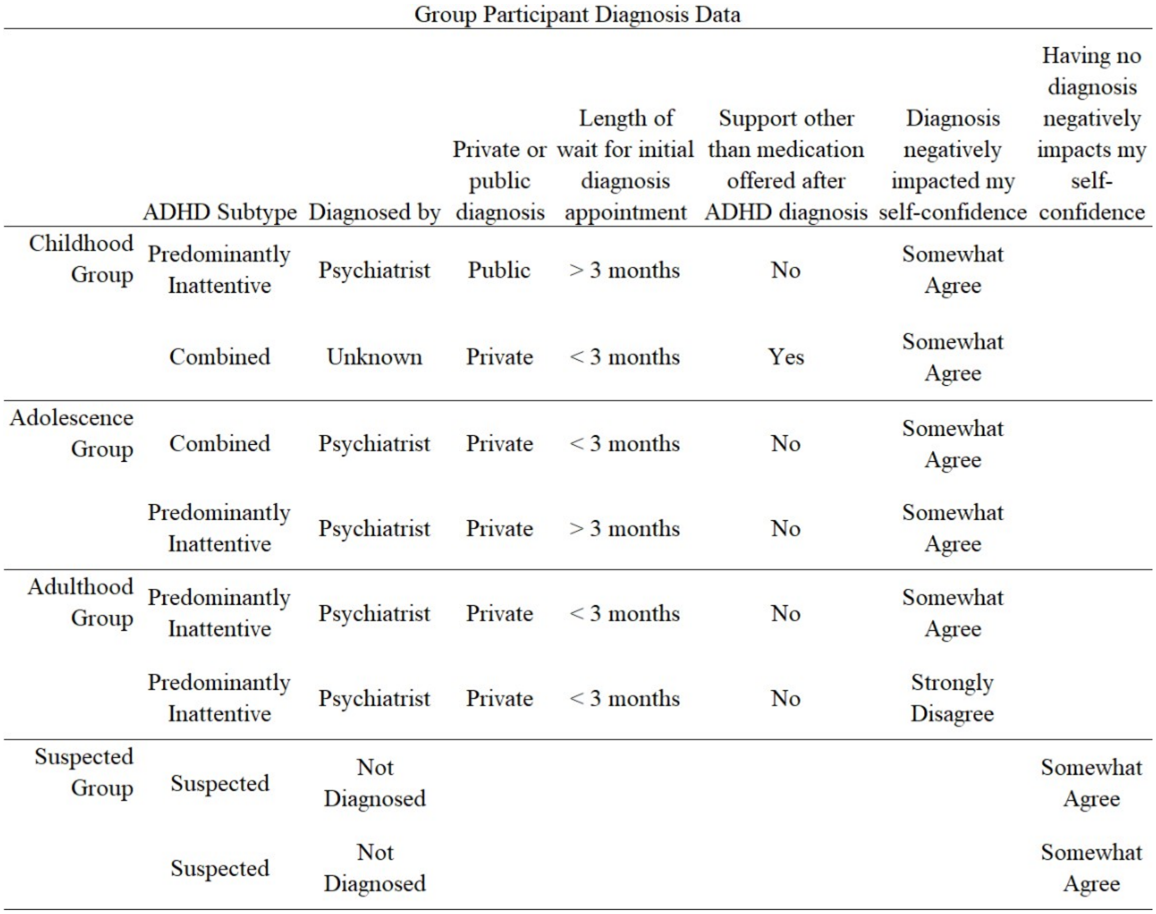
Map of participants geographical distribution

Experiences Related to Diagnosis

Most of the data from the Stage 1 surveys was examined with a case summary report conducted within SPSS, as detailed in *Table 7*. These revealed that along with those who suspect they have ADHD, there were participants in the Childhood and Adolescence and Adulthood Groups diagnosed with inattentive presentation and one with the combined presentation within the Childhood and Adolescence Groups. Of the three diagnosed groups, most participants were diagnosed by a psychiatrist and had received their diagnosis privately. Only one participant in the Childhood Group received a diagnosis through the public system. Two participants in the Childhood and Adolescence Groups waited longer than three months to see a psychiatrist. These waits can be a risk for students, especially if they need the diagnosis for special assessment conditions.

Table 7

Summary of participants' diagnoses information



Group Participant Diagnosis Data

	ADHD Subtype	Diagnosed by	Private or public diagnosis	Length of wait for initial diagnosis appointment	Support other than medication offered after ADHD diagnosis	Diagnosis negatively impacted my self-confidence	Having no diagnosis negatively impacts my self-confidence
Childhood Group	Predominantly Inattentive	Psychiatrist	Public	> 3 months	No	Somewhat Agree	
	Combined	Unknown	Private	< 3 months	Yes	Somewhat Agree	
Adolescence Group	Combined	Psychiatrist	Private	< 3 months	No	Somewhat Agree	
	Predominantly Inattentive	Psychiatrist	Private	> 3 months	No	Somewhat Agree	
Adulthood Group	Predominantly Inattentive	Psychiatrist	Private	< 3 months	No	Somewhat Agree	
	Predominantly Inattentive	Psychiatrist	Private	< 3 months	No	Strongly Disagree	
Suspected Group	Suspected	Not Diagnosed					Somewhat Agree
	Suspected	Not Diagnosed					Somewhat Agree

Only one participant from the Childhood Group was offered support from their psychiatrist beyond ADHD medication. The lack of support, such as cognitive behavioural therapy (CBT), which has been proven effective, represents a missed opportunity to help create a positive footing to build a new awareness of self for newly diagnosed individuals (Weiss et al., 2012). Furthermore, this lack of support links to individuals with ADHD, especially those with new diagnoses, who turn to online ADHD communities for support. It also reflects the crucial gap in support that associations such as ADHD NZ fill for people looking for direction and connection.

Responses to the survey questions about the perceived impact of a diagnosis on the participant's self-confidence showed that a diagnosis was a factor that negatively impacted self-confidence for both participants of the Childhood Group and one participant of the Adolescence Group. However, the Adulthood Group and remaining Adolescence Group participants recorded responses of 'somewhat and strongly disagree' regarding their diagnosis having a negative impact on their self-confidence. At the same time, participants in the Suspected Group felt that having no diagnosis negatively impacted their self-confidence, possibly due to the validation that can happen for adults when receiving a diagnosis (Hansson Halleröd et al., 2015). Response differences between participants diagnosed earlier than the other diagnosed participants may reflect the lack of agency felt when diagnosed early in life, as discussed by Eccleston et al. (2019). The negative impact, with or without a diagnosis, may relate to several different factors: the previously mentioned lack of support at diagnosis, internalised ableism (Campbell, 2008; Weiss et al., 2012), and the stigma related to a diagnosis of ADHD (Gwernan-Jones et al., 2016).

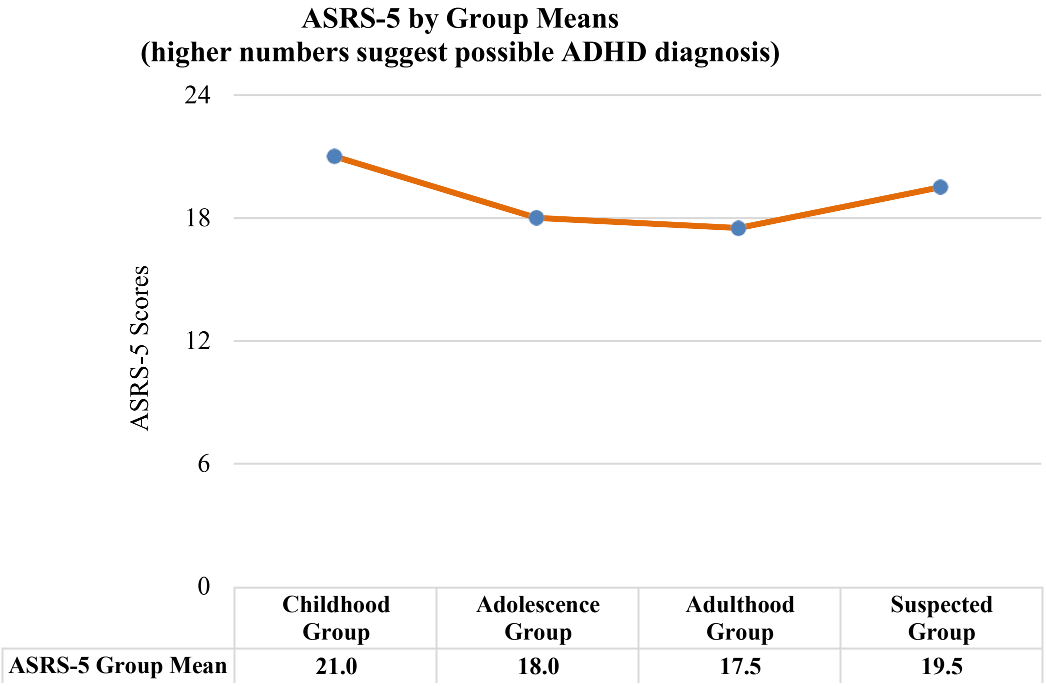
As seen with the Adulthood Group and the remaining Adolescence Group participant, despite ADHD being seen as a stigmatising diagnosis, awareness of a diagnosis has been shown to mediate other's negative judgements and perceptions; however, awareness may not negate self-judgements (Meza et al., 2019). Additionally, for those participants who characterized their diagnosis as having a negative impact on them, any contradictory viewpoints may relate to a combination of internal and external influences. These influences may include internalisation that females often experience with ADHD (Young et al., 2020); higher peer victimisation (Uneri et al., 2015); and the overall impact of executive function impairments (Kessler et al., 2010).

Adult ADHD Self-Report Screening Scale for DSM-V (ASRS-5)

The (ASRS-5) was used to assess the ADHD characteristics that participants may be experiencing. As reported earlier, the ASRS-5 is proven to be a valid and reliable ADHD screening tool despite consisting of only six questions (Ustun et al., 2017). Therefore, using the simple scoring method detailed by Ustun et al. (2017), each item was answered using a Likert scale ranging between zero and four (0 = never to 4 = very often), with a maximum possible score of 24. Higher scores indicate a greater level of ADHD characteristics. There was no missing data within the ASRS-5 responses. As seen in *Figure 4*, all scores were in the higher range, suggesting that participants were self-

Figure 4

Comparison of group ASRS-5 scores



	Childhood Group	Adolescence Group	Adulthood Group	Suspected Group
ASRS-5 Group Mean	**21.0**	**18.0**	**17.5**	**19.5**

reporting the elevated impact of ADHD characteristics. A One-Way ANOVA was used to analyse group means, which showed no significant differences at the p <.05 level [F (3,4) = 1.333, p = 0.381].

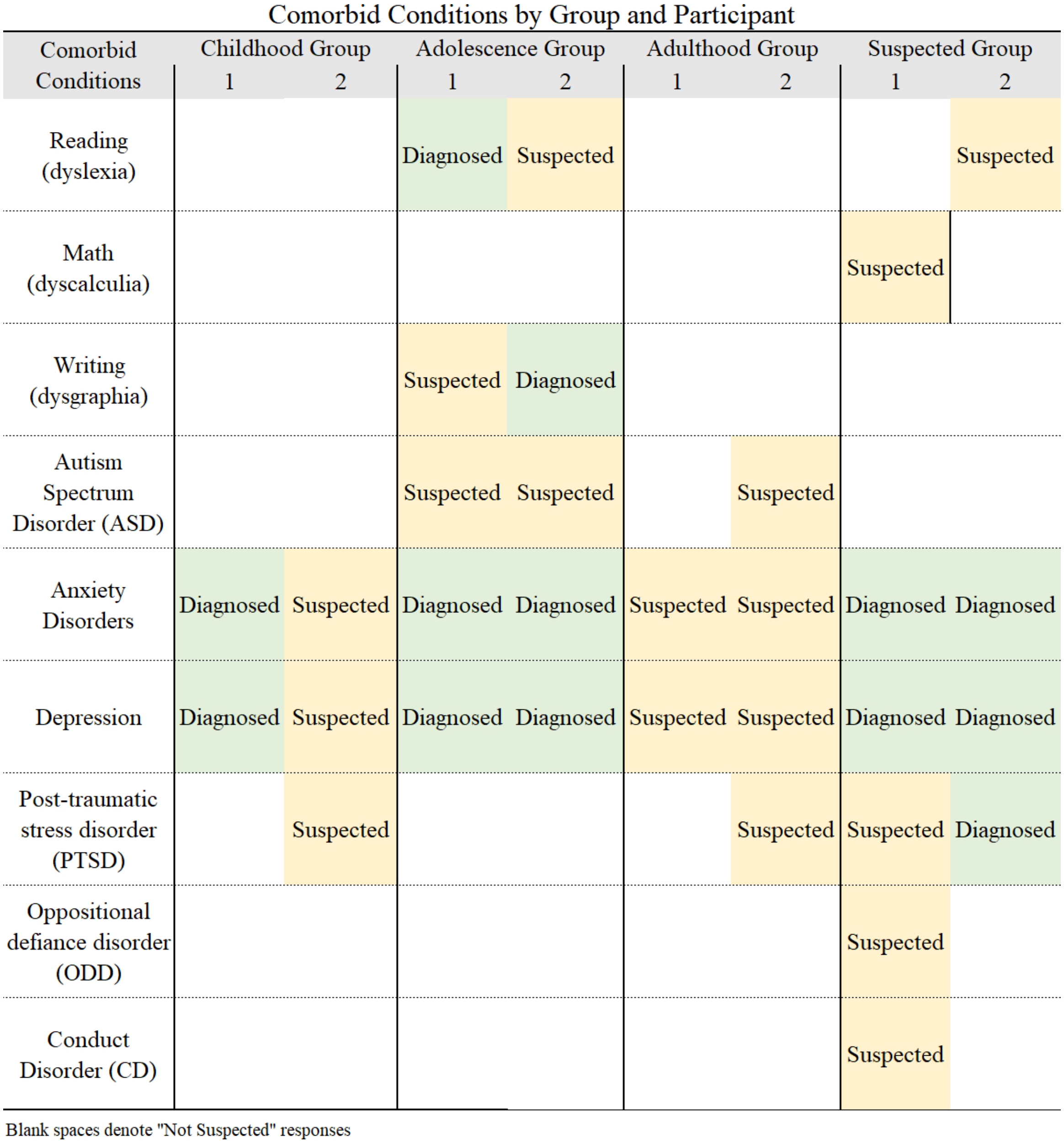
It was essential to validate the comparison of the Suspected Group participants for this study with those participants who had been formally diagnosed with ADHD. The ASRS-5 was used to support the participants' suspicions of having ADHD. Participants across all groups scored fifteen or above on the ASRS-5 (15-22 - with a maximum of 24). These scores indicate that Suspected Group participants scored as high on the ASRS-5 (19 and 20) as participants who had received a formal diagnosis. As an ADHD predictor, these ASRS-5 scores would be considered high enough to warrant further discussion regarding a full ADHD assessment (Ustun et al., 2017). As a result, all participants' ASRS-5 scores establish the foundation for comparing ADHD experiences across groups.

Comorbidity

As ADHD comorbidity is considered the rule rather than the exception, it was not surprising to find numerous diagnosed and suspected comorbid conditions among group participants. Anxiety and depression were suspected or diagnosed in all participants across all the groups. Comorbidities of this kind align with findings by Ahnemark et al. (2018), who stated that nearly half of adults diagnosed with ADHD later in life had previous diagnoses, mostly with anxiety and affect conditions. These findings align with research showing that ADHD, particularly in females, is often misdiagnosed as anxiety and depression rather than these diagnoses being the outcome of, and directly related to their underlying ADHD (Quinn & Madhoo, 2014; Solberg et al., 2018). As detailed in *Table 8*, only one participant in the Childhood group had received a diagnosis of

Table 8

Diagnosed and suspected comorbid conditions



Comorbid Conditions by Group and Participant

Comorbid Conditions	Childhood Group		Adolescence Group		Adulthood Group		Suspected Group	
	1	2	1	2	1	2	1	2
Reading (dyslexia)			Diagnosed	Suspected				Suspected
Math (dyscalculia)							Suspected	
Writing (dysgraphia)			Suspected	Diagnosed				
Autism Spectrum Disorder (ASD)			Suspected	Suspected		Suspected		
Anxiety Disorders	Diagnosed	Suspected	Diagnosed	Diagnosed	Suspected	Suspected	Diagnosed	Diagnosed
Depression	Diagnosed	Suspected	Diagnosed	Diagnosed	Suspected	Suspected	Diagnosed	Diagnosed
Post-traumatic stress disorder (PTSD)		Suspected				Suspected	Suspected	Diagnosed
Oppositional defiance disorder (ODD)							Suspected	
Conduct Disorder (CD)							Suspected	

Blank spaces denote "Not Suspected" responses

specific learning disorders in reading and writing in addition to anxiety and depression. Diagnoses other than anxiety and depression were only seen in the Childhood Group and Suspected Group participants. The Adolescence Group participants had the least diagnosed or suspected comorbid conditions. Participants in every group had at least three and as many as six suspected but undiagnosed conditions.

Treatments

The data relating to prescribed and nonmedical treatments was also explored and is detailed in *Table 9*. Participants in all groups reported having tried meditation/yoga

Table 9

Non-medical treatments and their perceived helpfulness

Non-Medical Intervention	Childhood Group Participants		Adolescence Group Participants		Adulthood Group Participants		Suspected Group Participants	
	1	2	1	2	1	2	1	2
Coffee		Currently Using - not very helpful		Currently Using - helpful	Currently Using - helpful	Currently Using - helpful	Currently Using - helpful	Previously used - helpful
Micro-nutrients		Currently Using - not very helpful				Previously used - not very helpful		Currently Using - helpful
Diet or Food Avoidance		Currently Using - helpful		Previously used - not very helpful	Currently Using - not very helpful	Previously used - not very helpful		
ADHD Coach				Previously used - not very helpful				
Apps	Previously used - not very helpful		Previously used - helpful	Previously used - not very helpful	Currently Using - helpful	Previously used - not very helpful	Currently Using - not very helpful	Previously used - helpful
Cognitive Behavioural Therapy (CBT)				Previously used - helpful				Previously used - helpful
Meditation / Yoga	Currently Using - not very helpful	Currently Using - helpful	Previously used - not very helpful	Previously used - not very helpful	Currently Using - not very helpful	Currently Using - helpful	Previously used - helpful	Previously used - helpful
Physical Exercise	Currently Using - helpful	Currently Using - helpful	Previously used - helpful	Previously used - not very helpful	Currently Using - helpful	Previously used - helpful	Previously used - helpful	Previously used - helpful
Alcohol or Illegal Substances	Currently Using - helpful		Previously used - not very helpful		Currently Using - not very helpful	Previously used - not very helpful	Previously used - helpful	Previously used - not very helpful

Blank spaces denote "Never Used" responses and physical exercise. Meditation and yoga had mixed results; however, eight of the seven participants found physical exercise most helpful, with coffee being the next most helpful treatment except within the Childhood Group. Despite most group participants agreeing that exercise was helpful, only three were currently using this non-medical treatment. The lack of continuity in using a treatment method that has been shown to be helpful both in research and the participants' personal experience reflects how ADHD affects daily activities – often with no rhyme or reason (Hagerman & Ratey, 2014). It is worth considering that research on exercise depends entirely on captive participants, i.e. children at school, which naturally creates external motivation for individuals with ADHD. Thus, external requirements can take the place of the interest-based motivation that is needed when external motivation is absent, i.e. when no one provides external requirements (American Psychiatric Association, 2013; Hagerman & Ratey, 2014). The paradox of this situation is what one participant called "ADHD penalties". In her interview, she explained she would like to exercise, but despite the knowledge that it would help and the desire to do it, she is impeded by ADHD characteristics such as time blindness and organisational impairments that she, in actuality, is attempting to minimise.

Three participants, one each from the Childhood, Adulthood, and Suspected Groups, had used micronutrients as a non-medical treatment. Only one participant in the Suspected Group was currently using them and finding them helpful. While positive research supports the use of micronutrients, whether it is feasible or not comes back to the same issues as described for using exercise – external vs internal motivation, ADHD penalties, and the additional ongoing monthly expense of $200 (Rucklidge & Blampied, 2011).

At least one participant from every group had tried ‘alcohol or other illegal substances’ to help with ADHD characteristics, with only one participant each from the Childhood and Suspected Groups finding it helpful. While there were no specific questions in the survey about substance abuse, participants were asked if they self-medicated with alcohol or illegal substances. The results across all groups show that self-medication with alcohol and other drugs was common. The risks of substance use disorder, prevalent among individuals with ADHD, can also be directly related to having ADHD (Kooij et al., 2012; Quinn & Madhoo, 2014; Rucklidge et al., 2016; Solberg et al., 2018). As one might imagine, the clash of negative self-worth and self-confidence and low impulse control makes for the perfect pathway to self-medicating, leading to alcohol and substance abuse.

When analysing survey results detailed in *Table 10* related to medical treatments and their helpfulness, it was found that medical treatments were much less prevalent than

Table 10

Medical treatments used and their perceived helpfulness

		Concerta	**Ritalin**	**Rubifen**	**Dexedrine**	**Strattera**
Childhood Group	**1**		Not very helpful	Not Helpful at		
	2	Very Helpful	Helpful			
Adolescence Group	**1**					
	2	Moderately Helpful		Helpful	Very Helpful	
Adulthood Group	**1**	Helpful				
	2		Helpful			
Suspected Group	**1**					
	2					

Blank spaces denote "Never Taken" responses.

non-medical treatments. This difference suggests that, knowingly or not, participants from all groups had attempted to find numerous means to help mitigate the ADHD characteristics that they felt were impacting them negatively. Among the group participants who had received a diagnosis and therefore had access to prescription medication, all but one had tried at least one medication available within New Zealand. Of the remaining participants, all but one in the Childhood Group found the medications to be either ‘somewhat helpful’ or ‘very helpful’, which aligns with research on the effectiveness of ADHD medication (Halmøy et al., 2009; Huss & Lehmkuhl, 2002). Four participants who were using medications also used non-medical treatments, which they perceived to be helpful. Participants' comments and views regarding medication will be detailed later in this chapter.

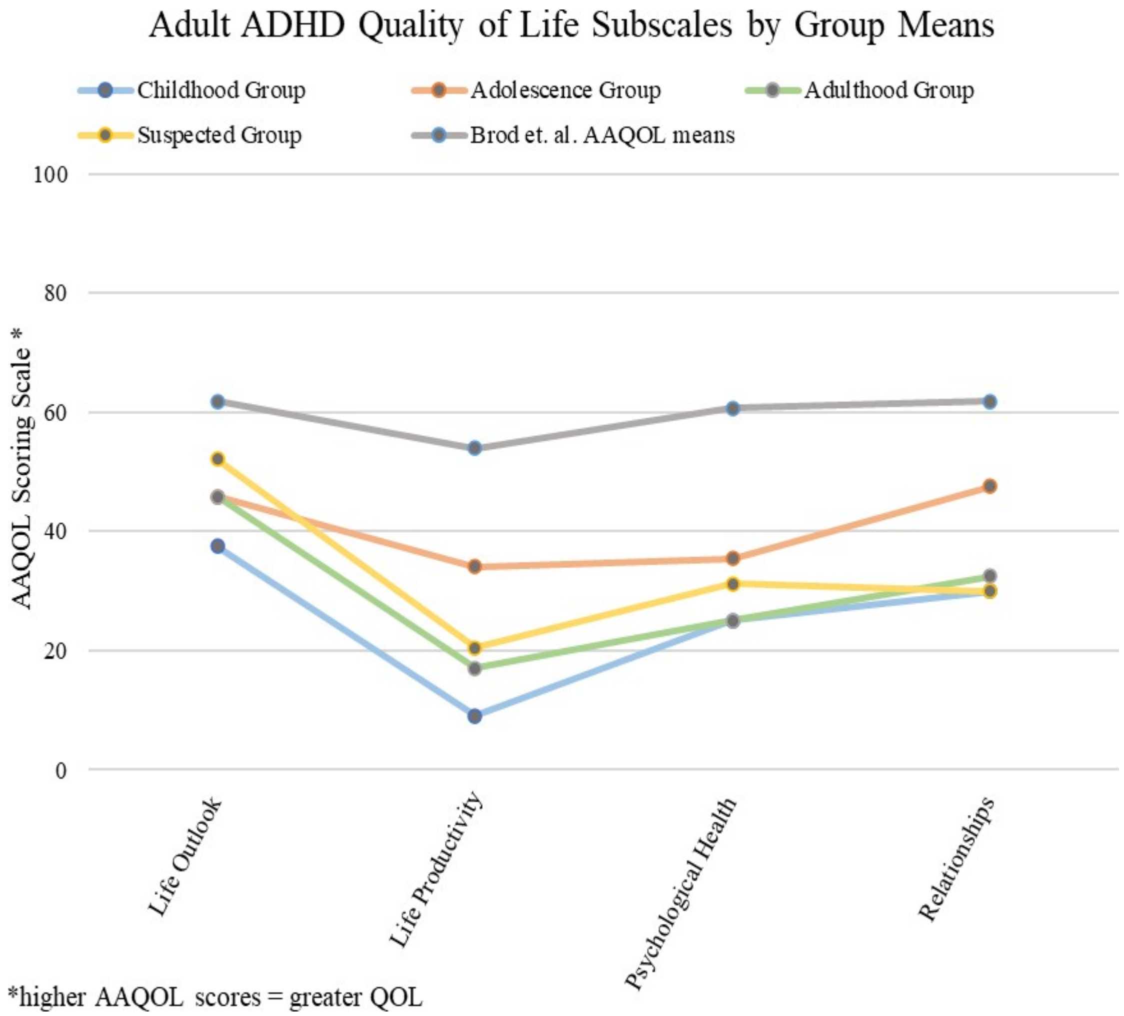
Adult ADHD Quality of Life Scale (AAQOL)

The AAQOL was used to assess the participants’ perceived quality of life within their current cultural and social norms in relation to their concerns, hopes and future goals. The statements were rated on a five-point Likert-like scale from one (Not at all/Never) to five (Extremely/Very Often). The total AAQOL scores were made up of four subscales: Life Outlook, Life Productivity, Psychological Health, and Relationships. There were three ‘not applicable’ answers within the Relationships subscale for the question related to intimate relationships. Therefore, all responses to this question were removed from the Life Outlook subscale mean calculation. A one-way between-groups analysis of variance was conducted to explore the group mean differences. The AAQOL results, like the ASRS-5 scores, show no statistically significant differences on the One-Way ANOVA, which was used to assess AAQOL group means at the $p < .05$ level [F

(3,4) = 1.129, $p = 0.437$]. The AAQOL subscale scores are displayed in *Figure 5* and reflect similarities between groups on each measure and differences in the subscale mean for those with ADHD.

Figure 5

Adult ADHD Quality of Life group means



The most considerable group difference was seen between the Childhood Group and Adolescent Group on the Life Productivity subscale. The Adolescent Group scores suggest that these participants experience a better overall quality of life than the other groups. This difference may reflect having fewer comorbid conditions than other group participants, as reported previously. That being said, the Adolescent Group mean was still low, and all four groups were shown to be well below the group means for those with ADHD as reported by Brod et al. (2006). One particular set of responses stood out from the Psychological Health scale, where participants were asked to report on how often they felt overwhelmed over the past two weeks. The responses were split between ‘often’ and ‘very often’. These results echo the findings of Asherson et al. (2012), who found that adults with ADHD expend disproportionate amounts of energy masking and trying to mitigate the impact of any impairments. Despite or possibly because of these expenditures, adults with ADHD may still experience being overwhelmed by low self-worth, restlessness, and mood issues.

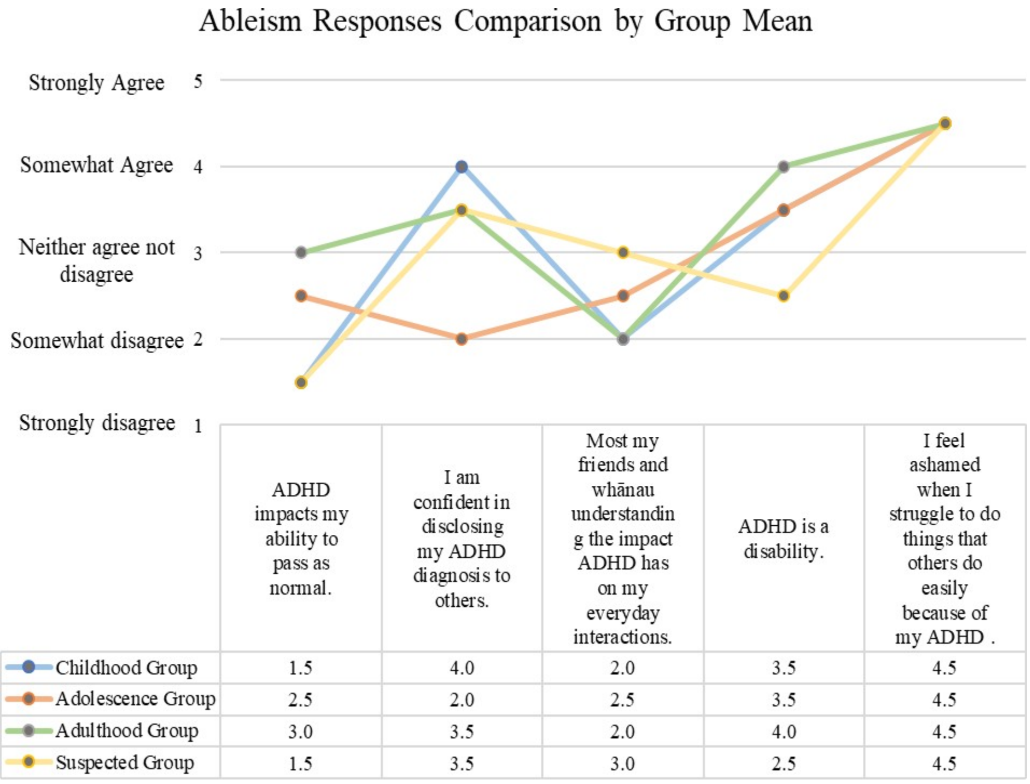
Brod et al. (2012) discussed that while ADHD symptomatology does not seem to increase over a lifetime, it does show cumulative negative consequences. This negative impact is evident when examining the AAQOL group results as participants from every group, despite their different backgrounds or individual journeys, scored primarily under the 50% mark. The social and financial effects of ADHD have been shown to be related to maintaining jobs, being promoted, managing budgets, and social interactions issues (Bjerrum et al., 2017). There are also societal costs related to higher medical costs (Asherson et al., 2012), driving accidents and increased interaction with the criminal justice system, although these social costs were not specifically part of this study (Young & Cocallis, 2019).

Ableism

The second research question of this study relates the participants' experiences related to external and internal ableism. Participants’ perceptions were explored using five questions relating to ableist ADHD perceptions or experiences. The question topics included disclosing their ADHD, others understanding their ADHD, their view of ADHD as a disability, their ability to pass as normal, and shame regarding the impact ADHD has on them. The researcher’s intent was to reveal the extent to which ableist discourses may have impacted or been internalised by participants. The questions used to query ableism related to shame and personal expectations, and viewpoints regarding ADHD. The group mean responses to these questions are detailed in *Figure 6*.

Figure 6

Ableism survey question responses by group means



	ADHD impacts my ability to pass as normal.	I am confident in disclosing my ADHD diagnosis to others.	Most my friends and whānau understanding the impact ADHD has on my everyday interactions.	ADHD is a disability.	I feel ashamed when I struggle to do things that others do easily because of my ADHD .
Childhood Group	1.5	4.0	2.0	3.5	4.5
Adolescence Group	2.5	2.0	2.5	3.5	4.5
Adulthood Group	3.0	3.5	2.0	4.0	4.5
Suspected Group	1.5	3.5	3.0	2.5	4.5

Participants from all groups agreed (using categories ‘somewhat’ and ‘strongly’) that they felt shame when their ADHD affected their ability to accomplish tasks that others could easily complete. These responses reflect the impact of being the ‘other’ and the favouring of ‘norms’ hidden in conscious and unconscious perceptions that value able-bodiedness and able-mindedness (Campbell, 2008; Friedman & Owen, 2017; Hosking, 2008). Additionally, most group participants felt that their ADHD characteristics impacted their ability to pass as normal. Feeling the need to pass as normal or mask reflects the importance of the concept presented by Degener (2016), stating that impairments, despite their impact on quality of life, are still simply variations of humankind that deserve to be acknowledged. Such acknowledgement and valuing of human variations would be a step toward an environment devoid of the necessity to mask.

Overall, group participants viewed ADHD as a disability; however, one participant strongly disagreed with this concept. The understanding of family and friends concerning ADHD received the most responses in the ‘somewhat disagree’ and ‘strongly disagree’ categories. While participants in the Childhood Group were least confident in disclosing their ADHD diagnosis, in the other three groups, participant responses were split between the ‘neither agree nor disagree’ and agreeing (‘somewhat’ and ‘strongly’) categories.

Stage Two Results: Individual Semi-Structured Interviews

Observations

The second stage of the study consisted of one-to-one interviews with the same eight participants conducted through the Zoom Online Meeting platform. Overall, responses to the interview questions were dependent on each participant's memory and their perception of those memories in relation to their current reality as aligned with phenomenological research. The themes that surfaced through analysis of the Stage 2 data are detailed in the following sections.

Educational Experiences

The prevailing themes regarding school experiences that participants perceived related to their ADHD were frustration, lack of agency, rejection, and shame. Within each group, participants described rejection expressed with some reference to feeling or being told that they did not belong, being "different", "odd one out", "didn't fit in", "I was too much work", and "feeling always on the outside". These external and internal influences are common among females with ADHD (Young et al., 2020). Bjerrum et al. (2017) state that this "awareness of being different" can be a key factor in cumulative levels of shame that undermine an individual's self-confidence (p. 1103). As detailed in the DSM-V, another similar experience the participants described was the frustration of being disconnected with education unless there was a specific interest or, as one participant in the Childhood group put it, she "never wanted to be there, it never gripped me"
(American Psychiatric Association, 2013). A participant within the Adolescence Group admitted to "skiving a lot of class to be in the music department because I felt calm there and I felt like I could do things there". Whereas a participant in the Suspected Group detailed the judgment and rejection experienced from a teacher that resulted in her leaving school:

> …the teacher in the year that I finished school saying that she didn't know why I even bothered being there because I wasn't trying. Which kind of

> really, yeah probably, rocked my emotions a little bit, because I'd actually been trying super hard. For me, I'd be trying like - really hard, but it was always hard to process things.

These experiences reflecting the participants' frustration and shame related to school settings are consistent with findings related to educational expectations and executive functioning difficulties (Barkley, 2015; Bjerrum et al., 2017). There were no discernible differences between groups concerning a lack of agency and reduced educational engagement regarding educational experiences, but they were related to extremes between outcomes (Eccleston et al., 2019; Uneri et al., 2015). These extremes were evident as more than one participant left school before their final year. Another participant found her way into a fulfilling career based on her passion. This outcome may be attributed to the family and educational support she reported receiving, which translated into self-confidence in her choices and direction.

Participants who experienced ‘academic success’, i.e. attaining a degree or other qualifications, were found in each group. Despite that success, “I don’t know how the hell I got through…” remained a mutual sentiment. For participants within the Adolescence, Adulthood and Suspected Group, academic strengths and success did not negate educational struggles. A participant within the Suspected Group summed up her educational struggles in the face of such abilities by saying:

> I was able to cope with school. However, finishing things and getting through my education in a way that was meaningful for my later (sic) on life and employment things was difficult.

Thus, regardless of their individual abilities in maths, reading, writing, and music, participants still reported experiencing persistent organisational and time management issues related to executive functions such as working memory, planning, and cognitive flexibility (Barkley, 2015; Logue & Gould, 2014). These executive functions all depend on the ability to switch between the task-positive network (TPN) and the default-mode network (DMN) (Hallowell & Ratey, 2021).

A sense of shame related to being put in "with the not so smart kids" or "in with the learning disabilities" was evident in the words and body language of the two participants in the Childhood Group during their interviews. While these participants may have needed academic support when they attended school, it was not experienced in ways that enhanced their evolving self-confidence. Such experiences may be an element of ADHD's cumulative negative impact on emotional well-being, as reported by Brod et al. (2012). These experiences may also reflect what Metzger and Hamilton (2020) referred to as the "double-edged sword of diagnosis" (p. 16). Their results were based on the Early Childhood Longitudinal Study, which collects nationally representative data on students in the United States from kindergarten through fifth grade annually. Metzger and Hamilton (2020) found that teachers who are aware of an ADHD diagnosis are more likely to rate students as under-achieving and less likely to acknowledge students with ADHD who achieve above their grade level. This lack of awareness by teachers may be due to a lack of experience working with students who have ADHD rather than professional development to support neurodivergent students compounded by the history of frequent ADHD diagnostic changes (Ohan et al., 2011).

Participants in the Adolescence, Adulthood, and Suspected Groups each referred to evaluation comments in their school reports. These comments made by teachers' included variations on "a lot of potential but needs to focus", "if she only put the work in", or "[needs to] try harder". Participants expressed that these statements were unhelpful and, at worst, a source of shame that could be particularly harmful if the student lacked knowledge about their impairment. Thus, these types of 'shame' statements further undermine self-confidence, a recurrent theme related to participants' educational engagement and social interactions within school settings (American Psychiatric Association, 2013; Uneri et al., 2015; Young & Woodhouse, 2020).

At least one participant in each of the Childhood, Adolescence and Suspected Groups interpreted their educational struggles as inner intellectual failings. An Adolescence Group participant expressed that "any successes I will put down to external causes and any failures I will put down to internal causes". Thus, without knowledge regarding executive functioning, and without the broader understanding of how their brains operate, i.e. the default-mode and task-positive networks, the participants came to their own conclusions (Abbas et al., 2019; Buckner et al., 2008; Chigome et al., 2018; Fox et al., 2005; Raichle, 2015; Spreng, 2012). These negative self-perceptions were revealed when several participants stated in their interviews that at some point in their schooling they decided they were "a bit dull", "stupid", or "just dumb". In contrast, the Adulthood Group participants also had negative self-perceptions, yet they made specific defensive statements such as, "I'm not dumb" and "slow, not stupid", which were in contrast to "dumb" statements made by other groups' participants. Nevertheless, despite these more positive statements, all group participants shared feelings and frustrations regarding learning and educational engagement, which, as previously stated, can be linked to struggles with executive functioning (Chigome et al., 2018; Kessler et al., 2010).

Experiences leading to ADHD

The experiences leading to the participants receiving a diagnosis or suspicion of ADHD were relatively similar across groups. Comments made by participants in their individual interviews when analysed between groups focused more on the positive aspect of support. Topics related to social interactions, externalised behaviours, and internalised struggles were discussed during the interviews. Whilst there were a few references to positive interactions with friends in school, participants generally described not making friends, difficulty keeping friends once connections were made, and being bullied. The social impacts related to ADHD characteristics have been researched extensively and were explicitly addressed in the DSM-V as part of the criteria of diagnosing ADHD (American Psychiatric Association, 2013; Bjerrum et al., 2017; Eccleston et al., 2019; Uneri et al., 2015).

The Childhood Group participants' experiences centred around behavioural issues at school or lack of focus, fidgeting, and "interrupting all the time" at home, as mentioned in the DSM-V criteria (American Psychiatric Association, 2013). The experience of being diagnosed came as a surprise to participants in the Adolescence Group as professionals were seeing them for other reasons, i.e. a formal dyslexia diagnosis and as part of a community health project. One of the Adolescence Group participants reflected on being in class as a child, saying that she felt that her teacher did not recognise her ADHD despite her being very hyperactive - "[I] was missed because I'm cis female, like, it was actually quite visible". Gender stereotypes have been shown to impact teachers' identification of ADHD characteristics, mistakenly identifying them as emotional and attention issues in females (Groenewald et al., 2009).

The experiences that led to diagnosis and suspicion of ADHD for the Adulthood and Suspected Group participants were related to family members such as children, grandchildren, husbands, or friends being diagnosed with ADHD (American Psychiatric Association, 2013; Swanson et al., 2007). One participant shared the discussion she had with a friend who told the participant she had made an appointment to discuss an ADHD diagnosis, saying:

> I was like, really? You? For what? And she said it's like these things, and I'm like but that's just normal. She's like, no it isn't – well that's normal for me… Ohhhh… okay.

Most of the Suspected and Adulthood Group participants discussed this revelational type of 'ADHD awakening'.

Experiences receiving a Diagnosis or not having a Diagnosis

Experiences relating to receiving or not having an ADHD diagnosis were linked to varying degrees of the participants' self-concept. Interestingly, even the suspicion of having ADHD was reported to positively impact self-awareness and understanding by participants within the Suspected Group. In contrast, one of the Childhood Group participants had no understanding of the diagnosis as a child but felt relief upon being re-diagnosed as an adult - it made her "feel better". The other Childhood Group Participant did not remember how she felt about being diagnosed as a child but said, "I denied it growing up, the label was negative". She also said, "[I] wanted to get rid of this label, like, I wanted to be normal" when explaining why she lied to both the school and her mum about not taking her medication. These feelings and behaviours are consistent with Eccleston et al. (2019), who reported links between this type of frustration and rejection of treatments and support by adolescents in their research. Participants in the Adolescence Group either felt confused because they received no explanation of what ADHD meant, or viewed the diagnosis as a relief. One participant stated that:

> having the diagnosis of ADHD and being told this is the reason why you do this, this is the reason why. You are not dumb - It was a revelation to me… It didn't mean suddenly I could do it, but it did, it gave me a purpose and it gave me… understanding why I do the things I do.

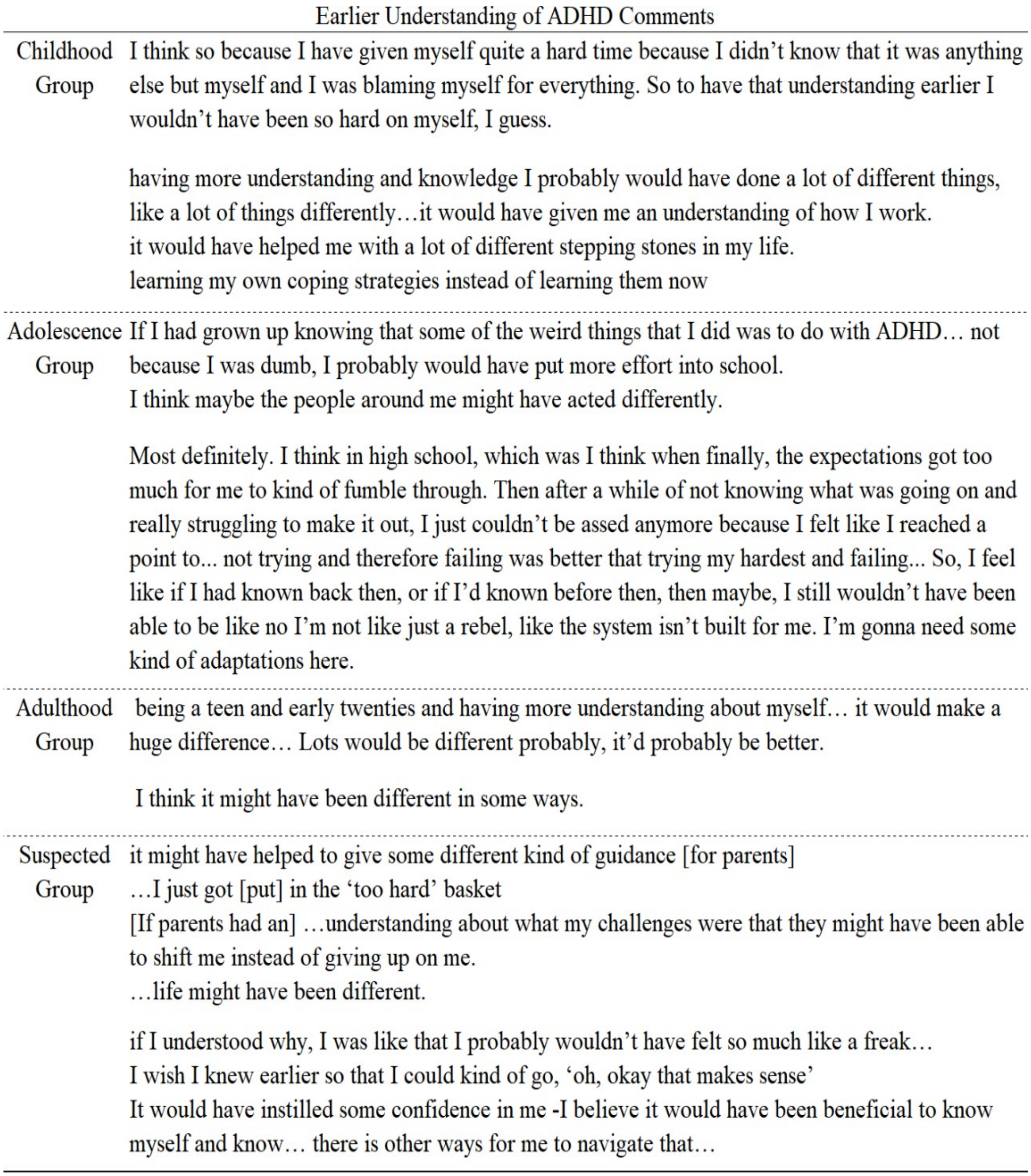
One participant in the Adulthood Group stated that getting a diagnosis was "like looking for something, like an explanation", while the other stated that she "felt together for the first time in my life". These sentiments were echoed by one participant of the Suspected Group who stated that "when I struggle, in my mind it helps me [to understand that chances are there is a reason]". The other Suspected Group participant was reflective, stating that "it would have been nice to know why I felt different". As Adults, all group participants saw their diagnosis as a way to gain additional tools to help them understand themselves and gain more self-confidence (Meza et al., 2019; Ohan et al., 2011; Pawaskar et al., 2020).

Early Understandings

Participants were asked if they believed their experiences would have been different if they had had an earlier understanding of how their brains worked. The answer to this question was unanimous among participants in all four groups – they believed that understanding how their brain worked would have made a difference. Themes of frustration, agency and shame in relation to their self-concept were evident in their

Table 11

Participant responses to helpfulness of early understanding



	Earlier Understanding of ADHD Comments
Childhood Group	I think so because I have given myself quite a hard time because I didn't know that it was anything else but myself and I was blaming myself for everything. So to have that understanding earlier I wouldn't have been so hard on myself, I guess. having more understanding and knowledge I probably would have done a lot of different things, like a lot of things differently…it would have given me an understanding of how I work. it would have helped me with a lot of different stepping stones in my life. learning my own coping strategies instead of learning them now
Adolescence Group	If I had grown up knowing that some of the weird things that I did was to do with ADHD… not because I was dumb, I probably would have put more effort into school. I think maybe the people around me might have acted differently. Most definitely. I think in high school, which was I think when finally, the expectations got too much for me to kind of fumble through. Then after a while of not knowing what was going on and really struggling to make it out, I just couldn't be assed anymore because I felt like I reached a point to... not trying and therefore failing was better that trying my hardest and failing... So, I feel like if I had known back then, or if I'd known before then, then maybe, I still wouldn't have been able to be like no I'm not like just a rebel, like the system isn't built for me. I'm gonna need some kind of adaptations here.
Adulthood Group	being a teen and early twenties and having more understanding about myself… it would make a huge difference… Lots would be different probably, it'd probably be better. I think it might have been different in some ways.
Suspected Group	it might have helped to give some different kind of guidance [for parents] …I just got [put] in the 'too hard' basket [If parents had an] …understanding about what my challenges were that they might have been able to shift me instead of giving up on me. …life might have been different. if I understood why, I was like that I probably wouldn't have felt so much like a freak… I wish I knew earlier so that I could kind of go, 'oh, okay that makes sense' It would have instilled some confidence in me -I believe it would have been beneficial to know myself and know… there is other ways for me to navigate that…

responses. The selection of comments detailed in *Table 11* reveals the participants' conclusions regarding how their ADHD experiences shaped their self-concept. The comments are similar, whether participants had a childhood diagnosis or not. As detailed previously, treatment with medication has positively affected later employment and reduced substance use, which can only happen if there is early diagnosis and supportive intervention (Halmøy et al., 2009; Huss & Lehmkuhl, 2002). Shame and its impact on participants' self-concept are related to the absence of understanding about how ADHD impacts their daily lives (Velotti et al., 2017). This impact is evident in interview transcripts as one participant asserted that she got to the point that "failing was better than trying my hardest and failing…". While other participants stated that "I wouldn't have been so hard on myself" or "I probably wouldn't have felt like such a freak". A participant in the Suspected Groups revealed the importance of family understanding of ADHD when she stated, "I just guess maybe if they have had some understanding about what my challenges were, that they might have been able to shift me instead of giving up on me".

These responses can be seen to reflect the participants' reduced quality of life related to unidentified and untreated ADHD and are consistent with findings reported by Asherson et al. (2012) and Brod et al. (2012). Participants also experienced the impact of having to work harder to maintain the status of being perceived as a normal member of society (Bjerrum et al., 2017). However, identifying ADHD alone did not mitigate the negative impacts on the Childhood Group participants as they still detailed difficulties and shame. This insight suggests that the type of treatment, personal support, and learned strategies may play a significant part in positive outcomes. This suggestion is consistent with the trial-and-error approach to treatment identified by Stein and McGough (2008).

Quality of Life Experiences

Themes relating to the overall quality of life fell under the topics of shame and frustration. Participants' shame was apparent when they talked about random things like difficulty driving, untidy homes, or hoarding that they hid even from best friends. "Hating schedules" and an inability to maintain a sense of time and organisation around everyday tasks were also common in the interviews data. One participant described how for her time is "wobbly". Over-thinking, depression, anxiety, and ruminations were common phenomena identified by almost all group participants (Quinn & Madhoo, 2014).

Other quality of life experiences discussed by participants were associated with relationships and related to self-worth and self-confidence. Some participants relationships were more stable, such as with family or partners. One participant within the Adolescence Group stated that she and her "siblings are best friends", and one participant in the Adulthood group described her long-term partner as her "rock". In contrast, the other Adulthood participant reported that she had decided that "relationships overwhelm me" after her third husband. However, even when participants described positive relational interactions (found across all groups), there was "an underlying current of, I don't feel good enough". Other statements made by participants related to being "self-sabotaging [for fear that friends] are just tolerating me", fear of missing social cues, or "I can't keep in contact… [I am] a bit too flaky". The diagnostic ADHD characteristics reflect the behavioural presentations of ADHD; however, they fall short of illustrating the daily impact participants experienced simply striving to engage or be accepted (Barkley, 2015; Bjerrum et al., 2017; Brod et al., 2012)

The occupational quality of life themes can be seen to reflect two sides of the same coin. All participants reported either having or wanting interest-based occupations that matched their energy and creativity levels with sufficient variability to maintain those interests, a key characteristic of ADHD (American Psychiatric Association, 2013). Participants identified their occupations as students, teachers, working with horses, orchard work, or entrepreneurial endeavours like candle making, photography and video making. Other participants discussed the frustration related to finding interest-based employment or feeling unemployable due to their ADHD characteristics.

Conversely, a Childhood Group participant reported the ease of getting hired but the negative experiences of keeping a job by stating that she “never had trouble getting a job but struggled to stay engaged”. In an interview, the other Childhood Group participant stated that she had to “try extra hard” in interviews to look like she does not have ADHD. One participant, each from the Adolescence, Adulthood, and Suspected Groups, reported that they were in employment that they enjoyed. These were jobs where their management and co-workers were aware and supportive of the participant’s ADHD or neurodivergence. However, one participant within the Adolescence Group stated that she now attends staff meetings online from a nearby room. She explained this arrangement saying;

> Ahhh, they've done this amazing thing. They've made staff meetings remote, and for some bizarre reason when I'm not in the room I can pay attention. I'm so happy about that. It's really, [laughing] it's hilarious

> because my office is three steps away from the staff room and that's where the staff meetings are. So, I’m literally just around the corner from the meeting doing it remote (sic). And everyone was like, ‘why isn’t Edith in here?’ and it’s just like, ‘she's fine, she's fine’… Do you want her in this room making noise? No…

While this arrangement supports the participant to better “pay attention”, it is punctuated with the rejection of her co-workers as she is aware that at least some of them do not want her physically in the same room.

One participant in each of the Adolescence, Adulthood, and Suspected Groups, reported the negative impact that ADHD characteristics had on their financial quality of life. Their experiences align with those expressed by other individuals with ADHD (Bjerrum et al., 2017). Among those participants, the theme of shame was linked to financial stress. The stress and shame resulting from impulse buying - large and small ticket items, online shopping, and loaning money on impulse – reportedly caused distress. One Adolescence Group participant expressed a sense of pride to have set in place a forced budgeting system. This budget was instigated after accumulating a large amount of credit card debt at an early age, which was subsequently paid off with family support.

Experiences with Medications

Although there were no specific interview questions relating to ADHD medication, all participants within the diagnosed groups mentioned medication when answering interview questions. The theme of agency emerged as twofold related to experiences with medication. First, for most of the Childhood and Adolescence Group participants, the initial taking of medication was a negative experience often due to a lack of agency and understanding regarding its benefits and why they were taking it. Participants reported that the medication created an “uneasy” feeling and emphasised how different they were from others. Another participant stated that she was better on medication, but at seventeen, there were no “life strategies or anything else put in place, it’s just diagnosis, medication”. This sentiment reflects the need for support for individuals and their families at and after diagnosis of ADHD. Support may counter adverse outcomes reported previously, including substance use, self-harm, and suicide (Barkley, 2015; Taylor et al., 2014). Second, agency was experienced within the same groups, Childhood and Adolescence, linked to the participants returning to medication after an absence of as long as fifteen years.

The Adulthood Group participants’ experiences were overwhelmingly positive and offered a path to improved self-confidence. Participants explained these experiences with statements like, “I feel different. I feel whole, and not as out there. And I think it’s that ‘out there’ stuff that made me like being alone”. Another participant stated that being off medication and restarting was “almost like I had been surviving for so long, like just surviving. And then it was like - wow, I can actually think, I can get shit done and keep on top of things”. Participants also reported how medication helped with the big things as well as “the little things that you didn’t even know are things”. These comments are aligned with research on the long-term benefit of medication for individuals with ADHD (Barkley, 2015; Hallowell & Ratey, 2021; Halmøy et al., 2009; Huss & Lehmkuhl, 2002).

Disability, Ableism, and 'passing as normal'.

Only three participants, both of the Childhood Group participants and one within the Adolescence Group, referred to themselves as having a disability. While not all participants referred to ADHD as a disability, they all shared situations where they experienced ableist expectations. These experiences related to the concept of ‘passing as normal’ were examined by the researcher through a Critical Disability Theoretical lens (Hosking, 2008). Participants' shared experiences covered many human interactions, including job interviews, work environments, sporting activities, educational settings, family interactions, and even grocery shopping. Interestingly, when asked about the personal impact that ‘passing as normal’ or masking their behaviours to fit in has, there is a link to the theme of rejection that impacted participants’ self-worth and self-concept. This theme is grounded in what Campbell (2008) referred to as “an ‘identity’ other than one’s own” (p. 157). Within the Childhood Group, participants’ responses to the impact of masking included that it “makes me feel insecure” or “makes me feel a bit of a failure at times”. One participant in the Adolescence Group stated that masking created “a whole heck of anxiety all of the time”, and the other reported that she felt the need to apologise constantly. Within the Adulthood Group, one participant stated that they “hate it… it is exhausting”. The other participant acknowledged that it probably does have an impact; however, she would “have to think about that one much longer” before answering as she had never considered it. Among the Suspected Group participants, responses related to “finding it hard to have… true friendships [that she can maintain]” and “that it doesn’t let me be who I am”. These experiences could be seen as related to the internal and external conscious and unconscious preferences of able-bodiedness and able-mindedness – the push to overcome - to not be ‘different’ or the ‘other’ (Campbell, 2008; Dolmage, 2017).

Internalised Ableism

The deep-rooted nature and internal efforts put into masking are further evident in participant responses to being asked if they would continue to mask their ADHD characteristics if society’s normative expectations suddenly disappeared. Themes of agency, rejection, and shame, which can bolster or undermine an individual’s self-worth and self-confidence, were evident in participants’ responses (Eccleston et al., 2019). Participants’ experiences were related to being bullied, unconstructive judgements of other people, and the learned ‘normal’ narrative. One participant each from the Childhood and the Suspected Groups stated they would be able to “just be me now”, and I would “let my freak flag fly”. However, the other group participants felt that even if society suddenly became more open and accepting of differences, it would be challenging to unlearn the expectations picked up over their wide-ranging lifetimes. “It takes so long to unlearn the narrative… but I would love to undo it”, replied one participant in the Adolescence Group. In the Adulthood Group, a participant explained the restraint on being their whole self, stating:

> I think I would relax a bit more. I’m constantly tense. Watching myself, watching what I am thinking, watching what I’m saying... I’d love to be me, but I just don’t think people could handle it.

This feeling of always needing to self-check was mirrored by an Adulthood Group participant who asserted, “It would be freeing to be more open and not police myself as much”. The ‘policing’ of self when interacting to avoid judgement and shame was relevant to participants in each group (Kattari et al., 2018; Velotti et al., 2017). This ‘policing’ links directly back to research regarding internalised ableism for individuals with invisible impairments and disabilities and how they produce varying versions of ableist discriminations (Kattari et al., 2018.

Chapter Summary

This chapter has presented demographic information about the diverse participants and the results for the Stages 1 survey and Stage 2 one-to-one interviews of this study. The between-group similarities and differences were examined and detailed using the survey and interview questions responses. While the sample size was small and therefore the results are not generalisable, they provide a window into the lives and experiences of adults with ADHD, more specifically, female/ish individuals with ADHD. The results reveal similar experiences between participants’ and within groups’ responses to survey questions. Similarities in responses were apparent regardless of participants’ diagnosis status or the life stage in which they were diagnosed. On the whole, experiences shared in the one-to-one interviews reflected similar influences related to their ADHD of rejection, frustration, shame, the impact of masking and ableism. These themes and insights constructed from survey responses and individual interviews will be discussed further in Chapter 5.

Chapter 5: Discussion and Conclusion

The purpose of this study was to explore similar and differing lived and ableist experiences of the eight participants – all who were adults with ADHD, two each who were diagnosed either in childhood, adolescence, or adulthood or suspected they have ADHD. As one of the most widely researched conditions within the DSMs, surprisingly, only a small percentage of the overall studies have examined ADHD through the voices of adults who experience the weight of its effects daily. Moreover, no studies could be found within Aotearoa New Zealand that solely gave the adult ADHD community a voice. This chapter will explore Stage 1 and 2 results and how they address the research questions.

Findings and Discussion

Diagnosis and Gender

The researcher expected that the two participants in the Childhood group would have more positive experiences than participants in the other groups due to their earlier diagnosis and support - however, this was not the case. The results reveal that although participants, who for this research were divided into one of four groups, had differing life paths and demographics, more often than not, their responses were similar within and between groups. Moreover, similarities were present despite the differences related to the stage of life when participants received a diagnosis or the amount of time since diagnosis. Within groups, connections revolved around timing and the methods that ADHD was introduced to the participants. Participants in the Childhood Group experienced typical presentations reported in the DSM-V, including internal and external behaviours such as not focusing, fidgeting, and "interrupting all the time" (American Psychiatric Association, 2013). However, the Adolescence Group participants were both diagnosed at age seventeen, for reasons outside typical ADHD characteristic recognitions, in this case, a mental health project and an assessment to confirm a suspected dyslexia diagnosis. In contrast, participants in the Adulthood and Suspected Groups identified having an 'ADHD awakening' when a family member or friend received an ADHD diagnosis. These moments were often experienced after years of thinking that their ADHD characteristics were either "normal" or they were "failing" at a personal level, or both (American Psychiatric Association, 2013; Swanson et al., 2007).

Participants in the Adolescence, Adulthood, and Suspected Group shared this experience of delayed ADHD recognition until they were on the verge of adulthood, well into adulthood, or not at all. There were multiple reasons why they missed being diagnosed with ADHD or were misdiagnosed with affect conditions only. One proposed explanation is that female presentations of ADHD characteristics are not often apparent until early adolescence (Murray et al., 2019). The DSM-V states that ADHD is predominantly diagnosed in young males; nevertheless, this randomised study that is the subject of this thesis consisted entirely of females or "female-ish" adults (American Psychiatric Association, 2013). These gender demographics line up with the ADHD New Zealand Adult Facebook Community that reported its membership as 70% female when this research began. Higher female demographics and the subsequent all-female groups for this research is unsurprising given that adult females are a growing demographic within the ADHD community (Murray et al., 2019). Consequently, later diagnoses may result in an increase in females seeking help and support, which could be seen to be reflected in the Adult ADHD Facebook Support Group statistics.

The importance of gender stereotypes in why these cases were not recognized earlier should not be overlooked. A participant within the Adolescence Group stated that she had displayed typical ADHD combined presentation behaviours as a child but felt that she was not diagnosed then because she is a “cis-female”. Stereotypical biases are deeply ingrained throughout history, and therefore, unsurprisingly, they are prevalent in the lengthy history of ADHD. For instance, the current concept of ADHD (as detailed in Chapter 2) was progressively formed over several centuries when females often did not receive a formal or equitable education. Therefore, female students were less likely than males to be recognized as having ADHD within educational settings. As time progressed, diagnosis and treatment have struggled to break free from the narrow male-centric view of ADHD (Groenewald et al., 2009). Moreover, gender ratios are often taken from previously diagnosed samples or meta-analyses of diagnosed samples based on gender-biased diagnoses, thus perpetuating male-centric data and ratios, such as can be found in Hasson and Fine (2012).

For decades, females have been an almost invisible ADHD minority, which has been justified on the basis of research suggesting females are more likely to present with inattentive ADHD characteristics (Young et al., 2020). However, this excuse is found lacking given that a short attention span was included in the DSM-II in 1968 as a characteristic of hyperkinetic disorder. Furthermore, the DSM-III published in 1980 included a diagnosis of attention deficit disorder with or *without* hyperactivity, and the current DSM-V published in 2013 includes the predominantly inattentive presentation of

ADHD (American Psychiatric Association, 2013; Epstein & Loren, 2013; Young et al., 2020). Thus, as if being hidden in plain sight, participants in the Adolescence, Adulthood, and Suspected Groups were not diagnosed as children. This lack of diagnosis is surprising given that most participants grew up in an era when information to recognize the ADHD characteristics they were experiencing was readily available. Consequently, as with the participants, many more women with ADHD are likely experiencing a shroud of invisibility that hides them, sometimes even from themselves. The experience of being caught up in society's conscious and unconscious gender biases and stereotypical perceptions or norms may be partially responsible for obstructing the identification and diagnosis of ADHD in females (Quinn & Madhoo, 2014; Young et al., 2020).

Additionally, females often experience increased comorbidities such as anxiety and depression, which every research participant reported experiencing (Solberg et al., 2018). Such diagnoses are often seen as an endpoint rather than recognised as the possible fall-out of undiagnosed ADHD (Quinn & Madhoo, 2014). Additionally, combined characteristics and hyperactivity-impulsivity characteristics can look different in females compared to males. Females are reported to be less overt and aggressive. Instead, ADHD characteristics present as difficulties with societal and relational interactions (Young et al., 2020). This difference can be seen among group participants' comments about fitting in – "[experiencing] an underlying current of, I don't feel good enough", keeping friends – "I'm self-sabotaging [for fear that friends] are just tolerating me", or maintaining friendships - "I can't keep in contact… [I am] a bit too flaky". Therefore, ADHD characteristics are often misunderstood due to masking effects and a lack of knowledge regarding female ADHD presentations, which further explains why female ADHD is often missed or misdiagnosed (Hinshaw et al., 2021; Quinn & Madhoo, 2014; Young et al., 2020).

These explanations ring true within the current study as the earliest diagnosis of a Childhood Group participant was at age six and was diagnosed with the combined presentation of ADHD. Combined and hyperactivity-impulsivity presentations exhibit more externalising behaviours and therefore are more likely to draw the attention of teachers and parents (American Psychiatric Association, 2013; Hinshaw et al., 2021). In contrast, the remaining Childhood Group participant was diagnosed later, at age eleven, with the predominantly inattentive presentation. Internalised characteristics of ADHD are less likely to draw attention. Therefore teachers may identify females as having emotional or attention difficulties rather than ADHD (Groenewald et al., 2009). These internalised characteristics are demonstrated in the participants' comments relating to not belonging, the feeling that "I was too much work", or thinking that "it was an inherent fault, that I was a bad person [for not being able to achieve what others could]". Comments such as these reflect the negative internal impact that ADHD has on participants' self-confidence.

Education

The educational experiences that participants related to their ADHD centred around themes of frustration, lack of agency, rejection, and shame. Statements regarding not belong, being "different", "odd one out", "didn't fit in", "I was too much work", and "feeling always on the outside" reflects current research regarding individuals with ADHD feeling less connected or in conflict with others due to their ADHD characteristics (Bjerrum et al., 2017; Eccleston et al., 2019; Hansson Scherman et al., 2015; Schreuer & Dorot, 2017) What is more these feelings can lead to cumulative levels of shame that undermine an individual's self-confidence (Bjerrum et al., 2017). As detailed in the DSM-5, another similar experience the participants described was the frustration of being disconnected with education unless there was a specific interest or, as one participant in the Childhood group put it, she "never wanted to be there, it never gripped me" (American Psychiatric Association, 2013). Participants in all groups discussed interest-based engagement and connections in educational settings. One participant reported an interaction with a teacher – saying;

> …she didn't know why I even bothered being there because I wasn't trying, which kind of really, yeah probably, rocked my emotions a little bit, because I'd actually been trying super hard.

The participant perceived the teacher's comments as both a judgment and rejection, which prompted her to end her schooling earlier than she had planned. This experience reflects the importance of early intervention as it has been shown to help individuals develop personal tools to help them cope with differing ADHD characteristics (Halmøy et al., 2009; Halperin et al., 2012). This participants' experience also highlights the negative impact a teacher's assumptions of a student's behaviours can have on the student's educational outcomes. Additionally, the same experiences reflect the importance of understanding how to better identify and support students with ADHD.

The flip-side of this experience was seen in the Childhood Group participants' retelling of being referred to academic support services by their teachers. However, attempts to engage the necessary support were rejected by participants. This rejection was made apparent in participants' comments regarding being put in "with the not so smart kids", which was expressed with a sense of embarrassment. Participants' educational experiences that they related to ADHD reflected the asymmetry of ADHD characteristics. While some participants enjoyed certain aspects of their educational experiences, they were also a minefield of differences and difficulties. These experiences had both short term and cumulative negative impacts on the participants' perceptions of themselves and their educational outcomes and well-being (Ahnemark et al., 2018; Bjerrum et al., 2017). Thus, the pivotal point in positive educational outcomes for students with ADHD seems to be not only the type of support given but, just as importantly, how it is delivered.

Diagnosis and Understanding ADHD

Both participants in the Childhood Group and one in the Adolescent group felt that their diagnosis harmed their self-confidence. However, the two participants in the Adulthood group and the remaining participant in the Adolescent Group disagreed ‘somewhat’ or ‘strongly’ that a diagnosis had a negative impact on their self-confidence. Additionally, the two participants in the Suspected Group felt that not having an ADHD diagnosis negatively impacted their self-confidence. It is possible that this view held by the participants (who felt the negative impact of having a diagnosis) was grounded in the lack of early ADHD understanding and how their ADHD characteristics link to experienced rejection and shame. This explanation is supported by participants responding positively, saying they “felt together for the first time in my life” when commenting on the impact of receiving a diagnosis and any related understandings.

Additionally, all participants agreed that it would have been helpful to have had an earlier understanding of how their brain worked, not simply a diagnosis. These perceptions are highlighted in statements made by a Childhood Group participant who stated that while "the label was negative", she found being re-diagnosed as an adult “reaffirming”. Negative perceptions of diagnoses could also be related to an ableist view of ADHD and disability overall. In reality, a label or diagnosis is a simple way to identify, in this case, a collection of traits or characteristics that impact the individual's interaction within themselves and the world around them. The negative perception of the label comes into being through the judgement and viewpoints of ADHD and the individual behaviours based on normative expectations (Campbell, 2008). As one Adolescence Group participant stated, “any successes I will put down to external causes and any failures I will put down to internal causes”. This type of internal judgement seemed to reflect a sense of shame for the participants in this study.

For participants in the Childhood Group, support and guidance seemed to be left to parents and teachers. Nevertheless, as these two participants shared, their parents did not have adequate knowledge or experience with ADHD and therefore did not know how to help. This lack of knowledge may have been shaped by outdated or misinformed perceptions and information about ADHD (Metzger & Hamilton, 2020). Moreover, the researcher conducted an online search for books regarding ADHD in children; the results returned mostly adult-focused books, e.g. for parents and teachers, based on coping with or ‘managing’ the ADHD child rather than helping them understand themselves. Only one participant within the Childhood Group, diagnosed at age six, stated that they received ADHD support other than medication following their diagnosis. However, in hindsight, the participant perceived that the help and guidance she received fell short of what she needed.

Across groups and participants, results revealed that struggles participants faced even with a diagnosis can be a side-note in a societal context, and the expectation of assimilation is often well established (Campbell, 2008). As one participant explained;

> I definitely think, as much as I know the arguments of like (sic) for and against early diagnosis and certainly mediation, I think knowing early enough to advocate for the person to be themselves is no bad thing. I think it probably would have made a big difference.

This suggestion for the increased personal agency alongside more constructive interventions and support may provide a better path forward for individuals with ADHD that could positively impact future outcomes.

Early Understanding

Participants were asked if they thought an earlier understanding of how their brains worked would have changed their experiences. The researcher's initial hypothesis was that participants in the Childhood Group would have a better understanding of the impact of their ADHD than participants in other groups. However, across all groups, participants' experiences related to their ADHD were quite similar regardless of whether they were diagnosed early or not.

This similarity among participants suggests that diagnosis alone does not create self-insight. When discussing early intervention, mutually shared topics between groups were related to understanding. One participant said that understanding her ADHD "would have helped me with a lot of different stepping stones in my life", while another said that understanding might have meant "guidance for my parents [to help support me] instead of giving up on me". Upon diagnosis, a lack of support and guidance, and parents' lack of knowledge about ADHD were the consistent messages related to participants' understandings about "why I wasn't normal", "how I work", their awareness to enable support, how to maintain friendships, and a better understanding of how to interact. It became clear through participants' comments that not having a complex understanding of ADHD and the impact it can have, meant they came to conclusions about themselves and their ADHD. Participants suggested that they reached logical explanations about themselves such as – I am a "freak" - "dumb" - "a bit dull" - "stupid" - "lazy" - "flaky". Thus, these early explanations that participants came to about why they experience the things they experienced, or "why I do the things I do", highlight the importance of early individual understanding of ADHD as a foundation for any subsequent ADHD interventions. This need for an early understanding of ADHD is emphasised by Hallowell and Ratey (2021) in their book titled ***ADHD 2.0***;

> Ignorance regarding ADHD costs lives. Literally. ADHD can be a scourge, an unremitting, lifelong ordeal, the reason a brilliant person never finds success but rather limps through life in frustration, shame, and failure, amid catcalls to try harder, get with the program (sic), grow up, or in some other way reform. It can lead to suicide, addictions of all kinds, felonious acts (the prisons are full of people with undiagnosed ADHD), dangerously violent behavior (sic), and a shorter life (p. xv).

Research has shown this statements by Hallowell and Ratey (2021) to be indisputable (American Psychiatric Association, 2013; Barkley, 2015; Taylor et al., 2014; Young, 2014; Young & Cocallis, 2019). Nevertheless, they fall short of fully expressing the cumulative emotional toll related to shame and frustration that ADHD can take on an individual, as reported by Brod et al. (2015) and echoed by the participants in this study.

Quality of Life

The emotional toll of ADHD is reflected in this research in the Adult ADHD Quality of Life Scale (AAQOL) results and the participants' interviews. Brod et al. (2006) reported that the lower mean scores of participants with ADHD on the AAQOL subscales reflected a poorer quality of life than non-ADHD participants. In comparison, the AAQOL subscale group mean scores for this current study were lower than the scores of individuals with ADHD reported by Brod et al. (2006). These differences could be due to this study's smaller sample size (n = 8) when compared to the study by Brod et al. (2006) that had a much larger sample size (n = 989). However, differences are also possible due to the impact of higher comorbid conditions in females as reported by Solberg et al. (2018). The results of studies by Brod et al. (2006) or Brod et al. (2015) that utilised the AAQOL subscales were not reported by gender. Therefore, comparisons regarding gender are not appropriate.

The AAQOL subscale results were used to compare group means regarding quality of life between research groups in this study. Higher AAQOL scores reflect a higher quality of life (Brod et al., 2006). The Adolescence Group mean was the highest out of all groups on the Life Productivity, Psychological Health and Relationship scales. The participants of the Adolescence Group both reflected on the added support of family and living at home, which may be reflected in the higher subscale scores. However, the groups' mean of the Suspected Group was slightly higher on the Life Outlook scale than other groups. Surprisingly, the Childhood Group recorded the lowest mean scores on all subscales. The researcher thought that the Childhood Group participants would have the earliest opportunity to receive support for their ADHD, leading to improved outcomes and higher AAQOL subscale scores. While there could be various reasons for the unexpected AAQOL scores, including lack of parental support and shame, more research is needed to evaluate these results.

One question within the Psychological Health scale asked – “during the past two weeks, how often have you felt overwhelmed?”. All participants responded often or very often, with the responses being split evenly between these two options. This ‘overwhelmed’ state was also reflected in participant interviews, with minimal variations detected between the eight participants in the four groups. Consequently, participants expressed the overriding feeling that somehow, they should be able to do better or “try harder”. Additionally, feelings of shame were connected to several topics, including organising themselves, untidy houses, motivation to clean, struggling with schedules, and depending on others.

Positive aspects of relationships were reported to create safe places, such as a partner being their “rock”, acceptance at work, or close bonds with siblings and children. Still, participants spoke about these relationships with an underlying frustration that they, the participant, should do or be more. The “underlying current of, I don’t feel good enough” expressed by one participant was reflected in most interview transcripts. Participants’ lack of self-confidence and self-worth seemed to be the basis of these feelings of inadequacy. These feelings inhibited the participants’ interactions with others, or else they lacked the personal insight that might have supported them to explain that whilst they can be “a bit flaky” about keeping in contact, that did not mean they did not want to be in contact with others.

This concept can be linked back to each inattention characteristic criteria in the DSM-V (American Psychiatric Association, 2013). These characteristics include missing details, often experiencing difficulties sustaining attention, not seeming to listen when spoken to directly, difficulty organising activities, often not following through with tasks, and forgetfulness in daily activities. All of these characteristics can impact the ability of individuals with ADHD to maintain meaningful relationships (American Psychiatric Association, 2013; Asherson et al., 2012; Bjerrum et al., 2017). Even when the diagnosis is predominantly hyperactive/impulsive, it is essential to note that inattentive characteristics can also have an impact. The word ‘predominantly’ in the diagnosis specification denotes an expected overlap between ADHD characteristics rather than an either/or characteristic presentation within the predominantly hyperactive/impulsive or predominantly inattentive ADHD diagnoses (American Psychiatric Association, 2013).

The inattentive characteristics that negatively impact relationships were also seen in participants' interview responses regarding their occupations and quality of life. One participant stated, “[I] never had trouble getting a job but struggled to stay engaged”. Engagement seemed to be a common thread between participants who enjoyed their jobs and those who struggled to maintain or get a job. As described previously, most participants expressed a level of shame at not doing better or being different even when they were happy with their job. This point is highlighted by the participant who happily joined staff meetings online from the next room instead of in person. It appeared to the researcher that the participant readily accepted that any fault in social interactions was her own and that she separated herself so that others would not have to suffer the uncomfortableness of her presence. These engagement issues and their related shame was discussed by most participants even when reporting a level of enjoyment in their occupation.

Participants in this research reported feeling like they were expected to “fit in” by trying “extra hard” to look like they do not have ADHD. They perceived this assimilation and personal suppression to meet the expected norm as reasonable, which may have been reinforced by earlier feelings of rejection and judgement (Campbell, 2008; Metzger & Hamilton, 2020). These results align with those by Velotti et al. (2017), who reported that females experience greater levels of shame and lower self-worth related to emotional suppression. The participant who attended an online staff meeting did not specifically report being aware of any judgement or rejection. Instead, she felt that the staff’s decision not to make space in the meeting for her to engage was reasonable rather than seeing it as a form of rejection, maybe because the arrangement meant that she could focus better on the content. Nevertheless, the participant reported that she knew other staff members did not want her physically in the room for the meeting. It would seem that the shame of earlier expectations can leave the onus on the individual with ADHD to fit in and the understanding that the ‘norm’ has no responsibility to make space for or accept them.

For many people with ADHD, occupational difficulties can directly flow into financial struggles (Bjerrum et al., 2017). These struggles were evident among participants in this study, some of whom referred to financial stress related to a lack of impulse control around spending. Participants reported struggling with online shopping, impulse buying and loaning money. Participants related these issues to impulsive ADHD characteristics, which impacted their financial stability. One participant in the Adolescent Group had established a strategy to help mitigate her financial stress by having ‘blind’ savings accounts. She could neither move money from the account nor see the total in the account without physically going to the bank. These experiences highlight the importance of individuals with ADHD having strategies or tools to manage the impact of their ADHD characteristics, particularly impulsivity. These strategies and tools are essential in mitigating financial struggles and improved agency and self-worth (Bjerrum et al., 2017).

Medications and Treatments

Additional tools that participants discussed were various treatments and medications. While there are concerns regarding stimulant medications due to the side effects they may cause (Yackobovitch-Gavan et al., 2021), research has shown that stimulant and non-stimulant ADHD medications improve employment outcomes and lower rates of substance use disorders. In contrast, untreated ADHD is related to higher rates of smoking, substance use, affect disorders, serious accidents, self-harm, and suicide (Kooij et al., 2012; Rucklidge et al., 2016; Taylor et al., 2014). Frustratingly, the treatments that could help avoid such outcomes are all connected to having a diagnosis, which, as participants attested, can be littered with roadblocks, i.e. referral restrictions and cost. Even when these roadblocks are overcome, the process of finding the proper medication and dosage requires a trial-and-error approach and needs to be reassessed regularly (Stein & McGough, 2008). However, while ADHD medication is a highly effective strategy to help cope with ADHD characteristics, it is only one tool in the toolbox. Among the participants who had received a diagnosis and therefore had the opportunity to receive a prescription of ADHD medication, four participants found medication ‘somewhat’ or ‘very’ helpful, and one participant found medication ‘not’ or ‘not very’ helpful. Of these participants, four tried two different medications, and another had tried three. Although the reasons for trying multiple medications are unknown, these results reflect the trial-and-error nature of finding an effective ADHD medication.

Interestingly, of the four participants within the diagnosed groups who found medication ‘somewhat’ or ‘very’ helpful, three were also currently using non-medical treatments, which they indicated were helpful. Participants reported experimenting with exercise, meditation, diets and food avoidance, micronutrients, caffeine, alcohol, and illegal substances. These additional treatments were used to help in conjunction with medication or when medication was not successful. Much like prescribed medication, there is also a level of experimentation necessary, which can be a journey to find strategies to help with the internal and external struggles related to ADHD (Barkley, 2015; Stein & McGough, 2008). As ADHD is heterogeneous, each individual with ADHD can find that particular tools help, or not, at particular times.

Ableism

The act of being one’s true self can take courage as one participant stated, “I’d love to be me, but I just don’t think people could handle it”. Sadly this courage and effort are often picked up by non-disabled and neurotypical individuals who try to inspire each other or in an attempt to reduce the stigmatisation of impairments and disabilities (Grue, 2015). The result can be what is termed 'inspiration porn’, which is typically used to inspire non-disabled people by showing them that life could always be worse – they could be disabled (Young, 2014). Another version is the inspiration of ‘if they can do it, why are you complaining’, which Grue (2015) calls the “supercrip narrative” (p. 1).

These depictions lead back to misrepresentations of disability. Turning this lens toward ADHD, inspiration porn is often experienced when people without ADHD use it to inspire those with ADHD. Successful people with ADHD like Richard Branson, Simone Biles, Justin Timberlake, and Emma Watson are held up as examples of what is achievable despite them having ADHD. Within Critical Disability Theory, these individuals are often referred to as the ‘overcomer’ – individuals achieving despite their impairments. However, this viewpoint could result in the individual with ADHD, who is not succeeding like the examples, being vulnerable to internal and external self-blame. The same concept holds for the trope that ADHD is a ‘gift’ or ‘superpower’. ADHD often has advantages or strengths, and these can be related to being imaginative, creative, inquisitive, and having a narrow focus on interests, often called hyperfocus (Hallowell & Ratey, 2021). These strengths are why some people believe that ADHD makes people more creative or able to look at things in ways that neurotypicals do not – for example, thinking outside the box (Bjerrum et al., 2017). However, there is a risk that the 'superpower' view is promoted singularly, leaving no room for the struggles that ADHD may produce for individuals despite these sometimes-added abilities or strengths.

Consequently, individuals with ADHD can be at additional risk of internalised ableism and self-incrimination that the participants of this study reported experiencing. These experiences draw on models of disability, such as the social model, which makes disability situational and external (Degener, 2016). While this model may help when taking aim at attitudes and beliefs related to ableism, it does not address the fact that those with ADHD find that their brains are their hindrance. This internal stumbling block results from impaired executive functioning and open “toggle switches” (Barkley, 2015;

Hallowell & Ratey, 2021). Thus, internal barriers reflect the relevance of the human rights model of disability that recognises impairments and disabilities as a natural difference of being that impacts the individual's quality of life yet still embodies humanity (Degener, 2016).

Conversely, with the promotion and valuing of able-bodiedness and able-mindedness, the stage is set to discredit and reject the humanity within disability. In response, these research participants and others with neurodivergent disabilities invisibly engage in the "policing" of self – attempting to hide neurodivergence from people they encounter by learning to mask their difficulties to avoid judgment, rejection, and the associated shame (Kattari et al., 2018). Strangers may not realise that shame restricts the "freak flag" from flying or that they are not engaging with someone's authentic self. These self-restrictions exemplify the "'identity' other than one's own" that Campbell (2008, p. 157) referred to, the 'passing as normal' or masking that those with invisible disabilities put extraordinary amounts of energy into maintaining. When asked about masking, one participant responded, "I hate it…it is exhausting. Other participants shared that masking "makes me feel insecure" and "makes me feel a bit of a failure at times". Therefore, rather than making the participants feel more confident by 'fitting in', policing and masking their behaviour had the opposite effect.

Individuals with ADHD can struggle to manage both the external and their own emotional and neurological influences, trying to appear as if they are functioning effortlessly (Bjerrum et al., 2017). However, rather than feeling included or normal, masking can alienate the masker from those one wishes to be included by, further highlighting their differences. Often, this can seem like being the proverbial duck, who appears to calmly glide across the water while the feet paddle feverishly under the surface. These efforts can occur while attempting to act on the commands of “try harder” and “needs to focus” and working diligently to be perceived and accepted as a normal member of society (Bjerrum et al., 2017). All goes to plan until it does not, homework or a meeting forgotten, schoolbooks, keys or phones are lost, or there is simply no fuel left in the tank to paddle any further. The roadblocks set in place by ableism restrict acceptance of self and others, often in the most challenging moments. The resulting frustration and shame create difficulties that may lead to more significant stress, affect disorders, substance use, self-harm, and even suicide (Balazs & Kereszteny, 2017; Barkley, 2015; Eccleston et al., 2019; Taylor et al., 2014). What is more, the energy put toward maintaining the normative facade subsequently means that often there can be little left to realise one’s individual aspirations and potential.

Conclusion

This study was primarily exploratory with the central aim of researching the similar and differing lived and ableist experiences between adults with ADHD in Aotearoa New Zealand. The focus groups included individuals who had received an ADHD diagnosis in childhood, adolescence, and adulthood and those who suspect they have ADHD. The eight participants, two for each focus group, were recruited from the ADHD NZ Adult Facebook Support group. Online survey software was used to collect data, including responses to the ASRS-5 to assess ADHD characteristics and the AAQOL to assess ADHD related quality of life. The participants' lived experiences as they related them to ADHD were also explored through one-to-one online interviews. All data were synthesised and re-evaluated using a mixed-method design with theoretical frameworks of hermeneutic phenomenology and critical disability theory. As detailed in this Chapter, the key findings of this study revealed minimal differences between group experiences and outcomes. However, on the whole, the research revealed that participants' experiences, as they related to ADHD, centred around similar themes of frustration, rejection, shame, and a lack of personal agency. The themes that emerged related to the research topics, including diagnoses, education, early intervention, quality of life, and ableism. Participants reported that the experiences influenced the policing and masking of their ADHD characteristics in an attempt to pass as normal.

The absence of early guidance and support regarding their ADHD resulted in the participants lacking the crucial knowledge they needed to navigate life externally and internally. Additionally, this lack of understanding led participants to make conclusions about themselves and the world around them based on their experiences. When those experiences were negative, e.g. "I was too much work", being the "odd one out", or the rejection of parents "just giving up on me", they often resulted in negative self-worth and confidence. Participants expressed these outcomes as a lack of agency and frustration and felt rejection and shame that they now relate to their experiences of having diagnosed or suspected ADHD. Participants' negative experiences seemed to develop when they could not meet ableist expectations due to personal challenges related to their ADHD characteristics.

Consequently, much of the energy needed to cope with ADHD characteristics or build a toolbox of valuable ways to help minimise their challenges seemed to be diverted toward policing and masking to meet society's ableist expectations. Comprehensive ADHD information and support upon diagnosis and within the 'helping' community, i.e.

educators and health professionals, would be one step to reducing ableism and improving personal outcomes. Moreover, these results support the need to consider adaptable ADHD support tailored to the changing focus and motivations that are a feature of ADHD characteristics. Such support is fundamental to more positive outcomes for individuals with ADHD. Returning to the mantra of ‘nothing about us without us’, understanding the internal impacts of ADHD is only possible through hearing the voices of individuals with ADHD (Charlton, 1998). When combined with current ADHD research about how ADHD brains process information, the insights gathered through those who have ADHD are surely the most beneficial approach to creating an ADHD toolbox to individualise support and improve outcomes, which in turn improves societal outcomes.

This study provides a small window into the lived experiences of individuals with diagnosed or suspected ADHD. Whilst limited in scope, it generates thought-provoking insights and further questions about the often invisible penalties participants experience related to their ADHD. “ADHD penalties” may be overlooked by treatment and outcome-focused research whether the similar internal experiences the participants of this study reported are a widespread ADHD phenomenon regardless of differing demographics and life trajectories.

Implications

This study has implications for individuals with diagnosed ADHD and ADHD characteristics within Aotearoa New Zealand (and internationally). The importance of early support, understanding of impairments and treatments, and the impact of shame that can accompany living with ADHD may promote positive internal awareness for individuals with ADHD. These findings may also benefit counsellors, psychologists, and medical experts who support individuals of any age with diagnoses and treatment. Practitioners, teachers, and ADHD support staff who are instrumental in positive long-term outcomes and early diagnosis, misdiagnosis, and late diagnosis of ADHD may also benefit.

Limitations and Strengths

This study has a number of limitations. Designed as a quasi-exploratory pilot study, the research was undertaken with a small sample of a much larger and more diverse New Zealand cohort. While participants were randomly chosen, selection bias exists as participants were only selected from members of the ADHD NZ Adult Support Group who registered their interest in the research. The small sample size was also a limitation as it restricted statistical calculations and generalisations. The researcher’s status as an insider in this study related to being an adult with ADHD and member of the ADHD NZ Adult Support Group is a limitation that required a continual rechecking of bias. In line with hermeneutic phenomenology, this rechecking was intended in order that the data would speak for itself beyond the researcher's personal experiences. Equally, this personal connection was also a strength in terms of my personal insight and the comfort and rapport of shared ADHD experiences with research participants. Other strengths of this research included having authorised access to research instruments that have been proven valid and reliable repeatedly, including the ASRS-5 to assess the severity of ADHD characteristics and the AAQOL to assess participants' quality of life.

Recommendations for Further Study

This study provides a foundation for a much larger proposed study in the future by the researcher, possibly as a PhD. Hence, a number of recommendations for further research are now detailed. First, while the ableism question in the one-to-one interviews gave insight into how the participants engaged with their impairments, an ableist microaggression scale like the one validated by Kattari (2018) would likely better assess internal ableist perceptions. Second, while one-to-one interviews might not be feasible in an extensive study, the researcher proposes open-answer survey questions regarding more experientially based topics and treatment and support options. Third, adding questions regarding coping mechanisms, which were not discussed in this study, might interest others with ADHD or those supporting them to develop or add to an ADHD toolbox. Fourth, further questions are proposed regarding treatments, their effectiveness, and the lack of availability to medical professionals that might restrict the opportunity for diagnosis and the trial-and-error of medications. Finally, with the knowledge that autism spectrum condition is highly comorbid with ADHD, it would be sensible to open future research to the ASD community and any other New Zealand based ADHD communities. These additions could be essential so as not to miss those diagnosed with ADHD who identify more as autistic.

Final Comments

This study gives a voice to the often unseen and unheard burden that ADHD can have on individuals with diagnosed or suspected ADHD. The Oxford Learner's Dictionary defines knowledge as "information, understanding and skills that you gain through education or experience". The information and understanding that the participants gained through their experiences often resulted in self-recrimination. They were left to believe that they were the ‘problem’ because they did not “fit in” or meet society's expectations. Comfortable in its valuing of able-bodiedness and able-mindedness, society progresses, at best, with little or no awareness of the struggles others may be experiencing. At worst, they proceed with the feeling that the ‘other’ suffer from moral failings. In this light, and by this study’s results, the participants may not be the actual ‘problem’. On the contrary, they have exhibited considerable resilience in the face of adversity, which goes unrecognised, even by themselves.

Building a personal toolbox is not often discussed in the literature despite what is known about the variability of ADHD presentations and, thus, the need for varied coping techniques (Bjerrum et al., 2017; Hansson Halleröd et al., 2015; Holthe & Langvik, 2017; Young et al., 2020). This variability means that an ADHD toolbox is not one-size-fits-all as individuals with ADHD deal with different presentations in different situations. Additionally, ADHD boredom may impact the use of a tool, or its effectiveness may wane. Consequently, while neurotypical individuals without ADHD may need a toolbox with a couple of tools to meet life’s daily challenges, it may be that the individuals with ADHD need a garage full of tools that they can interchange depending on the situation. There is a need to promote the individual agency to build a toolbox, support, and flexibility in conjunction with inclusion and the internal and external recognition of ADHD difficulties and strengths. Ultimately, the goal should be to increase a person’s self-worth, decrease adverse outcomes, and promote the importance of valuing the authentic self.

References

Abbas, A., Bassil, Y., & Keilholz, S. (2019). Quasi-periodic patterns of brain activity in individuals with attention-deficit/hyperactivity disorder. *NeuroImage: Clinical, 21*, 101653. https://doi.org/https://doi.org/10.1016/j.nicl.2019.101653

Ahnemark, E., Di Schiena, M., Fredman, A. C., Medin, E., Söderling, J. K., & Ginsberg, Y. (2018). Health-related quality of life and burden of illness in adults with newly diagnosed attention-deficit/hyperactivity disorder in Sweden [Article]. *BMC Psychiatry, 18*(1), 1-11. https://doi.org/10.1186/s12888-018-1803-y

Allen, R. E. S., & Wiles, J. L. (2016). A rose by any other name: participants choosing research pseudonyms. *Qualitative Research in Psychology, 13*(2), 149-165. https://doi.org/10.1080/14780887.2015.1133746

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5®)*. American Psychiatric Publishing.

Anbarasan, D., Kitchin, M., & Adler, L. A. (2020). Screening for Adult ADHD. *Curr Psychiatry Rep, 22*(12), 72-72. https://doi.org/10.1007/s11920-020-01194-9

Antshel, K. M. (2008). Attention-deficit hyperactivity disorder in the context of a high intellectual quotient/giftedness. *Developmental Disabilities Research Reviews, 14*(4), 293-299. https://doi.org/10.1002/ddrr.34 (ADHD and modifiers of the syndrome: Influences on educational outcomes)

Antshel, K. M., Faraone, S. V., Maglione, K., Doyle, A., Fried, R., Seidman, L., & Biederman, J. (2009). Is adult attention deficit hyperactivity disorder a valid diagnosis in the presence of high IQ? *Psychological Medicine, 39*(8), 1325-1335. https://doi.org/10.1017/S0033291708004959

Asherson, P., Akehurst, R., Kooij, J. J. S., Huss, M., Beusterien, K., Sasané, R., Gholizadeh, S., & Hodgkins, P. (2012). Under diagnosis of adult ADHD: Cultural influences and societal burden. *Journal of Attention Disorders, 16*(5_suppl), 20S-38S. https://doi.org/10.1177/1087054711435360

Balazs, J., & Kereszteny, A. (2017). Attention-deficit/hyperactivity disorder and suicide: A systematic review. *World journal of psychiatry, 7*(1), 44. https://doi.org/10.5498/wjp.v7.i1.44

Barkley, R. (2015). *Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment* (4 ed.). The Guilford Press.

Barkley, R. A., & Peters, H. (2012). The earliest reference to ADHD in the medical literature? Melchior Adam Weikard's description in 1775 of "attention deficit"(Mangel der Aufmerksamkeit, Attentio Volubilis). *Journal of Attention Disorders, 16*(8), 623-630. https://journals.sagepub.com/doi/10.1177/1087054711432309?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%3dpubmed

Berberat, J., Huggenberger, R., Montali, M., Gruber, P., Pircher, A., Lövblad, K.-O., Killer, H. E., & Remonda, L. (2021). Brain activation patterns in medicated versus medication-naïve adults with attention-deficit hyperactivity disorder during fMRI tasks of motor inhibition and cognitive switching. *BMC Medical Imaging, 21*(1), 53. https://doi.org/10.1186/s12880-021-00579-3

Biesta, G. (2010). Pragmatism and the philosophical foundations of mixed methods research1. In C. Teddlie & A. Tashakkori (Eds.), *Sage handbook of mixed* *methods in social & behavioral research* (2nd ed., pp. 95-118). Thousand Oaks: SAGE Publications, Inc. https://doi.org/10.4135/9781506335193.n4

Bjerrum, M. B., Pedersen, P. U., & Larsen, P. (2017). Living with symptoms of attention deficit hyperactivity disorder in adulthood: a systematic review of qualitative evidence. *JBI Database of Systematic Reviews & Implementation Reports, 15*(4), 1080-1153. https://doi.org/10.11124/JBISRIR-2017-003357

Brod, M., Adler, L. A., Lipsius, S., Tanaka, Y., Heinloth, A. N., & Upadhyaya, H. (2015). Validation of the adult attention-deficit/hyperactivity disorder quality-of-life scale in European patients: comparison with patients from the USA. *ADHD Attention Deficit and Hyperactivity Disorders, 7*(2), 141-150. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4449381/pdf/12402_2014_Article_160.pdf

Brod, M., Johnston, J., Able, S., & Swindle, R. (2006). Validation of the adult attention-deficit/hyperactivity disorder quality-of-life Scale (AAQoL): a disease-specific quality-of-life measure. *Quality of Life Research, 15*(1), 117-129. https://doi.org/DOI 10.1007/s11136-005-8325-z

Brod, M., Schmitt, E., Goodwin, M., Hodgkins, P., & Niebler, G. (2012). ADHD burden of illness in older adults: a life course perspective. *Quality of Life Research, 21*(5), 795-799. https://doi.org/http://dx.doi.org/10.1007/s11136-011-9981-9

Buckner, R. L., Andrews-Hanna, J. R., & Schacter, D. L. (2008). The brain's default network. *Annals of the New York Academy of Sciences, 1124*(1), 1-38. https://doi.org/https://doi.org/10.1196/annals.1440.011

Caci, H., Asherson, P., Donfrancesco, R., Faraone, S. V., Hervas, A., Fitzgerald, M., & Döpfner, M. (2015). Daily life impairments associated with childhood/adolescent attention-deficit/hyperactivity disorder as recalled by adults: results from the European Lifetime Impairment Survey. *CNS spectrums, 20*(2), 112-121. https://doi.org/10.1017/S1092852914000078

Campbell, F. a. K. (2008). Exploring internalized ableism using critical race theory. *Disability & Society, 23*(2), 151-162. https://doi.org/10.1080/09687590701841190

Campbell, F. K. (2009). *Contours of ableism: The production of disability and abledness*. Palgrave Macmillan.

Charlton, J. I. (1998). *Nothing about us without us: Disability, oppression and empowerment* (1 ed.). University of California Press. www.jstor.org/stable/10.1525/j.ctt1pnqn9

Chen, Q., Hartman, C. A., Haavik, J., Harro, J., Klungsøyr, K., Hegvik, T.-A., Wanders, R., Ottosen, C., Dalsgaard, S., Faraone, S. V., & Larsson, H. (2018). Common psychiatric and metabolic comorbidity of adult attention-deficit/hyperactivity disorder: A population-based cross-sectional study [Article]. *PLoS ONE, 13*(9), 1-12. https://doi.org/10.1371/journal.pone.0204516

Chigome, A. K., Matsangaise, M. M., & Meyer, J. C. (2018). Adult attention deficit hyperactivity disorder and its management [Article]. *South African Pharmaceutical Journal, 85*(3), 31-38. http://ezproxy.canterbury.ac.nz/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=130868846&site=ehost-live

Clements, S. D. (1966). *Minimal brain dysfunction in children : terminology and identification : phase one of a three phase project*. U.S. Dept. of Health, Education and Welfare; [for sale by the Supt. of Docs., U.S. Govt. Print. Off.].

Creswell, J. W., & Plano Clark, V. L. (2018). *Designing and conducting mixed methods research* (Third ed.). SAGE.

Degener, T. (2016). Disability in a human rights context. *Laws, 5*(3), 35. https://doi.org/10.3390/laws5030035

Dewey, D. (2018). What Is comorbidity and why does it matter in neurodevelopmental disorders? *Current Developmental Disorders Reports, 5*(4), 235-242. https://doi.org/10.1007/s40474-018-0152-3

Dolmage, J. T. (2017). *Academic ableism: disability and higher education*. Ann Arbor: University of Michigan Press. https://doi.org/10.3998/mpub.9708722

Dunn, P. M. (2006). Sir Frederic Still (1868–1941): the father of British paediatrics. *Archives of disease in childhood. Fetal and neonatal edition, 91*(4), F308-F310. https://doi.org/10.1136/adc.2005.074815

Eccleston, L., Williams, J., Knowles, S., & Soulsby, L. (2019). Adolescent experiences of living with a diagnosis of ADHD: a systematic review and thematic synthesis. *Emotional and Behavioural Difficulties, 24*(2), 119-135. https://doi.org/10.1080/13632752.2019.1582762

Epstein, J. N., & Loren, R. E. A. (2013). Changes in the definition of ADHD in DSM-5: Subtle but important. *Neuropsychiatry, 3*(5), 455-458. https://doi.org/10.2217/npy.13.59

Fox, M. D., Snyder, A. Z., Vincent, J. L., Corbetta, M., Van Essen, D. C., & Raichle, M. E. (2005). The human brain is intrinsically organized into dynamic, anticorrelated functional networks. *Proceedings of the National Academy of Sciences of the United States of America, 102*(27), 9673-9678. https://doi.org/10.1073/pnas.0504136102

Fredriksen, M., Dahl, A. A., Martinsen, E. W., Klungsoyr, O., Faraone, S. V., & Peleikis, D. E. (2014). Childhood and persistent ADHD symptoms associated with educational failure and long-term occupational disability in adult ADHD. *ADHD Attention Deficit and Hyperactivity Disorders, 6*(2), 87-99. https://doi.org/10.1007/s12402-014-0126-1

Friedman, C., & Owen, A. L. (2017). Defining disability: Understandings of and attitudes towards ableism and disability [Article]. *Disability Studies Quarterly, 37*(1), 2-2. https://doi.org/10.18061/dsq.v37i1.5061

Garcia-Argibay, M., Pandya, E., Ahnemark, E., Werner-Kiechle, T., Andersson, L. M., Larsson, H., & Du Rietz, E. (2021). Healthcare utilization and costs of psychiatric and somatic comorbidities associated with newly diagnosed adult ADHD. *Acta Psychiatr Scand*. https://doi.org/10.1111/acps.13297

Goodman, D. W. (2009). ADHD in adults: update for clinicians on diagnosis and assessment. *Primary Psychiatry, 16*(11), 38.

Groenewald, C., Emond, A., & Sayal, K. (2009). Recognition and referral of girls with Attention Deficit Hyperactivity Disorder: case vignette study. *Child: Care, Health and Development, 35*(6), 767-772. https://doi.org/10.1111/j.1365-2214.2009.00984.x

Grue, J. (2015). The problem of the supercrip: Representation and misrepresentation of disability. In *Disability Research Today* (pp. 220-234). Routledge.

Gudmundsdottir, G. B., & Brock-Utne, B. (2010). An exploration of the importance of piloting and access as action research. *Educational Action Research, 18*(3), 359-372. https://doi.org/10.1080/09650792.2010.499815

Gwernan-Jones, R., Moore, D. A., Cooper, P., Russell, A. E., Richardson, M., Rogers, M., Thompson-Coon, J., Stein, K., Ford, T. J., & Garside, R. (2016). A systematic review and synthesis of qualitative research: the influence of school context on symptoms of attention deficit hyperactivity disorder. *Emotional and Behavioural Difficulties, 21*(1), 83-100. https://doi.org/10.1080/13632752.2015.1120055

Hagerman, E., & Ratey, J. J. (2014). *Spark : the revolutionary new science of exercise and the brain*. Little, Brown and Co.

Hallowell, E. M., & Ratey, J. J. (2021). *ADHD 2. 0 New science and essential strategies for thriving with distraction--from childhood through adulthood*. Random House Publishing Group.

Halmøy, A., Fasmer, O. B., Gillberg, C., & Haavik, J. (2009). Occupational outcome in adult ADHD: impact of symptom profile, comorbid psychiatric problems, and treatment: a cross-sectional study of 414 clinically diagnosed adult ADHD patients. *Journal of Attention Disorders, 13*(2), 175-187.

Halperin, J. M., Bédard, A.-C. V., & Curchack-Lichtin, J. T. (2012). Preventive Interventions for ADHD: A Neurodevelopmental Perspective. *Neurotherapeutics, 9*(3), 531-541. https://doi.org/10.1007/s13311-012-0123-z

Hansson Halleröd, S. L., Anckarsäter, H., Råstam, M., & Hansson Scherman, M. (2015). Experienced consequences of being diagnosed with ADHD as an adult - a qualitative study. *BMC Psychiatry, 15*(1), 31-31. https://doi.org/10.1186/s12888-015-0410-4

Hansson Scherman, M., AnckarsäTer, H., Hansson HalleröD, S., & RåStam, M. (2015). Experienced consequences of being diagnosed with ADHD as an adult – a qualitative study. *BMC Psychiatry, 15*(1), 1-13. https://bmcpsychiatry.biomedcentral.com/track/pdf/10.1186/s12888-015-0410-4.pdf

Hasson, R., & Fine, J. G. (2012). Gender differences among children with ADHD on continuous performance tests: A meta-analytic review. *Journal of Attention Disorders, 16*(3), 190-198. https://doi.org/10.1177/1087054711427398

Heelan, P., A., & Schulkin, J. (1998). Hermeneutical philosophy and pragmatism: a philosophy of science. *Synthese (Dordrecht), 115*(3), 269-302. https://doi.org/10.1023/A:1005032631417

Hinshaw, S. P., Nguyen, P. T., O'grady, S. M., & Rosenthal, E. A. (2021). Annual Research Review: Attention-deficit/hyperactivity disorder in girls and women: underrepresentation, longitudinal processes, and key directions. *Journal of Child Psychology and Psychiatry*. https://doi.org/10.1111/jcpp.13480

Holthe, M. E. G., & Langvik, E. (2017). The strives, struggles, and successes of Women diagnosed with ADHD as adults. *SAGE Open, 7*(1), 215824401770179. https://doi.org/10.1177/2158244017701799

Horton-Salway, M. (2018). *The discourse of ADHD: Perspectives on attention deficit hyperactivity disorder* (1st ed. 2018.. ed.). Cham : Springer International Publishing : Imprint: Palgrave Macmillan.

Hosking, D. L. (2008). Critical disability theory. A paper presented at the 4th Biennial Disability Studies Conference at Lancaster University, UK,

Huss, M., & Lehmkuhl, U. (2002). Methylphenidate and substance abuse: A review of pharmacology, animal, and clinical studies. *Journal of Attention Disorders, 6*(1_suppl), 65-71. https://doi.org/10.1177/070674370200601S09

Ishaque, M., Wallace, D. J., & Grandhi, R. (2017). Pneumoencephalography in the workup of neuropsychiatric illnesses: a historical perspective. *Neurosurgical Focus FOC, 43*(3), E10. https://doi.org/10.3171/2017.6.Focus17238

Jangmo, A., Kuja-Halkola, R., Pérez-Vigil, A., Almqvist, C., Bulik, C. M., D'onofrio, B., Lichtenstein, P., Ahnemark, E., Werner-Kiechle, T., & Larsson, H. (2021). Attention-deficit/hyperactivity disorder and occupational outcomes: The role of educational attainment, comorbid developmental disorders, and intellectual disability. *PLoS ONE, 16*(3), e0247724-e0247724. https://doi.org/10.1371/journal.pone.0247724

Janson, A. (2017). *The lived experience of invisible disability for children, youth and their families in New Zealand: State of the sector report*. Disability Connect. https://www.researchgate.net/profile/Annick-Janson/publication/318393192

Kattari, S. K., Olzman, M., & Hanna, M. D. (2018). You look fine!: Ableist experiences by people with invisible disabilities. *Affilia, 33*(4), 477-492. https://doi.org/10.1177/0886109918778073

Kaushik, V., & Walsh, C. A. (2019). Pragmatism as a research paradigm and its implications for social work research. *Social Sciences, 8*(9), 255.

Kern, J. K., Geier, D. A., Sykes, L. K., Geier, M. R., & Deth, R. C. (2015). Are ASD and ADHD a continuum? A comparison of pathophysiological similarities between the disorders. *Journal of Attention Disorders, 19*(9), 805-827. https://doi.org/10.1177/1087054712459886

Kessler, R. C., Adler, L., Ames, M., Demler, O., Faraone, S., Hiripi, E., Howes, M. J., Jin, R., Secnik, K., Spencer, T., Ustun, T. B., & Walters, E. E. (2005). The World Health Organization Adult ADHD Self-report Scale (ASRS): A short screening scale for use in the general population. *Psychol Med, 35*(2), 245-256. https://doi.org/10.1017/s0033291704002892

Kessler, R. C., Green, J. G., Adler, L. A., Barkley, R. A., Chatterji, S., Faraone, S. V., Finkelman, M., Greenhill, L. L., Gruber, M. J., Jewell, M., Russo, L. J., Sampson, N. A., & Van Brunt, D. L. (2010). Structure and diagnosis of adult attention-deficit/hyperactivity disorder: analysis of expanded symptom criteria from the Adult ADHD Clinical Diagnostic Scale. *67*(11), 1168.

Kooij, J. J. S., Bijlenga, D., Salerno, L., Jaeschke, R., Bitter, I., Balázs, J., Thome, J., Dom, G., Kasper, S., Nunes Filipe, C., Stes, S., Mohr, P., Leppämäki, S., Casas, M., Bobes, J., Mccarthy, J. M., Richarte, V., Kjems Philipsen, A., Pehlivanidis, A., Niemela, A., Styr, B., Semerci, B., Bolea-Alamanac, B., Edvinsson, D., Baeyens, D., Wynchank, D., Sobanski, E., Philipsen, A., Mcnicholas, F., Caci, H., Mihailescu, I., Manor, I., Dobrescu, I., Saito, T., Krause, J., Fayyad, J., Ramos-Quiroga, J. A., Foeken, K., Rad, F., Adamou, M., Ohlmeier, M., Fitzgerald, M., Gill, M., Lensing, M., Motavalli Mukaddes, N., Brudkiewicz, P., Gustafsson, P., Tani, P., Oswald, P., Carpentier, P. J., De Rossi, P., Delorme, R., Markovska Simoska, S., Pallanti, S., Young, S., Bejerot, S., Lehtonen, T., Kustow, J., Müller-Sedgwick, U., Hirvikoski, T., Pironti, V., Ginsberg, Y., Félegyházy, Z., Garcia-Portilla, M. P., & Asherson, P. (2019). Updated European Consensus Statement on diagnosis and treatment of adult ADHD. *European Psychiatry, 56*, 14-34. https://doi.org/10.1016/j.eurpsy.2018.11.001

Kooij, J. J. S., Huss, M., Asherson, P., Akehurst, R., Beusterien, K., French, A., Sasané, R., & Hodgkins, P. (2012). Distinguishing comorbidity and successful management of adult ADHD. *Journal of Attention Disorders, 16*(5_suppl), 3S-19S. https://doi.org/10.1177/1087054711435361

Kushki, A., Anagnostou, E., Hammill, C., Duez, P., Brian, J., Iaboni, A., Schachar, R., Crosbie, J., Arnold, P., & Lerch, J. P. (2019). Examining overlap and homogeneity in ASD, ADHD, and OCD: a data-driven, diagnosis-agnostic approach. *Translational Psychiatry, 9*(1), 318. https://doi.org/10.1038/s41398-019-0631-2

Lange, K. W., Reichl, S., Lange, K. M., Tucha, L., & Tucha, O. (2010). The history of attention deficit hyperactivity disorder. *Attention deficit and hyperactivity disorders, 2*(4), 241-255. https://doi.org/10.1007/s12402-010-0045-8

Lee, S. S., Humphreys, K. L., Flory, K., Liu, R., & Glass, K. (2011). Prospective association of childhood attention-deficit/hyperactivity disorder (ADHD) and substance use and abuse/dependence: A meta-analytic review. *Clinical psychology review, 31*(3), 328-341. https://doi.org/10.1016/j.cpr.2011.01.006

Liu, L., Feng, X., Li, H., Cheng Li, S., Qian, Q., & Wang, Y. (2021). Deep learning model reveals potential risk genes for ADHD, especially Ephrin receptor gene EPHA5. *Briefings in Bioinformatics*. https://doi.org/10.1093/bib/bbab207

Logue, S. F., & Gould, T. J. (2014). The neural and genetic basis of executive function: attention, cognitive flexibility, and response inhibition. *Pharmacology, biochemistry, and behavior, 123*, 45-54. https://doi.org/10.1016/j.pbb.2013.08.007

Martinez-Badía, J., & Martinez-Raga, J. (2015). Who says this is a modern disorder? The early history of attention deficit hyperactivity disorder. *World journal of psychiatry, 5*(4), 379-386. https://doi.org/10.5498/wjp.v5.i4.379

Mayoh, J., & Onwuegbuzie, A. J. (2015). Toward a conceptualization of mixed methods phenomenological research. *Journal of Mixed Methods Research, 9*(1), 91-107. https://doi.org/10.1177/1558689813505358

Metzger, A. N., & Hamilton, L. T. (2020). The Stigma of ADHD: Teacher Ratings of Labeled Students. *Sociological perspectives*, 73112142093773. https://doi.org/10.1177/0731121420937739

Meza, J. I., Monroy, M., Ma, R., & Mendoza-Denton, R. (2019). Stigma and attention-deficit/hyperactivity disorder: negative perceptions and anger emotional reactions mediate the link between active symptoms and social distance [Article]. *ADHD Attention Deficit and Hyperactivity Disorders, 11*(4), 373-382. https://doi.org/10.1007/s12402-019-00302-x

Ministry of Health – Manatū Hauora. (2020). *Annual update of key results 2019/20: New Zealand Health Survey*. https://www.health.govt.nz/publication/annual-update-key-results-2019-20-new-zealand-health-survey

Murray, A. L., Booth, T., Eisner, M., Auyeung, B., Murray, G., & Ribeaud, D. (2019). Sex differences in ADHD trajectories across childhood and adolescence [Article]. *Developmental Science, 22*(1), Article e12721. https://doi.org/10.1111/desc.12721

New Zealand Ministry of Health. (2001). *New Zealand guidelines for the assessment and treatment of attention-deficit/hyperactivity disorder* (0478261756;9780478261769;0478261764;9780478261752;). http://canterbury.summon.serialssolutions.com/2.0.0/link/0/eLvHCXMwfV3fS8MwED4cguxNp-L8xYHP1dAfaffgk1gnwzeRvZXYJvqgnQ_u e7Nlu7gYMSerQkaUruvkvuvhBF4a0KtnQC7EwFbD7RJtVJamMTVco4ZaJMhaUyajPptU2NWWXGbDexm1fw-z7NACPiAQ2iUGZqPp83megwhbDWie4JOl5R8PiH4aYsUdDDrnlo7frLA7bW_uSHNOrOxGXYhaXcHNGerUd08OK3x4-phMpiH63IH0thsJKodgYwZQA9NmsaTpY31kHmvHAsPJtN5GNQWWGV-L37hIva5FDJ8RJceZrOE-L88fVhGnQ9LvwaUNGOSXiKL1jU9ozYlVo5BxWTCSBS7yaB3xNFWmcutjBsYxr_W82YbmQcip_ewiJEeE4x0KBsVQKz6PMdNVzQsI3lkuuS9h2mmr3qj_V18-NQPs1mKKfPb38srKs5

Ohan, J. L., Visser, T. a. W., Strain, M. C., & Allen, L. (2011). Teachers' and education students' perceptions of and reactions to children with and without the diagnostic label "ADHD". *Journal of School Psychology, 49*(1), 81-105. http://dx.doi.org/10.1016/j.jsp.2010.10.001

Pawaskar, M., Fridman, M., Grebla, R., & Madhoo, M. (2020). Comparison of quality of life, productivity, functioning and self-esteem in adults diagnosed with ADHD and with symptomatic ADHD. *Journal of Attention Disorders, 24*(1), 136-144. https://doi.org/10.1177/1087054719841129

Peoples, K. (2020). *How to write a phenomenological dissertation: a step-by-step guide* (Vol. 56). SAGE Publications, Incorporated.

Pitcher, T. M., Piek, J. P., & Hay, D. A. (2003). Fine and gross motor ability in males with ADHD. *Developmental Medicine & Child Neurology, 45*(8), 525-535.

Quinn, P. O., & Madhoo, M. (2014). A review of attention-deficit/hyperactivity disorder in women and girls: uncovering this hidden diagnosis. *The primary care companion for CNS disorders, 16*(3), PCC.13r01596. https://doi.org/10.4088/PCC.13r01596

Raichle, M. E. (2015). The brain's default mode network. *Annual review of neuroscience, 38*(1), 433-447. https://doi.org/10.1146/annurev-neuro-071013-014030

Rucklidge, J. J., & Blampied, N. M. (2011). Post-earthquake psychological functioning in adults with attention-deficit / hyperactivity disorder: Positive effects of micronutrients on resilience. *New Zealand Journal of Psychology, 40*(4), 51-57. https://www.psychology.org.nz/journal-archive/NZJP-Vol.40-No.4-Distributionfinalpp51-571.pdf

Rucklidge, J. J., Downs-Woolley, M., Taylor, M., Brown, J. A., & Harrow, S.-E. (2016). Psychiatric comorbidities in a New Zealand sample of adults with ADHD.

Journal of Attention Disorders, 20(12), 1030-1038. https://doi.org/10.1177/1087054714529457

Salvi, V., Migliarese, G., Venturi, V., Rossi, F., Torriero, S., Viganò, V., Cerveri, G., & Mencacci, C. (2019). ADHD in adults: Clinical subtypes and associated characteristics. *Rivista di Psichiatria, 54*(2), 84-89.

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

Singer, J. (1999). Why can't you be normal for once in your life? From a problem with no name to the emergence of a new category of difference. *Disability discourse*, 59-70.

Solberg, B. S., Halmøy, A., Engeland, A., Igland, J., Haavik, J., & Klungsøyr, K. (2018). Gender differences in psychiatric comorbidity: a population-based study of 40 000 adults with attention deficit hyperactivity disorder. *Acta Psychiatrica Scandinavica, 137*(3), 176-186. https://doi.org/10.1111/acps.12845

Spencer, T. J., Biederman, J., Madras, B. K., Dougherty, D. D., Bonab, A. A., Livni, E., Meltzer, P. C., Martin, J., Rauch, S., & Fischman, A. J. (2007). Further evidence of dopamine transporter disregulation in ADHD: A controlled PET imaging study using altropane. *Biological psychiatry (1969), 62*(9), 1059-1061. https://doi.org/10.1016/j.biopsych.2006.12.008

Spreng, R. N. (2012). The fallacy of a "task-negative" network [Opinion]. *Frontiers in Psychology, 3*(145). https://doi.org/10.3389/fpsyg.2012.00145

Stein, M. A., & Mcgough, J. J. (2008). The pharmacogenomic era: promise for personalizing attention deficit hyperactivity disorder therapy. *Child and adolescent psychiatric clinics of North America, 17*(2), 475-490. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2413066/pdf/nihms43805.pdf

Still, G. F. (1902). The Goulstonian Lectures. *Some abnormal psychical conditions in children*, 1008-1012.

Swanson, J. M., Kinsbourne, M., Nigg, J., Lanphear, B., Stefanatos, G. A., Volkow, N., Taylor, E., Casey, B. J., Castellanos, F. X., & Wadhwa, P. D. (2007). Etiologic subtypes of attention-deficit/hyperactivity disorder: Brain imaging, molecular genetic and environmental factors and the dopamine hypothesis. *Neuropsychology Review, 17*(1), 39-59. https://doi.org/10.1007/s11065-007-9019-9

Tatlow-Golden, M., Prihodova, L., Gavin, B., Cullen, W., & Mcnicholas, F. (2016). What do general practitioners know about ADHD? Attitudes and knowledge among first-contact gatekeepers: systematic narrative review [Article]. *BMC Family Practice, 17*, 1-15. https://doi.org/10.1186/s12875-016-0516-x

Taurines, R., Schmitt, J., Renner, T., Conner, A. C., Warnke, A., & Romanos, M. (2010). Developmental comorbidity in attention-deficit/hyperactivity disorder. *ADHD Attention Deficit and Hyperactivity Disorders, 2*(4), 267-289. https://link.springer.com/article/10.1007/s12402-010-0040-0

Taurines, R., Schwenck, C., Westerwald, E., Sachse, M., Siniatchkin, M., & Freitag, C. (2012). ADHD and autism: differential diagnosis or overlapping traits? A selective review. *ADHD Attention Deficit and Hyperactivity Disorders, 4*(3), 115-139. https://link.springer.com/article/10.1007%2Fs12402-012-0086-2

Taylor, M. J., Lichtenstein, P., Larsson, H., Anckarsäter, H., Greven, C. U., & Ronald, A. (2016). Is there a female protective effect against attention-deficit/hyperactivity disorder? Evidence from two representative twin samples [Article]. *Journal of the American Academy of Child and Adolescent Psychiatry, 55*(6), 504-512.e502. https://doi.org/10.1016/j.jaac.2016.04.004

Taylor, M. R., Boden, J. M., & Rucklidge, J. J. (2014). The relationship between ADHD symptomatology and self-harm, suicidal ideation, and suicidal behaviours in adults: a pilot study. *ADHD Attention Deficit and Hyperactivity Disorders, 6*(4), 303-312. https://doi.org/10.1007/s12402-014-0139-9

U.N. General Assembly. (1989). *Conventions on the Rights of the Child*. UN General Assembly. http://treaties.un.org/doc/Treaties/1990/09/19900902%2003-14%20am/ch_IV_11p.pdf

U.N. General Assembly. (2006). *Convention on the rights of persons with disabilities and optional protocol*. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

Uneri, O. S., Senses-Dinc, G., & Goker, Z. (2015). The quality of life (QoL) in attention deficit hyperactivity disorder (ADHD). *ADHD -New Directions in diagnosis and treatment*, 197. https://www.intechopen.com/chapters/49036

Ustun, B., Adler, L. A., Rudin, C., Faraone, S. V., Spencer, T. J., Berglund, P., Gruber, M. J., & Kessler, R. C. (2017). The World Health Organization adult attention-deficit/hyperactivity disorder self-report screening scale for DSM-5. *Jama psychiatry, 74*(5), 520-527. https://jamanetwork.com/journals/jamapsychiatry/articlepdf/2616166/jamapsychiatry_ustun_2017_oi_170010.pdf

Velotti, P., Garofalo, C., Bottazzi, F., & Caretti, V. (2017). Faces of Shame: Implications for Self-Esteem, Emotion Regulation, Aggression, and Well-Being. *The Journal of Psychology, 151*(2), 171-184. https://doi.org/10.1080/00223980.2016.1248809

Vildalen, V. U., Brevik, E. J., Haavik, J., & Lundervold, A. J. (2019). Females With ADHD report more severe symptoms than males on the adult ADHD self-report scale. *J Atten Disord, 23*(9), 959-967. https://doi.org/10.1177/1087054716659362

Weiss, M., Murray, C., Wasdell, M., Greenfield, B., Giles, L., & Hechtman, L. (2012). A randomized controlled trial of CBT therapy for adults with ADHD with and without medication. *BMC Psychiatry, 12*(1), 30-30. https://doi.org/10.1186/1471-244X-12-30

Willcutt, E. G., Pennington, B. F., Duncan, L., Smith, S. D., Keenan, J. M., Wadsworth, S., Defries, J. C., & Olson, R. K. (2010). Understanding the complex etiologies of developmental disorders: behavioral and molecular genetic approaches. *Journal of developmental and behavioral pediatrics: JDBP, 31*(7), 533. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2953861/pdf/nihms229312.pdf

World Health Organization. (1997). *WHOQOL: Measuring quality of life*. World Health Organization Geneva.

World Health Organization. (2011). World report on disability 2011. https://www.who.int/disabilities/world_report/2011/report.pdf

World Health Organization. (2020). *Disability and health*. Retrieved 10/09/2021 from https://www.who.int/news-room/fact-sheets/detail/disability-and-health

Yackobovitch-Gavan, M., Mimouni-Bloch, A., Gabbay, U., Carmi, D., Goldstein, B., Keinan-Boker, L., Bloch, S., & Meyerovitch, J. (2021). Sex Specific Long-Term Height and BMI Trajectories of Stimulant Treated Children Diagnosed with Attention-Deficit/Hyperactivity Disorder. *The Journal of Pediatrics*. https://doi.org/https://doi.org/10.1016/j.jpeds.2021.07.018

Young, S. (2014). *I'm not your inspiration, thank you very much.* TED Talks. https ://www.ted.com/ talks /stell a_young _i_m_not_your_inspi ratio n_thank _you_very_ much?langu age=en.

Young, S., Adamo, N., Ásgeirsdóttir, B. B., Branney, P., Beckett, M., Colley, W., Cubbin, S., Deeley, Q., Farrag, E., Gudjonsson, G., Hill, P., Hollingdale, J., Kilic, O., Lloyd, T., Mason, P., Paliokosta, E., Perecherla, S., Sedgwick, J., Skirrow, C., Tierney, K., Van Rensburg, K., & Woodhouse, E. (2020). Females with ADHD: An expert consensus statement taking a lifespan approach providing guidance for the identification and treatment of attention-deficit/ hyperactivity disorder in girls and women [Review]. *BMC Psychiatry, 20*(1), Article 404. https://doi.org/10.1186/s12888-020-02707-9

Young, S., & Cocallis, K. M. (2019). Attention Deficit Hyperactivity Disorder (ADHD) in the prison system [Review]. *Current Psychiatry Reports, 21*(6), Article 41. https://doi.org/10.1007/s11920-019-1022-3

Young, S., & Woodhouse, E. (2020). Assessment and treatment of substance use in adults with ADHD: a psychological approach. *Journal of Neural Transmission*. https://doi.org/10.1007/s00702-020-02277-w

Appendices

Appendix A: Permission to Post Expression of Interest Advert

From: Amy Murray <ajmurray.nz@gmail.com>
Sent: Tuesday, 22 September 2020 1:54 pm
To: ADHD New Zealand <info@adhd.org.nz>
Subject: Re: Welcome to ADHD New Zealand

Hello Raewyn,

I received the info pack you sent out. It is quite extensive, and I appreciate the direction the support takes.

As I mentioned I will be placing a request to ADHD NZ about posting an invitation on the Adult ADHD NZ Facebook page to gather expressions of interest for participants for my thesis research. I was wondering if you could advise me if the request should be addressed to anyone specific?

Many thanks,

Amy Murray

On Wed, 23 September 2020 at 16:27, ADHD New Zealand <info@adhd.org.nz> wrote:
Hi Amy,

Thank you for getting back to me. I am glad to hear that you have received the Information Pack.

Feel free to send any FB request to me – I will be able to post it on your behalf.

Thank you for supporting ADHD New Zealand – please let me know if you need anything further.
Kind regards
Raewyn

Raewyn Heays
National Coordinator
ADHD New Zealand

Amy Murray <ajmurray.nz@gmail.com>
24 September 2020, 11:25
to ADHD

Hi Raewyn,

I will first need to send through the permission request which I will do shortly.

Once that is agreed and I have received ethics approval I will be back in contact with you about actually posting the advertisement for participants. Hopefully, this will be sometime in November.

Many thanks,

Amy

Dear Raewyn Haeys,

I am a Master of Disability, and Inclusion Studies student at the University of Waikato, New Zealand and a recent Adult ADHD NZ Facebook group and ADHD NZ member. I am writing to request permission to post an advertisement in the Adult ADHD NZ Facebook support group to invite members via an Expression of Interest to participate in my thesis research project.

The proposed research centres on the experiences of adults (a) who suspect they could have Attention-deficit/hyperactivity disoder (ADHD), and (b) who have received a diagnosis of ADHD in childhood, adolescence, or adulthood within a New Zealand context. I view this proposed research as a pilot study with the hope of expanding the research to include parents' and educators' perceptions of ADHD in New Zealand at PhD level. My research supervisor is Dr Janette Kelly-Ware.

Results are expected to provide a clear picture of the impact ADHD and ableism have on the lives of individuals with ADHD and highlight any differences between the four groups - adults diagnosed in childhood, adolescence, adulthood, and adults with suspected ADHD.

The Participant Information Sheet and draft advertisement for this research project are included below for your consideration.

Upon permissions and ethics approval I will confirm with you the proposed timing for posting the attached advertisement.

If you have any questions about my research or if this request meets with your approval, please contact me at am506@students.waikato.ac.nz.

Many thanks,

Amy Murray

2 Attachments

Appendix B: Permission Request to use the AAQOL Scale

From: Amy Murray <am506@students.waikato.ac.nz>
Sent: Sunday, 20 September, 2020 11:33 pm To: Meryl Brod
<mbrod@thebrodgroup.net> Subject: Permission request for use of AAQoL

Dear Dr Brod,

I am a Master of Disability and Inclusion Studies student at the University of Waikato, New Zealand and am interested in using the Adult ADHD Quality of Life Questionnaire (AAQoL) as part of my thesis research project. This research is centred on the experiences of adults (a) who suspect they could have Attention-deficit/hyperactivity disoder (ADHD), and (b) who have received a diagnosis of ADHD in childhood, adolescence, or adulthood within a New Zealand context. I view this proposed research project as a pilot study with the hope of expanding the research to include parents' and educators' perceptions of ADHD in New Zealand at PhD level. My research supervisor is Dr Janette Kelly-Ware.

In this project, the AAQoL Questionnaire would be part of an online survey completed by eight participants recruited from the Adult ADHD New Zealand Facebook support group. I believe the AAQoL Questionnaire will support the development of a comprehensive understanding of any current quality of life differences between the four distinct groups in addition to supporting the qualitative aspect of the research.

With permission, there are a few changes that I would like to modify the questionnaire to the New Zealand context, i.e. from the life productivity subscale question 5 "checkbooks" are no longer used in daily lives in New Zealand. Additionally, 'others' in question 25 of the Relationships subscale would work better if I can replace it with 'friends and whānau' as this is a commonly used and understood terminology within New Zealand.

If permission is granted, I would appreciate receiving a copy of the test questionnaire, along with the standard instructions for administering the test, and scoring procedures.

In addition to using the instrument, I also request your permission to reproduce it in my master's thesis appendix. The thesis will be published in the University of Waikato Research Commons.

I would like to use and reproduce the questionnaire under the following conditions:

- I will use the AAQoL Questionnaire only for my research project and will not sell or use it for any other purposes.

- I will include a statement of attribution and copyright on all copies of the instrument. If you have a specific statement of attribution that you would like me to include, please provide it in your response.

- At your request, I will send a copy of my completed thesis to you upon its completion and/or provide a hyperlink to the final manuscript.

If you do not control the copyright for these materials, I would appreciate any information you can provide concerning the proper person or organisation I should contact for permission to adapt and use the AAQoL Questionnaire.

If you have any questions regarding this request - the terms and conditions, or if it meets your approval, please contact me at am506@students.waikato.ac.nz.

Kind regards, Amy Murray
____ Amy Murray
MDInS student
University of Waikato/New Zealand ORCID:0000-0001-6624-9237
Recent Research:
Murray, A., & Sotardi, V. (2020)Exploring experiences and academic outcomes of first-year university students with and without perceived disabilities or impairments.International Journal of Disability, Development & Education (CIDJ)doi.org/10.1080/1034912X.2020.1811842

On Tue, 22 September 2020 at 03:01, Meryl Brod <mbrod@thebrodgroup.net> wrote:

Hello Amy,

Thank you for your interest in using the AAQoL in your dissertation. Jane will send you a copy and if you could please mark up and send me a track changes version with your requested changes that would be appreciated. If these changes are acceptable, you have my permission to use the adapted version and include in your thesis.

Best regard, Meryl

Meryl Brod PhD President
The Brod Group 219 Julia Ave.
Mill Valley, CA 94941 Phone (415) 381 5532

Fax (415) 381 0653
www.thebrodgroup.net

From: Amy Murray <am506@students.waikato.ac.nz>
Sent: Monday, September 21, 2020 6:46 PM
To: Meryl Brod <mbrod@thebrodgroup.net>
Subject: Re: Permission request for use of AAQoL

Hello Dr Brod,
I appreciate your quick response to my request.

I have tracked the requested changes on the document Jane sent through and attached it below for your review.
Many thanks, Amy Murray

On Tue, 22 September 2020 at 16:14, Meryl Brod <mbrod@thebrodgroup.net> wrote:
Thank you Amy and good luck with your research. I look forward to hearing the results.
Regards,
Meryl

Meryl Brod PhD President
The Brod Group 219 Julia Ave.
Mill Valley, CA 94941 Phone (415) 381 5532
Fax (415) 381 0653
www.thebrodgroup.net

From: Amy Murray <am506@students.waikato.ac.nz>
Sent: Monday, September 21, 2020 16:46 PM To: Meryl Brod
<mbrod@thebrodgroup.net> Subject: Re: Permission request for use of AAQoL

Hi Meryl,
Thank you for making this process so easy. I will let you know how it goes.
Stay well, Amy

Appendix C: Participant Information Sheet

Unheard Voices: Experiences of Adults

with ADHD

within Aotearoa New Zealand

Participant Information sheet

Researcher Introduction

My name is Amy Murray, a master's student at the University of Waikato. This research is part of my thesis to complete a Master of Disability and Inclusion Studies. My academic supervisor is Dr Janette Kelly-Ware from Te Kura Toi Tangata School of Education.

Project description and invitation

The objective of this research is to explore and compare the life experiences of adults with suspected and diagnosed ADHD.

Participant identification and recruitment

Adults residing in New Zealand age 18 years or over with suspected or diagnosed ADHD can register an Expression of Interest via an online registration form related to participatingin this research. Registered individuals will be grouped into four (4) groups:

1. Diagnosed at age 12 or younger (Childhood Group)
2. Diagnosed at age 13 and 17 (Adolescence Group)
3. Diagnosed at 18 and older (Adulthood Group)
4. 18 and over who suspect they have ADHD but have not been diagnosed(Suspected Group).

Two (2) participants from each group will be randomly selected to participate.

Project procedures

This research will be conducted in two stages.

Stage 1 - Selected participants will receive an email invitation to join the research project. The invitation will include a link to the Consent Form and Survey. This stage will take approximately ten to fifteen (10-15) minutes. The invitation will be active for two (2) weeks,after which if there if Stage 1 is incomplete the invitation will be withdrawn.

Stage 2 – Will request you to be individually interviewed by the researcher. An online form will be made available to schedule the interview. Interviews will be conducted and recordedvia Zoom at a time that best suits you. The scheduling form will also have an option for you to specify a pseudonym (fake name) to be used for this research, if not specified the researcher will choose one.

You will be sent a $50 Prezzy card for your participation upon completion of Stage 2.

It is important that you to be as comfortable as possible for the interview so please have anysupport people you feel you need. Do not be concerned about the timing of your answers or if you feel you need to move while being interviewed.

A transcript of the interview will be emailed to allow for edits, clarifications, and final approval. If there is no response to the transcript email after two weeks, the researcher will assume thetranscript has been approved as is.

Participants' rights
You are under no obligation to accept this invitation. If you decide to participate, you havethe right to:

- decline to answer any question
- withdraw from the study at any time up until the Interview Transcript. is registered as approved
- ask any questions about the research project at any time during participation
- provide information on the understanding that your name will not be used unless you give permission
- be given a summary of the research and a link to the finished thesis which will be stored in the University of Waikato Research Commons
- ask for the recording to be paused at any time during the interview.

Data Management
All participant information will be carefully managed to ensure that privacy and confidentiality are maintained. The interview recordings will be transcribed. All identifying information will be changed or removed. Recordings, transcriptions, and any other associated information will be securely stored, only myself and my supervisor will have access to these. Upon completion of the project, all data will be stored and protected in asecure hard-drive for a total of five (5) years.

Project contacts
If you are interested in participating in this project or have any questions, please feel free to contact me (Amy Murray) using the email or phone details provided below. You may also use the contact details below to contact my supervisor or me any time throughout the study if you have questions, concerns or wish to provide feedback.

Project Contacts:

Researcher: Amy Murray	**Supervisor:** Dr Janette Kelly-Ware
Email: am506@students.waikato.ac.nz	**Email:** janette.kelly@waikato.ac.nz
Phone:	

<u>If you need support, feel free to contact</u>
Lifeline - 0800 543 354

Samaritans - 0800 726 666
Depression helpline - 0800 111 757
Anxiety phone line - 0800 269 4389 1737need to talk? - Call or text 1737
ADHD NZ - 09-625 1754
http://www.adhd.org.nz/info@adhd.org.nz

This project has been reviewed and approved by the University of Waikato Human Ethics Committee: 2020#77. If you have any concerns about the conduct of this research, please contact Waikato Human Research Ethics Committee (Health)

Appendix D: Expression of Interest Facebook Advertisement

THE UNIVERSITY OF
WAIKATO
Te Whare Wānanga o Waikato

Unheard Voices: Adults with ADHD within Aotearoa New Zealand

There is little research within New Zealand about the lives and experiences of adults with ADHD.
This research project intends to explore the experiences of adults who have been or suspect they could be diagnosed ADHD to provide a clear picture of what it is like to live with ADHD.

You are invited to register an Expression of Interest to participate in this research project if you are:
- age 18 and over

and
- suspect you have ADHD

or
- have been formally diagnosed with ADHD

Participants will be asked to:
- answer an online survey (10 -15 minutes)

and
- be available for an individual interview via Zoom (approximately 1 hour).

Participants will receive a $50 Prezzy Card after interview

Participants will be randomly selected from individuals who register an Expression of Interest to participate by completing this 2 minute

REGISTRATION FORM

For further information please follow this link to the Participant Information Sheet
or contact Amy Murray at am506@students.waikato.ac.nz or Dr Janette Kelly-Ware (Research Supervisor) at janette.kelly@waikato.ac.nz

Appendix E: Expression of Interest Survey

Register an Expression of Interest to Participate

The purpose of this research project is to give a voice to and understand better the experiences and perceptions of individuals with Attention Deficit Hyperactivity Disorder (ADHD) within Aotearoa New Zealand context.

This research is being conducted by Amy Murray at the University of Waikato, New Zealand as part of a Master of Disability and Inclusion Studies degree.

Individuals who are 18 years or older and have been formally diagnosed at any time over the course of their life or believe they could be diagnosed with attention deficit hyperactivity disorder (ADHD) are invited to register their interest to participate in this research project by completing this digital form.

Survey and interview questions will relate to participants and their experiences and perceptions as they relate to ADHD. Registered adults will be sorted into four groups:

- Childhood Group - ADHD diagnosis at age 12 or younger
- Adolescence Group - ADHD diagnosis between ages 13 and 17
- Adulthood Group - ADHD diagnosis at age 18+
- Suspected Group - suspected but undiagnosed ADHD age 18+

Two participants will be chosen at random from each group.

All participants will be notified by email of their acceptance status for this research project.

Individuals who are chosen to participate will receive an email containing a link to the Consent Form and Stage 1 Survey.
Participation is voluntary.
Participants can withdraw at any time without any consequences.
Stage 1 of the research project involves a Survey which will take participants approximately ten to fifteen (10-15) minutes to complete.

Stage 2 of the research project involves individual interviews which will take place via Zoom and last approximately 1 hour.
Interviews will be scheduled at their convenience.
Participant responses will be confidential.
All information will be kept confidential and be stored in a password protected electronic format.
Each participant who completes Stage 1 and 2 of this project will receive a $50 Prezzy card.
The results of this research will be used for scholarly purposes only and may be shared with the research supervisor and examiner.

Participant information sheet provides further details.
If participants have any questions about this research project, please contact Amy Murray at am506@students.waikato.ac.nz. This research project has received ethical approval from the University of Waikato Human Research Ethics Committee.

○ Name (1) ____

○ Email Address (2) ____

Have participants been formally diagnosed with ADHD?

○ Yes, I have been diagnosed by a registered psychologist. (1)

○ Yes, I have been diagnosed by a psychiatrist. (2)

○ I suspect I have ADHD, but have not been formally diagnosed (3)

At what age were you *first* diagnosed with ADHD?

____

Appendix F: Stage 1 Consent and Survey

Research Project Participant Consent Form

The purpose of this research project is to give a voice to and understand better the experiences and perceptions of individuals with Attention-deficit/hyperactivity disoder (ADHD) with Aotearoa New Zealand context. Amy Murray is conducting this research to complete a master's thesis at the University of Waikato, New Zealand.

You have been invited to participate in this research based on you being 18 or older and because you have stated that you have been diagnosed with, or you suspect that you have ADHD.

Questions will relate to you and your experiences and perceptions as they relate to ADHD.

Stage 1 is the invitation to this study and involves the completion of this Consent Form and the Survey which will take approximately ten to fifteen (10-15) minutes.

Stage 2 will consist of an individual interview with the researcher in an online setting. (i.e. Zoom). The interview lasting approximately one (1) hour will be conducted at a time that suits you and will be video and audio-recorded.

Participation is voluntary.
You may choose not to participate.
You can withdraw at any time without any consequences.
Your responses will be confidential.
There will be no automatic collection of identifying information such as IP address.
All information will be kept confidential and be stored in a password-protected electronic format.
Each participant who completes both stages of this research will receive a $50 Prezzy card.
The results of this research will be used for scholarly purposes only and may be shared with University of Waikato representatives.

If you have any questions about this research study, see the Participant Information Sheet or contact Amy Murray at am506@students.waikato.ac.nz. This research has been reviewed, met, and received ethical approval from the University of Waikato Human Ethics Committee [enter #].

Electron consent:
Please select your choice below.

Clicking the "Agree" button below indicates that;

- **You have read the above information**
- **You voluntarily agree to participate**
- **You are at least 18 years of age**

If you do not wish to participate in this research study, please decline participation by clicking on the "Disagree" button.

○ Disagree
○ Agree

End of Block: Consent

Start of Block: Demographics

What is your age?

____

Please specify your gender.

○ Non-conforming or Gender variant
○ Female
○ Male
○ Prefer not to say

What is the highest level of education you have completed?

○ Level 2 NCEA or less
○ Secondary graduate (University Entrance or Level NCEA 3)
○ Some university but no degree
○ Trade degree or diploma
○ Bachelor's degree
○ Master's degree
○ Doctoral degree
○ Professional degree (JD, MD)

Choose one or more ethnicity to describe yourself:

- ☐ Māori
- ☐ Pacific Island
- ☐ European
- ☐ Central American
- ☐ Australian
- ☐ Asian
- ☐ Middle Eastern
- ☐ African
- ☐ South American
- ☐ North American
- ☐ Prefer not to say
- ☐ Not listed - Please Specify

____

Page Break

Are you a New Zealand citizen or resident

- ○ Citizen
- ○ Resident
- ○ Neither

What is your relationship status?

- ○ Single
- ○ Committed relationship (married or partnered)
- ○ Widowed
- ○ Divorced
- ○ Separated
- ○ Prefer not to say

Page Break

Which statement best describes your current status?

☐ Working (paid employee)
☐ Working (self-employed)
☐ Student
☐ Not working (temporary layoff from a job)
☐ Not working (looking for work)
☐ Not working (retired)
☐ Not working (health/disability related)
☐ Prefer not to say

End of Block: Demographics

Start of Block: ADHD info

Have you been formally diagnosed with ADHD

○ Yes, I have been diagnosed by a registered psychologist.
○ Yes, I have been diagnosed by a psychiatrist.
○ I suspect I have ADHD, but have not been formally diagnosed

Skip To: View of no diagnosis If – 'Have you been formally diagnosed with ADHD' = I suspect I have ADHD, but have not been formally diagnosed

What type of ADHD have you been diagnosed with?

○ Predominantly Inattentive
○ Predominantly Hyperactive
○ Combined Inattentive and Hyperactive
○ Not sure

Please respond to the following statements regarding your experience receiving an ADHD diagnosis.

	Yes	No
I received a diagnosis through the private system.	○	○
I waited longer than three (3) months for an initial appointment with a psychologist or psychiatrist.	○	○
I was offered support other than medication after my ADHD diagnosis	○	○

What ADHD medications have been prescribed for you to help reduce the impact of ADHD symptoms?

Please respond only to those medications you have tried and indicate how helpful it was by stars (1 being not helpful at all and 5 being very helpful).

Concerta	☆	☆	☆	☆	☆
Ritalin	☆	☆	☆	☆	☆
Rubifen	☆	☆	☆	☆	☆
Dexedrine	☆	☆	☆	☆	☆
Strattera	☆	☆	☆	☆	☆

I feel that being diagnosed with ADHD had a negative impact on my self-confidence.

☐ Strongly disagree

☐ Somewhat disagree

☐ Neither agree nor disagree

☐ Somewhat agree

☐ Strongly agree

Skip To: Other Measures If –'I feel that being diagnosed with ADHD had a negative impact on my self-confidence.' = Strongly disagree

Skip To: Other Measures If – 'I feel that being diagnosed with ADHD had a negative impact on my self-confidence.' = Somewhat disagree

Skip To: Other Measures If – 'I feel that being diagnosed with ADHD had a negative impact on my self-confidence.' = Neither agree nor disagree

Skip To: Other Measures If – 'I feel that being diagnosed with ADHD had a negative impact on my self-confidence.' = Somewhat agree

Skip To: Other Measures If – 'I feel that being diagnosed with ADHD had a negative impact on my self-confidence' = Strongly agree

I feel not having diagnosis of ADHD has a negative impact on my self-confidence.

☐ Strongly disagree
☐ Somewhat disagree
☐ Neither agree nor disagree
☐ Somewhat agree
☐ Strongly agree

Which, if any, of the following measures are you currently using or have previously used specifically to help reduce the impact of ADHD symptoms?

Please respond to each measure regarding use and whether the measure is helpful (never used, have previously used not very helpful/helpful, or currently using not very helpful/helpful).

	Never used	Previously used - not very helpful	Previously used - helpful	Currently Using - not very helpful	Currently Using - helpful
Micro-nutrients/Vitamins	○	○	○	○	○
Diets/Food Avoidance	○	○	○	○	○
ADHD coach	○	○	○	○	○
Organisational Apps (reminder, to do, or calendar apps)	○	○	○	○	○
Cognitive Behavioural Therapy (CBT)	○	○	○	○	○
Meditation and/or yoga	○	○	○	○	○
Physical exercise	○	○	○	○	○
Drinking coffee	○	○	○	○	○
Self-medicating with alcohol or illegal substances	○	○	○	○	○

Many people with ADHD also have or are suspected to have or have had some of the following conditions.

Please respond to each condition (Not Suspected, Suspected but not diagnosed, or Diagnosed).

	Not suspected	Suspected but not formally diagnosed.	Diagnosed
Reading (dyslexia)	○	○	○
Math (dyscalculia)	○	○	○
Writing (dysgraphia)	○	○	○
Autism Spectrum Disorder (ASD)	○	○	○
Anxiety Disorders	○	○	○
Post-traumatic stress disorder (PTSD)	○	○	○
Oppositional defiance disorder (ODD)	○	○	○
Conduct Disorder (CD)	○	○	○
Depression	○	○	○

End of Block: ADHD info

Start of Block: Ableism

Please respond to the following statements.

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
ADHD impacts my ability to pass as normal.	○	○	○	○	○
I am confident in disclosing my ADHD diagnosis to others.	○	○	○	○	○
Most my friends and whānau understanding the impact ADHD has on my everyday interactions.	○	○	○	○	○
ADHD is a disability.	○	○	○	○	○
I feel ashamed when I struggle to do things that others do easily because of my ADHD.	○	○	○	○	○

End of Block: Ableism

Start of Block: ASRS-5

Check the box that best describes how you have felt and conducted yourself over the past 6 months.

	Never	Rarely	Sometimes	Often	Very Often
How often do you have difficulty concentrating on what people are saying to you even when they are speaking to you directly?	○	○	○	○	○
How often do you leave your seat in meetings or other situations in which you are expected to remain seated?	○	○	○	○	○
How often do you have difficulty unwinding and relaxing when you have time to yourself?	○	○	○	○	○
When you're in a conversation, how often do you find yourself finishing the sentences of the people you are talking to before they can finish them themselves?	○	○	○	○	○
How often do you put things off until the last minute?	○	○	○	○	○
How often do you depend on others to keep your life in order and attend to details?	○	○	○	○	○

End of Block: ASRS-5

Start of Block: AAQoL

The following questions are about how ADHD has impacted your life over the PAST 2 WEEKS. Please answer each question - there are no right or wrong answers.
During the PAST 2 WEEKS, how often have you felt:

	Not at all	A little	Somewhat	A lot	Extremely
Keep the house/apartment clean or uncluttered	○	○	○	○	○
Manage your finances (balancing your bank accounts, paying bills on time)	○	○	○	○	○
Remember important things	○	○	○	○	○
Get your shopping done (such as for food, clothes or household items)	○	○	○	○	○
Pay attention when interacting with others	○	○	○	○	○

During the PAST 2 WEEKS, how difficult has it been for you to:

	Never	Rarely	Sometimes	Often	Very often
Overwhelmed	○	○	○	○	○
Anxious	○	○	○	○	○
Depressed	○	○	○	○	○
You have not been able to meet others' expectations of you (either at home or at work)	○	○	○	○	○
You annoyed people	○	○	○	○	○
Getting things done requires too much effort	○	○	○	○	○
People are frustrated with you.	○	○	○	○	○

During the PAST 2 WEEKS, how often have you felt:

	Never	Rarely	Sometimes	Often	Very often
You have overreacted in difficult or stressful situations	○	○	○	○	○
Your energy is well spent (has positive results)	○	○	○	○	○
Able to enjoy time spent with friends and whanau	○	○	○	○	○
You can successfully manage your life	○	○	○	○	○
As productive as you would like to be	○	○	○	○	○

During the PAST 2 WEEKS, how troubled have you been by:

	Not at all	Rarely	Somewhat	A lot	Extremely
Tension in relationships	○	○	○	○	○
Not having quality time to spend with friends and whānau	○	○	○	○	○

During the PAST 2 WEEKS, how troubled have you been by:

	Not at all	Rarely	Somewhat	A lot	Extremely
Feeling fatigued	○	○	○	○	○
Fluctuations (ups and downs) in your emotions	○	○	○	○	○

During the PAST 2 WEEKS, how much of a problem has it been for you to:

	Not at all	Rarely	Somewhat	A lot	Extremely
Complete projects or tasks (either at work or at home)	○	○	○	○	○
Get started with tasks you don't find interesting	○	○	○	○	○
Balance multiple projects	○	○	○	○	○
Get things done on time	○	○	○	○	○
Keep track of important items (such as keys, wallet)	○	○	○	○	○

During the PAST 2 WEEKS, how often have you felt:

	Never	Rarely	Sometimes	Often	Very Often	Not Applicable
Good about yourself	○	○	○	○	○	○
People enjoy spending time with you	○	○	○	○	○	○
Your intimate relationship is going well emotionally	○	○	○	○	○	○

End of Block: AAQoL

Thank you for being part of Stage 1 of this research project
your participation is greatly appreciated!
I will be in touch via email to organise a time that is convenient to you for the Stage 2 interview.
Tēnā rawa atu koe!
Thank you very much!

Appendix H: Stage 1 Consent and Survey Email

Hello [RecipientFirstName]

Thank you for registering interest in Unheard Voices: Adults with ADHD within Aotearoa New Zealand research I am conducting with the support of The University of Waikato.

I am happy to inform you that you have been randomly selected to participate in Stage 1 and 2 of this research.

Please carefully read and click on an answer button in the question below. This action will open a link to the remainder of the Stage 1 survey.

Please contact me if you have any questions.

Thank you again for your willingness to share your experiences.

Kind regards,

Amy Murray
am506@students.waikato.ac.nz
phone number

$[q://QID1/QuestionText]

Follow the link to opt out of future emails:
$[l://OptOutLink?d=Click here to unsubscribe]

Appendix I: Stage 1 Completion and Stage 2 Scheduling Email

Hello $[m://FirstName]

Thank you for completing Stage 1 of this research project.

Please, schedule an "open" appointment slot on the linked calendar for your Stage 2 interview.

Meetings will be conducted via Zoom Meeting at
https://zoom.us/j/7829061704?pwd=SDhya0hKOVl0Y2FoM3V6Um1EdjNiZz09
Just enter the following meeting ID and passcode at the appointment time.
Meeting ID: 782 906 1704
Passcode: 339637

Let me know if you have any problems with the link or if there is not a suitable time available over the next few weeks.

Many thanks,

Amy Murray
phone number

Appendix J: Participant Reminder Emails

Participant Stage 1 Reminder

Hello [FirstName]

I know life gets busy, but thankfully there are still a few days left to complete Stage 1 in the Adult ADHD Research Project. Your invitation to participate will be active until Saturday, 28 November.

The website for the survey is [l://SurveyLink?d=Take%20the%20survey]

If the link does not work, copy, and paste this URL [l://SurveyURL] into the address bar of your Internet browser.

Your participation in this research is voluntary. Your completion and submission of the questionnaire indicate your consent to participate in the study (please read the "Participant Information Sheet" linked on the survey for more information). If you wish to opt out of this research please email me at am506@students.waikato.ac.nz or follow this link [l://OptOutLink?d=Click here to unsubscribe]

Many thanks,
Amy Murray

Appendix K: Participant Stage 1 Final Reminder

Hello [FirstName]

Just a quick reminder - today is the *last day* to take your place as part of the Adult ADHD Research Project. Your invitation to participate will only remain active until this this evening at **7 pm - 28 November**.

If you would still like to participate, please complete the survey at [l://SurveyLink?d=Take%20the%20survey]

If the link does not work, you can copy and paste this URL [l://SurveyURL] into the address bar of your internet browser.

Many thanks,

Amy Murray

If you would like to opt out please follow this link - $[l://OptOutLink?d=opt%20out]

Appendix L: Stage 2 Participant Interview Questions

<u>Stage 2 - Participant Interviews</u>

<u>Introduction</u>

Hello I am Amy Murray. Thank you for being here with me today. We will be discussing questions which are generally related to your life experiences. You can choose not to answer any questions or stop this interview if you need to. Do you consent to taking part in this research interview? I would like to add that I also have ADHD
Do you have any questions for me before we get started?

<u>If participants are unsure or get lost in their thoughts, I will use prompts such as;</u>

- Can you tell me more about what that?
- You stated that…, can you explain further?
- Thank you for that answer, the next question… (to prompt moving on)
- I will restate questions if the participant seems lost or unsure about what I am asking.
- What was that about?
- What did that mean to you?

<u>Questions</u>

1. Let's start with education;

1. Which school experiences stand out in your memories that you feel relate to having ADHD?

2.

3. Now we are going to shift;

2. Can you tell me about the feeling and experiences that led to your diagnosis of ADHD?

4. or

5. Can you tell me about the feelings and experiences make you suspect you have ADHD?

6.

3. Can you talk to me about the initial feelings you remember experiencing when being diagnosed with ADHD?

7. or

    8. Can you talk to me about the feelings you experience about having not received an ADHD diagnosis?

    9.

4. Can you tell me about experiences that you perceive to be related to having ADHD that impact your quality of life?

    10.

    11. We are going to take another shift now.

    12. [Ask the participant to read a short definition of ableism - shared screen.}

    13. “Ableism renders disability as abject [without dignity], invisible, disposable, less than human, while able-bodiedness [able-mindedness] is represented as at once ideal, normal, and the mean or default.”

    14. [Dolmage, Jay T. Academic Ableism: Discourses of Disability (pp. 6-7). University of Michigan Press *additions mine*]

5. If ableism is the valuing of ‘normal’, can you tell me about a time you have experienced the expectations that you ‘pass as normal’?
6. What impact has this had on you?
7. If nobody out there had those expectations on you, do you think you would still have them on yourself?

8. Do you feel that if you had had an earlier understanding of the way that your brain works, that things would have been different or would be different?

That question marks the end of this interview. I will e-mail the transcript of this session back to you within the next two (2) weeks. Can you please email me your address so I can post your Pressie Card. Do you have any further questions for me?
Thank you for your time and willingness to speak with me.