A Deficit in Attention to Assessment and Supports for Adults with ADHD in Aotearoa New Zealand

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Abstract

Outdated understandings, referral bias, and stereotypes of Attention-deficit/hyperactivity disorder (ADHD) lead to diagnostic delays. Individuals with ADHD struggle with many aspects of life and have an increased risk of poorer outcomes. Many adults living with undiagnosed ADHD will not have access to support to help manage the difficult aspects of ADHD. In Aotearoa, New Zealand, it has been suggested that ADHD assessments are inaccessible. The aim of this research was to examine access to assessment and supports for adults with ADHD/suspected ADHD in Aotearoa by exploring the perceptions and lived experiences of adults diagnosed with ADHD in adulthood. This research also sought to explore the impact of late diagnosis, misdiagnosis, and/or missed diagnosis of ADHD on adults in Aotearoa. This research was underpinned by a blend of paradigms, generating a research foundation of a critical neurodiversity paradigm. This blend enabled exploration of the impacts of social structures and the challenging of neuronormative, oppressive structures while centring neurodivergent voices. Hermeneutic phenomenology was utilised to support the centring of lived experience and for its appreciation of researcher lived experience. Following semi-structured interviews, Interpretive phenomenological analysis was utilised to interpret the experiences of nine adults with ADHD. Analysis revealed participants were impacted by neuronormativity and ableism which nurtured the development of negative self-perceptions and mental distress. Late diagnosis meant that participants spent their younger years internalising the constant reinforcement of difference and failure in their social environments. Receiving a diagnosis provided participants with self-understanding and connection with people who have similar experiences. The findings also revealed that access to ADHD assessment is dependent on either privilege or crisis. The participants in this study suggested several recommendations to improve ADHD healthcare for themselves and for other people seeking support. The findings of this research have implications for the improvement of policies regarding ADHD, from the perspectives of adults with ADHD.

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Most importantly, I thank the adults who took the time to share their experiences and expertise for the purpose of this research. Your contribution is greatly appreciated. This research is dedicated to our ADHD community in Aotearoa, to those who are diagnosed and to those who are on their journey to diagnosis. I wish you all the best.

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Chapter 1: Introduction

This chapter sets out the rationale for this study by providing contextualisation beginning with a brief overview of Attention-deficit/hyperactivity disorder (ADHD). The imperative for health care provision is provided through an overview of disability rights followed by an outline of the process of accessing ADHD healthcare in Aotearoa, New Zealand[1]. Issues concerning access are then highlighted followed by the rationale and aims for this study respectively.

1.1 Attention-Deficit/Hyperactivity Disorder

Defined as a neurodevelopmental disorder, ADHD is characterised by symptoms of inattention (for example, easily distracted and forgetful) and/or hyperactivity (for example, impulsivity; excessive talking; and difficulty waiting; Nguyen & Hinshaw, 2020). Zalsman and Shilton (2016, p. 4) characterise ADHD as "expressed primarily by the distribution of attention over many stimuli without the ability to focus on a single stimulus for a period of time". In Aotearoa, a Māori conceptualisation of ADHD was offered by Keri Opai (2022, para. 6) who introduced the Te Reo Māori term for ADHD – aroreretini, which means "attention goes to many things". The intention behind developing this term was to shift away from primarily negative conceptualisations to a more positive conceptualisation encompassing te ao Māori (the Māori worldview).

Global prevalence rates of ADHD differ slightly across the literature, however, the World Federation of ADHD International Consensus Statement (Faraone et al., 2021) stated that 5.9% of youth and 2.8% of adults have ADHD worldwide, which is nearly 9% of the population. For young people, boys are more commonly affected by ADHD than girls (Faraone et al., 2021). In Aotearoa, prevalence data for ADHD is currently lacking and no data exists on the prevalence of adult ADHD, including diagnosis rates in adults. Data on ADHD prevalence among children in Aotearoa was estimated to be 3% in 2021/2022 based on results from the New Zealand Health Survey which asked parents/caregivers if they had ever been told by a doctor that their child has attention deficit disorder (ADD) or ADHD. The Ministry of Health (2022a) accepted that this number is not likely to be an accurate representation as there may be people who are unaware their child has ADHD. The gap in statistical data on ADHD prevalence is reflective of how little is known and investigated regarding ADHD in Aotearoa.

Empirically, the Dunedin longitudinal study (Moffitt et al., 2015) found a childhood ADHD prevalence of 6% and an adult ADHD prevalence of 3%. The study utilised a representative Dunedin birth cohort of 1,037 participants. The prevalence rates suggested in the Dunedin study were based on the diagnostic criteria of the Diagnostic and Statistical Manual of Mental Disorders (third edition; DSM-III) which has since been superseded by several editions with updated diagnostic criteria; the DSM-5-TR is the most recent edition (American Psychiatric Association, 2022, Moffitt et al., 2015).

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[1] Aotearoa hereafter

1.2 Right to Health

All people with impairments have a right to health, this includes people living with ADHD. The United Nations Convention on the Rights of People with Disabilities (UNCRPD) is an international treaty of human rights outlining what is needed for disabled people[2] to enjoy human rights on an equal basis to all people (Office for Disability Issues, 2016a). The definition of disability set out in the UNCRPD states: "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (United Nations, 2006, p. 3). The social model of disability underpins the UNCRPD, which situates disability as being caused by barriers in society that prevent people with impairments from exercising their human rights (Gordon, 2018). The New Zealand Government is a signatory of the UNCRPD and ratified the convention in 2008 (Francis Watene et al., 2021). In line with article 25 of the UNCRPD, signatories recognise that disabled people have the "right to the enjoyment of the highest attainable standard of health" and as such, shall:

> *(a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;*
>
> *(b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons;*
>
> *(c) Provide these health services as close as possible to people's own communities, including in rural areas;*
>
> *(d) Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;*
>
> *(e) Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;*
>
> *(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability* (United Nations, 2006, p. 16).

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[2] In Aotearoa, the term 'disabled people/person' is used instead of 'people/person with disabilities'. This use of language was decided during consultation and development of the New Zealand Disability Strategy 2016-2026 to recognise "the term 'disabled people' is a source of pride, identity and recognition that disabling barriers exist within society and not with us as individuals" (Office for disability issues, 2016b, p. 13). Individuals from this community may use different language to identify themselves.

A commitment to the UNCRPD means that the New Zealand Government agrees that all disabled people have the rights afforded by the UNCRPD and that steps must be taken to ensure these rights are realised and enjoyed. Individuals impaired by ADHD must have access to early identification, interventions, and services needed specifically for ADHD, and including services that reduce and prevent further disability as stipulated by the UNCRPD.

The New Zealand government supports the social model of disability and has committed to the New Zealand Disability Strategy 2016-2026 with the vision that "New Zealand is a non-disabling society – a place where disabled people have an equal opportunity to achieve their goals and aspirations, and all of New Zealand works together to make this happen" (Office for Disability Issues, 2016b, p. 6). The New Zealand Disability Strategy identified eight outcome areas that would contribute to the fruition of this vision. Outcome three related to health and wellbeing at the highest attainable standard and would mean "access to mainstream health services is barrier-free and inclusive" and "services that are specific to disabled people, including mental health and aged care services, are high quality, available and accessible" (Office for Disability Issues, 2016b, p. 29). Ratifying the UNCRPD and committing to the New Zealand Disability Strategy demonstrates the New Zealand Government has an awareness of the standard of healthcare provision required and has subsequently committed to achieve it.

1.3 Accessing ADHD Healthcare in Aotearoa

In Aotearoa, the General Practitioner (GP) is the first port of call for people who suspect they have ADHD. Following a conversation with the GP about why ADHD is suspected, the GP should then provide information about the assessment process and make a referral to the appropriate specialist (ADHD New Zealand, n.d). There are certain specialists that are authorised to diagnose ADHD including Clinical Psychologists, Psychiatrists, Neurologists, and Paediatricians. Adults with suspected ADHD may be referred for a publicly funded assessment through Adult Mental Health Services or to a private specialist. Adult Mental Health Services provide support to "people with the highest mental health and addiction needs, and often people experiencing ADHD do not meet the high threshold for access" (Ministry of Health, 2022b, p. 3). Individuals referred to a private specialist must self-fund the cost of the assessment appointment which can come at a great cost suggested to range between $400.00 to $3,000.00 (Health Committee, 2023; Ministry of Health, 2022b).

Once a referral is accepted and an appointment has been booked, rating scale questionnaires are typically sent for completion prior to the assessment[3] (ADHD New Zealand, n.d; National Institute for Health and Clinical Excellence, 2018). The duration of assessment ranges from one hour to eight hours or more depending on the complexity with 90 minutes being the typical duration (ADHD New Zealand, n.d). Once diagnosed, a treatment plan[4] is discussed and put in place (ADHD New Zealand, n.d).

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[3] See Chapter 2 for more information about assessment.

[4] See Chapter 2 for more information about treatment.

Treatment plans that include medication require a psychiatrist consultation. For individuals diagnosed by psychiatrists, medication may be prescribed by the end of the appointment (Ministry of Health, 2022b). Individuals diagnosed by other specialists are required to make an additional appointment with a psychiatrist to discuss medication. Unlike medications used for mental health conditions, stimulant medications used to treat ADHD are classified as controlled drugs under the Misuse of Drugs Act 1975. The act limits initial prescribing authority to paediatricians or psychiatrists who are invested with the ability to apply for Special Authority. This then grants a GP or nurse practitioner the ability to prescribe the diagnosed individual with stimulant medication for up to two years with regular monitoring. Upon expiration of Special Authority, the diagnosed individual must book an additional appointment with a psychiatrist or paediatrician to apply for Special Authority renewal (Ministry of Health, 2022b). When an individual is prescribed ADHD medication for the first time, they must make an additional appointment with the psychiatrist after one month to review the effectiveness of the medication and to address any side effects due to prescribing restrictions. These additional appointments place an additional financial burden on people with ADHD due to the exorbitant fees associated with specialist appointments.

1.4 Problematic Access

Despite the New Zealand Government's commitment to the UNCRPD and the New Zealand Disability Strategy, there is a lack of academic literature relating to the accessibility and availability of diagnosis and treatment for individuals with suspected ADHD in Aotearoa. Attempts have been made to rectify this gap through volunteer efforts and are present within the grey literature. For example, ADHD New Zealand (2021), published findings from their 2021 survey of adults with ADHD which examined: the awareness of others; individual awareness; challenges of ADHD; prescription challenges; wait times; and types of support (ADHD New Zealand, 2021). The survey findings highlighted the difficulty adults with ADHD experience when seeking support/treatment; when accessing prescriptions; the barriers of wait times (with a median of three months following referral and 33% disclosing they gave up waiting). In addition, an Aotearoa based ADHD advocate conducted an independent study exploring the experiences of adults seeking diagnosis and treatment for ADHD in Aotearoa (McCarthy, 2021). The findings indicated diagnosis and treatment were inaccessible due to financial barriers; racial and gender inequity; and insufficient understanding from doctors/general practitioners.

While these findings are informative and illuminate fundamental issues in the New Zealand Governments fulfilment of obligations, they are not accepted as evidence due to the missing components central to research. For instance, a study was conducted in Aotearoa by I Am Hope for the Key to Life Charitable Trust which collected and reviewed 1000 letters that had been left behind by individuals who had attempted and/or completed suicide. Letters were submitted by their loved ones/recipients of the letters and by the writers who had survived attempted suicide (I Am Hope, 2020). The purpose of the study was to contribute knowledge to support and strengthen suicide prevention efforts in Aotearoa. The *1000 Letters* report was dismissed by government health agencies who called for the destruction of the data due to the absence of ethics approval and concerns relating to privacy and safety (Williams, 2020).

Aside from the independent studies mentioned, issues surrounding access to diagnosis and treatment have been indicated in a multitude of Aotearoa based news articles, highlighting the difficulties faced by individuals with ADHD/suspected ADHD when seeking support. Explained by Psychotherapist Kyle MacDonald in an article published by New Zealand Herald (Harris, 2021), the wait lists for individuals who sought diagnosis were tremendous, which was indicative of a specialist shortage. Moreover, individuals perceived as “high functioning” were often unable to access public funding for assessment as they did not qualify (Harris, 2021). Similarly, the issue of long wait lists and wait times was discussed in a Stuff article (Harris, 2022) which indicated that the number of adults seeking diagnosis had been increasing. Wait times had subsequently risen with the average wait time of 180 days for the initial appointment in the region under Counties Manukau District Health Board (DHB) and 105 days under Auckland DHB (Harris, 2022). A Radio New Zealand (2023) interview with Dr Bryan Betty of General Practice NZ highlighted the difficulty of getting publicly funded assessments. In many regions, referrals were being sent back to GP’s due to there being "literally no capacity" (Radio New Zealand, 2023, para 6).

The independent studies and news articles presented highlight a problematic reality in terms of ADHD specific healthcare in Aotearoa. Issues relating to ADHD specific healthcare have been highlighted internationally. In the United Kingdom, ADHD has been “under-identified, under-diagnosed, and under-treated" due to “cultural and structural barriers” within the health system (Young et al., 2021, p. 1). ADHD, being under-diagnosed and under-treated, was also found to be an issue across Europe and in other parts of the world (Coghill, 2017; Kooij et al., 2019). While this issue has been lightly touched on in the literature, there has not yet been research which has sought to explore the perceptions and lived experiences of adults accessing diagnosis and treatment for suspected ADHD.

1.5 Research Rationale

This study explores the perceptions and experiences of adults diagnosed with ADHD in adulthood, specifically regarding accessing assessment and supports. The New Zealand Government has obligations under the UNCRPD and has committed to the New Zealand Disability Strategy. This signals an agreement that people with impairments should have access to the services they need. However, the grey literature has suggested that there is limited access to ADHD assessment in Aotearoa yet there is currently no empirical evidence of this. There is a limited understanding of the impact of ADHD in Aotearoa, for example, there is no available data on the prevalence of ADHD among adults. Globally, empirical data has suggested people with ADHD have an increased risk of poor mental health, co-occurring mental health conditions, and suicidality (Balazs & Kereszteny, 2017; Diallo et al., 2022; Faraone et al., 2021; Fuller-Thomson et al., 2022; Giupponi et al., 2020; Ogrodnik et al., 2023; Rucklidge et al., 2014; Sultan et al., 2021; Zalsman & Shilton, 2016).

While this study is unable to compensate for the lack of empirical data in Aotearoa, it contributes to an understanding of what is required to gain access to assessment, what barriers present along the way, and the frustrations of navigating barriers at a time when people are in distress wanting to understand and make sense out of their lives. Importantly, this study sheds light on the impacts of living with unidentified and undiagnosed ADHD. It is anticipated that the findings of this study may provide an imperative for the New Zealand Government to meet their obligations under the UNCRPD.

1.6 Research aim

Given apparent difficulties regarding access to diagnosis and support, this study sought to examine access to assessment and supports for adults with ADHD/suspected ADHD in Aotearoa by exploring the perceptions and experiences of adults who have suspected ADHD, engaged with assessment and support services, and later received a diagnosis. The study was centred on the following questions:

1. How do adults in Aotearoa perceive and experience accessing assessment services for an ADHD diagnosis and subsequent treatment/support?
2. How are adults in Aotearoa impacted by the current pathways to ADHD assessment and supports?
3. How are adults in Aotearoa impacted by late diagnosis, misdiagnosis and/or missed diagnosis of ADHD?

Chapter 2: Literature Review

This chapter will provide an overview of the literature pertinent to ADHD. In particular, this chapter will explore definitions of ADHD systematically by first reviewing clinical definitions suggested by academics in the field of ADHD. Subsequently, the exploration will veer towards expanded and debated definitions in the literature. Conceptualisations developed through qualitative research informed by lived experience expertise will be examined in addition to topics including the history of ADHD; contemporary understandings of ADHD; prospects; and diagnosis and treatment. It is important to note that while there is tremendous value in phenomenological insights, qualitative research enquiring on lived experience was scarce within the literature.

2.1 Definitions of ADHD

The framing of ADHD has been critically and carefully considered throughout this section to avoid perpetuating stigmatization towards individuals with ADHD. Subscribing to simplified definitions (for example, the tendency to refer to individuals with ADHD as “hyperactive” or “inattentive”) risks a perpetual misunderstanding leading to delays in diagnosis and persistent stereotypes that stigmatise people with ADHD (Asherson et al, 2012; Faraone et al., 2021). Simplified definitions that only focus on biomedical and psychological definitions often appear in journal articles about ADHD related phenomena (Demontis et al., 2023; Loh et al., 2022; van Lieshout et al., 2017). So, while I begin with clinical conceptualisations of ADHD, I move to providing an overview of how ADHD has been defined and then expand using additional perspectives to ascertain a deeper understanding ADHD.

2.1.1 Clinical Definitions

The Diagnostic and Statistical Manual of Mental Disorders (DSM) was developed by the American Psychiatric Association to classify mental disorders and is used in clinical practice internationally, including in Aotearoa (Cooper, 2004). The first edition in the DSM series was published in 1952, followed by its second edition in 1968. There have been many issues raised about the DSM throughout its history including in this second edition due to the inclusion of homosexuality within mental disorder classifications (Horwitz, 2021). Following public backlash and academic debate, homosexuality was replaced with a classification for “homosexuals who are unhappy about being gay” and was termed ‘Sexual Orientation Disorder’ (Cooper, 2004, p. 2). In 1980, the DSM started to gain recognition within the field of psychiatry with the publication of DSM-III (Horwitz, 2021). Throughout the many editions and revisions, the DSM has been heavily debated among psychiatry and related fields for its portrayals of disorders (Horwitz, 2021); its biomedical focus (Lafrance & McKenzie-Mohr, 2013); and other concerns relating to specific classifications (Nemeroff et al., 2013).

In its most recent edition, the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) defined ADHD as a neurodevelopmental disorder which involves the presence of inattention and disorganisation, with or without hyperactivity-impulsivity; and at impairing levels (American Psychiatric

Association [APA], 2022). The DSM-5-TR characterises inattention and disorganisation as an "inability to stay on task, seeming not to listen, and losing materials necessary for tasks, at levels that are inconsistent with age or developmental level" (APA, 2022, para 7). Hyperactivity-impulsivity was characterised as involving "overactivity, fidgeting, inability to stay seated, intruding into other people's activities, and inability to wait—symptoms that are excessive for age or developmental level" (APA, 2022, para 7). Presentation of both inattention symptoms in addition to hyperactivity and impulsivity symptoms demonstrate a third category known as combined ADHD (APA, 2022).

Diagnostic guidelines have been developed by expert groups for the World Health Organisation (WHO) on mental and behavioural disorders, referred to as the International Classification of Diseases 11th Revision (ICD-11). These guidelines posit similar characteristics of ADHD as outlined in the DSM-5, albeit with more depth. The ICD-11 states that in addition to distractibility and issues with organisation, inattention refers to "significant difficulty in sustaining attention to tasks that do not provide a high level of stimulation or frequent rewards" (WHO, 2022, para. 1). Hyperactivity is referred to as an excess of motor activity in addition to problems with remaining still. Impulsivity is referred to as responding to immediate stimuli without consideration for risk or consequence (WHO, 2022).

Clinicians worldwide subscribe to the definitions and diagnostic guidelines set out in both the DSM and the ICD (Doernberg & Hollander, 2016; Drechsler et al., 2020; Kooij et al., 2019). Understandings of ADHD have evolved over the decades, yet the DSM and ICD (and their various updates) remain clinically significant for diagnosis. Advancements in collective knowledge have demonstrated that ADHD is more heterogenous and broad than what is set out in these guidelines which create challenges for clinicians who must fill the gaps by relying on their own knowledge (Drechsler et al., 2020). Furthermore, this reliance brings an additional concern where individuals with suspected ADHD must place trust in the discretion and knowledge of clinicians which would be arguably inconsistent. The evolution of understanding is set out in the following two sections.

2.1.2 Historical Understandings

The clinical existence of ADHD spans two centuries, with the first reports of symptoms consistent with ADHD emerging from European countries; however, the condition was not initially referred to as ADHD during its early conceptualisations (Faraone et al., 2021). The first text describing the condition was written by a German physician and philosopher by the name of Melchior Adam Weikard in 1775 (Barkley & Peters, 2012; Faraone et al., 2021; Ramsay, 2021). Weikard often challenged the medical theories and science of his time and published his first medical textbooks anonymously; Barkley and Peters (2012) suggest this was to avoid critique from the medical establishment. A translated version of Weikard's description details a condition referred to as "Lack of Attention, Attentio Volubilis" similar to DSM-IV[5], albeit described in depth (Barkley & Peters, 2012). Several of Weikard's claims have since been found to be

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[5] The DSM-IV was the current edition at the time of Barkley and Peters' (2012) article.

incorrect, such as the belief that poor parenting caused ADHD, or that women were more inattentive than men; and that solitary confinement, steel powder, sour milk, cold baths, and horse-riding could ‘cure’ hyperactivity (Barkley & Peters, 2012).

In the eighteenth and nineteenth centuries, symptoms of ADHD were attributed to problems with a child’s personality that could not be corrected (Taylor, 2011). By the early twentieth century, the condition (now known as ADHD) began to be understood as a syndrome and was termed “hyperkinetic disorder” and later termed “minimal brain dysfunction” (Faraone et al., 2021; Taylor, 2011). During the latter half of the twentieth century, ADHD was included in the DSM-II and was referred to as “hyperkinetic reaction of childhood” (American Psychiatric Association, 1968; Epstein & Loren, 2013; Ramsay, 2021). The term “attention deficit disorder (ADD)” arrived with the DSM-III near the end of the twentieth century and continued to have further name changes (Epstein & Loren, 2013; Ramsay, 2021; Taylor, 2011). The present term “Attention Deficit/Hyperactivity Disorder” was adopted in the publication of DSM-III-R while the term ADD was removed in the same edition (Epstein & Loren, 2013). Publication of the DSM-IV introduced three types of ADHD; “(predominantly Inattentive, predominantly Hyperactive Impulsive, and Combined), defined by the presence of excessive symptoms of inattention and/or hyperactivity-impulsivity” (Epstein & Loren, 2013, p. 1). In the DSM-5, the term ADHD remained while “types” of ADHD changed to “presentations” of ADHD (Epstein & Loren, 2013).

ADHD was previously understood to be a childhood condition which resolved in early adulthood (Asherson et al, 2012; Zalsman & Shilton, 2016). However, empirical dispute and investigation led to an update in criteria and recognition, reflecting the persistence of ADHD across the lifespan (Johnson et al., 2021; Zalsman & Shilton, 2016). The continuation of ADHD into adulthood was first identified in studies conducted in the 1960s and 1970s (Ramsay, 2021). It should be noted that while some individuals diagnosed with ADHD in childhood may gradually outgrow symptoms, most people with ADHD experience a reduction in symptoms of hyperactivity and impulsivity as they develop through adolescence (Brown, 2013). However, other symptoms tend to persist with potential to intensify throughout adulthood, for example, difficulty managing emotions, focusing and staying focused, starting tasks, and using working memory (Brown, 2013).

Even with the amended criteria to include adults, controversy has remained among mental health professionals, particularly in cases where adults are perceived to be functioning reasonably well (Asherson et al., 2012). An example can be seen in the perception that it is not possible for adults with occupations regarded as high-powered or successful, to have ADHD; despite reporting symptoms that cause distress and have detrimental impacts on their lives (Asherson et al., 2012). Such misconceptions often result in missed diagnosis where ADHD is not considered, or misdiagnosis where an incorrect diagnosis is administered (Asherson et al., 2012; Johnson et al., 2021). This research will go some way to address some of these deficits by talking with adults diagnosed as adults.

Presentation differences of ADHD between boys and girls in childhood have historically been not well understood resulting in low diagnosis rates for girls compared with boys (Silva et al., 2020; Klefsjö et al., 2021). Interestingly, the diagnostic rates between genders even out during adulthood (Silva et al., 2020) with women more likely to receive their first diagnosis in their adult years (Ahmad et al., 2019). It has been suggested that the gendered difference of diagnostic rates between boys and girls may be a result of referral bias, due to increased externalised behaviours that occur more frequently among boys (Gaub & Carlson, 1997, as cited in Brown, 2013). García (2019) supported the notion of a referral bias, highlighting the less noticeable inattentive presentation of girls with ADHD. Furthermore, gendered referral bias continues to contribute to the underdiagnosis of girls and women (García, 2019; Mowlem et al., 2019).

A good example of changes in understandings of adult diagnosis in Aotearoa has been from the Dunedin Multi-disciplinary Health and Development Study (a longitudinal cohort study conducted over four decades) whose findings indicated a possibility for symptom onset in adulthood (Moffitt et al., 2015). The research project has followed a Dunedin birth cohort since their birth in 1972 conducting regular assessments and interviews. The findings revealed that from the last assessment (38 years of age), 31 participants were diagnosed as having ADHD with only three ADHD cases diagnosed in childhood. Moffitt and colleagues (2015) suggested their findings challenge the previous assumptions of ADHD as a childhood condition; and additionally bring into question whether adult ADHD is the same disorder as childhood ADHD.

There remains debate in this area though, so while some academics support the notion of adult on-set ADHD (Asherson & Agnew-Blais, 2019; Caye et al., 2017; Cooper et al., 2018), others have rejected the possibility (Sibley et al., 2018; Ahmed et al., 2019). The latter argued that there is little evidence to indicate late onset of ADHD and suggest caution in assessment, arguing that comorbid conditions should be considered (Sibley et al., 2018; Ahmed et al., 2019). What remains is a consensus that diagnostic decisions of any kind should be adequately and comprehensively considered to avoid misdiagnosis and that functional impairment in adults should be considered. However, it could be argued that apprehension toward adult diagnoses of ADHD is a harmful over-correction. Thus, the debates historically have largely focused on adult-onset conflicts rather than looking for solutions or providing support.

2.1.3 Contemporary Developments in Understanding

Rivas-Vazquez and colleagues (2023) suggest that ADHD is underdiagnosed. Based on estimated prevalence (2.5% to 4.4%) of adults meeting ADHD criteria, they suggested only 20% of adults with ADHD are diagnosed and receive some form of treatment. Their findings indicate definitions and conceptualisations of ADHD continue to be disputed. Foreman (2018a) highlighted the controversy surrounding ADHD and described a movement in critical psychiatry consisting of both mendacious arguments and legitimate criticism. Some of the more legitimate criticism is centred around ADHD as a medicalised social construct (Foreman, 2018a). Foreman (2018a) argued that such criticism can be refuted due to advances in the evidence clarifying genetics, epidemiology, and neurobiology. Foreman’s (2018a) article appears to respond to claims made by Timimi (2018a) in which it was argued that ADHD is not a factor of nature but rather a factor of culture. Additionally, Timimi (2018a, p. 1) stated that “ADHD is unlikely to be either scientifically or clinically useful” and concluded that the concept of ADHD is expired and “should be discarded” (p. 9). The debate between Foreman and Timimi continued following the mentioned articles with rebuttals directed at each authors publication (Foreman, 2018b; Timimi, 2018b).

The debate between the two psychiatrists serves as a clear example of dispute within the academic field of ADHD and illuminates the problematic nature of positioning ADHD as a speculative sport for outsider academics. Arguing the usefulness of ADHD is insulting and dismissive of people with ADHD and exposes the necessity for an epistemological shift to phenomenological enquiry. As an aspiring academic with ADHD, I took great issue with this contribution to the field for two reasons. Firstly, it is evidence that there may be psychiatrists who do not believe ADHD is a condition and may not diagnose individuals who meet the criteria of ADHD. Secondly, it perpetuates confusion around ADHD when clarity is needed, contradicting established scientific discoveries as explained below.

Attempting to dispel misconceptions, the World Federation of ADHD published an international consensus statement of conclusions based on scientific evidence compiled by a team consisting of a multitude of experts in the field (Faraone et al., 2021). The consensus statement acknowledged criticism which viewed ADHD diagnosis as subjective due to the absence of a biological test which the authors claimed was unfounded (Faraone et al., 2021). Furthermore, the authors considered ADHD as a valid condition due to “1) well-trained professionals in a variety of settings and cultures agree on its presence or absence using well-defined criteria and 2) the diagnosis is useful for predicting a) additional problems the patient may have” (Faraone et al., 2021, p. 793). Additionally, guidelines for ADHD diagnosis have been endorsed and published by professional associations (Faraone et al., 2021). The consensus statement highlighted the findings of several neuroimaging studies which found small differences in brain functioning and structure between individuals with ADHD and individuals without ADHD; while also highlighting findings that genetic and environmental factors both contribute to aetiology of ADHD (Faraone et al., 2021).

Anbarasan and colleagues (2020, p. 71) have also highlighted a growing recognition of further symptoms beyond those identified in the DSM-5 such as executive functioning deficits including: “response inhibition, non-verbal working memory, verbal working memory, emotional and motivational self-regulation, planning, and problem-solving" and emotional dysregulation. Symptoms of emotional dysregulation involve mood lability, impulsivity, emotional over-reactivity and affective disturbances (Anbarasan et al., 2020). Similarly, Barkley (2021) raised the issue of executive function and argued that beyond the symptoms of ADHD posited in the DSM-5, ADHD is a self-regulation disorder, as opposed to an attention disorder which it is often referred to as. While raising these points, Barkley (2021) acknowledged a lack of consensus for the definition of executive function within the literature, resulting in the stagnation of conceptual progress regarding the role of executive function in ADHD.

Putting forward a ‘new understanding of ADHD’, Clinical Psychologist Dr Thomas E. Brown situated ADHD as a syndrome of impairments in executive function (Brown, 2013). Brown developed a model conceptualising executive functions that are used by all individuals but are impaired in individuals with ADHD (Brown, 2006). The model encompasses six categories of cognitive functions, each detailing specific functions:

> *i) Activation: Organising, prioritising and activating to work.*
>
> *ii) Focus: Focusing, sustaining, and shifting attention to tasks.*
>
> *iii) Effort: Regulating alertness, sustaining effort, and processing speed.*
>
> *iv) Emotion: Managing frustration and regulating emotions.*
>
> *v) Memory: Utilising working memory and accessing recall.*
>
> *vi) Action: Monitoring and self-regulating action.* (Brown, 2006, p. 39)

In his clinical studies, Brown found that individuals with ADHD tend to have specific aspects of executive functioning that they do not experience difficulty in when performing certain tasks due to the presence of personal interest (Brown, 2006). Furthermore, Brown suggested that the executive functions themselves were not impaired but rather the network responsible for managing the activation of executive functions as they appeared to be activated spontaneously. As such, activation of the executive functions is dependent on individual interest or threat (Brown, 2006). Brown’s descriptions provide more depth of understanding in comparison to over-simplified definitions that summarise individuals with ADHD as “hyperactive” or “inattentive”.

It is promising that there is more recognition of the complexities of ADHD, particularly in adults. However, much of this debate has focussed on ADHD from a clinical perspective. Literature on lived experience perspectives of ADHD is currently limited, particularly in Aotearoa, and from people who get diagnosed as adults. In a phenomenological idiographic study, Redshaw and McCormack (2022) explored the life experiences of nine individuals with ADHD. The findings of the study highlighted experiences of “otherness”, related to feeling different to others, being viewed negatively, and feeling as though the use of medication effects sense of self. The findings also highlighted experiences of a constant need to be “doing” physically (through impulsive physical activity) and mentally (through impulsive mental activity). Further to this constant need, the unbearable impact of boredom was highlighted alongside the urge to escape situations of boredom. The findings also illustrated some advantages of having ADHD as perceived by participants such as optimism, energy, problem solving abilities, curiosity, and adventurousness. Contrastingly, some positives were also perceived negatively depending on context, “for instance, hyperactive, irrational, off-task, impulsive, and distractible in the classroom" (Redshaw & McCormack, 2022, p. 25).

Debate about definitions, presentation of ADHD in adults, and experiences all point to a complexity in this area, and a focus on definition, value of diagnosis and not on support or treatment options for people with ADHD. More qualitative research is needed to explore adults perspectives. One of the reasons for this is that the outcomes for people with ADHD, including those undiagnosed, can be negative. These will be explored in the next section.

2.2 Life Prospects with ADHD

This section provides an overview of possible life prospects associated with ADHD. Risk outcomes appeared more frequently within the literature compared to positive outcomes. The following sub-sections explore concerns, mental health conditions, and positive prospects of ADHD. This section is largely based on research with people with a diagnosis of ADHD which is important to note as the risks for people who go undiagnosed are arguably higher yet unmeasurable as they are difficult to identify.

2.2.1 Prospects of Concern

Research suggests that people with ADHD have an increased risk of poorer outcomes, including problems with health, education, work, and mental distress (Faraone et al., 2021; Nigg, 2013; Zalsman & Shilton, 2016). In fact, there is some evidence to suggest that life expectancy is reduced for people with ADHD due to these issues (Barkley, 2020). This suggests that individuals with ADHD are at higher risk of certain outcomes at different periods of life. These are discussed in turn.

School seems to be a period of high risk for people with ADHD such as school dropout, increased likelihood of antisocial behaviour, and more likely to leave school before the end of high school. This then means that less people with ADHD go onto tertiary education (Zalsman & Shilton, 2016). In an Australian based study utilising data from two longitudinal studies, children with ADHD were found to have poorer educational outcomes than children without ADHD (Zendarski et al., 2022). This finding was consistent across all measures of reading, numeracy, attendance, school engagement, parental expectations, and peer victimisation. A positive aspect of this study was that they included diagnosed children and children who screened positive for ADHD but did not meet the full diagnostic criteria. Similarly, college students with ADHD in the United States were found to have lower grades than their peers without ADHD (DuPaul et al., 2021). These findings called for earlier educational support for students with ADHD to address educational difficulties and to further support children and adolescents in school (DuPaul et al., 2021; Zendarski et al., 2022).

Within the work environment, there has been research that suggests people with ADHD are more likely to experience employment difficulties such as job searching, participating in interviews, and job performance (Zalsman & Shilton, 2016; Gordon & Fabiano, 2019). While difficulties with inattention have been suggested to impact functioning at work (Fuermaier et al., 2021), the work environment can also exacerbate symptoms of ADHD (Webster, 2018). Employment challenges also arise for individuals with ADHD through being unable to meet their own standards, even though performance evaluations were not negative (Fuermaier et al., 2021). The difficulties experienced by people with ADHD in employment contributes to stress, anxiety, and exhaustion (Oscarsson et al., 2022). Accommodations can be made to support people with ADHD in the workplace. For example, managers can implement regular meetings, provide structured feedback, supplement verbal information with clear written information, provide a private office to reduce distractions, allow flexible working hours, allow productive movements, and ensure structured breaks are planned during long meetings (Adamou et al., 2013).

The increased risk of drug and alcohol abuse, mental distress and antisocial behaviour has been linked to why individuals with ADHD are disproportionately represented in both men's and women's prisons (Ginsberg et al., 2010; Farooq et al., 2016; Young & Cocallis, 2021). Young and Cocallis (2021) emphasised that the key issue surrounding higher rates of offending was a lack of assessment and support for managing ADHD, resulting in symptoms being unrecognised and misunderstood. Early identification and treatment of symptoms associated with ADHD could be beneficial for individuals and for society pointing to the need for better assessment procedures, better support for accessing medication and psychological support and education for all people involved in supporting young people (Young & Cocallis, 2021). Young adults with ADHD were found to be significantly more likely to experience criminal justice system interactions in an Aotearoa based study (Anns et al., 2023). The study found that in Aotearoa, individuals diagnosed with ADHD are more than twice as likely to be prosecuted by police, charged, and convicted in addition to the nearly five times higher risk of incarceration compared to individuals without ADHD (Anns et al., 2023). The authors suggested that changes are required within the justice system in Aotearoa to ensure equitable treatment, including early identification and improved responsiveness (Anns et al., 2023).

2.2.2 Mental health and co-occurring conditions

Evidence suggests that individuals with ADHD experience an increased risk of poor mental health (Faraone et al., 2021, Zalsman & Shilton, 2016). In a large-scale review of empirical evidence relating to ADHD, Faraone and colleagues (2021) suggested that individuals with ADHD have an increased risk of co-occurring mental health conditions, substance use disorders, injuries, suicidality, and premature death. The literature also suggests individuals with ADHD are at higher risk of experiencing co-occurring psychiatric conditions such as major depressive disorder, social phobia, bipolar disorder, anxiety disorder, personality disorders, autism spectrum disorder and suicidality (Balazs & Kereszteny, 2017; Choi et al., 2022; Diallo et al., 2022; Hours et al., 2022; Rucklidge et al., 2014). A recent study conducted by Ogrodnik and colleagues (2023) investigated mental health outcomes in adults with diagnosed ADHD compared with adults who did not have ADHD (and had tested below the cutoff of the Connors Adult ADHD Rating Scale). The research found significantly greater anxiety, depression and perceived stress in the adult ADHD group compared with the control group. Additionally, 50% of participants in the ADHD group reported experiencing symptoms of anxiety, depression, or perceived stress at severe levels and participants with “more severe” ADHD reported experiencing more mental distress (Ogrodnik et al., 2023, p. 702). This level of severity was not found among the control group. In a cross-national study which involved 15,991 first year college students, 58.4% of participants with ADHD reported at least one comorbid condition, and 30.7% reported at least two comorbid conditions (Mak et al., 2022). In Aotearoa New Zealand, research findings indicated adults with

ADHD experienced higher rates of major depressive disorder, social phobia, substance abuse, and alcohol abuse (Rucklidge et al., 2014).

Increased rates of mental distress and other psychiatric conditions have been linked to an increase in suicide ideation (e.g. Balazs & Kereszteny, 2017; Sultan et al., 2021) but also have serious implications for treatment and support for individuals with ADHD (Rucklidge et al., 2014). Sultan and colleagues (2021) utilised a national survey which involved fully structured interviews of 6483 participants aged between 13 and 18 years (617 had ADHD). The results showed the ADHD group were three times more likely to experience suicidal thoughts, plans and attempts, respectively (Sultan et al., 2021). Fuller-Thomson and colleagues (2022) also found a heightened risk of suicide for adults with ADHD compared with adults without ADHD within their Canadian study. The findings indicated that one in seven adults with ADHD had attempted suicide compared to the non-ADHD group where one in 37 adults had attempted suicide (Fuller-Thomson et al., 2022). Balazs and Kereszteny (2017) suggest that the assessment and treatment of symptoms associated with ADHD and co-occurring conditions is paramount for preventing suicide.

As highlighted above, people with ADHD are more likely to experience poorer psychological and emotional wellbeing than people who do not have ADHD. There is limited literature on why this population experience reduced mental health. There have been several theories suggested, including low levels of self-compassion (Beaton et al, 2022), trauma (Fuller-Thomson et al., 2022), and poor self-esteem (Capelatto et al., 2014). Beaton and colleagues (2022) suggest that because people with ADHD are more likely than non-ADHD people to experience failure, stigma, rejection, and daily stress; there is an impact caused by these experiences and the internal responses to adverse experiences. Fuller-Thomson and colleagues (2022) suggested lower education attainment, substance abuse, history of depression, and childhood exposure to domestic violence are forms of trauma leading to suicide attempts among people with ADHD. Several studies have identified a relationship between ADHD and lower self-esteem (Capelatto et al., 2014; Klimkeit et al., 2006; Mazzone et al., 2013). Interestingly, Pawaskar and colleagues (2020) found that adults with diagnosed ADHD had better self-esteem than individuals who had symptoms of ADHD without diagnosis. It was suggested that the diagnosed group had access to support to manage ADHD that the undiagnosed group were unable to access, highlighting the importance of diagnosing adults with suspected ADHD (Pawaskar et al., 2020).

Lastly, it has been suggested that the characteristics of ADHD are directly contributing to poorer mental health outcomes. For example, Brown (2013) suggested that high incidence of depression and anxiety amongst people with ADHD was due to impaired emotional regulation which describes difficulty managing emotional responses. People with ADHD struggle to direct their attention away from their interests or concerns and may give excessive attention to depressing or fearful thoughts (Brown, 2013). This means that people with ADHD may struggle more than those without ADHD to overcome negative emotions and thus, struggle to overcome episodes of depression and anxiety.

The variety of theories pertaining to the heightened risk of reduced mental health for people with ADHD all share one common factor. That is, the undisputed risk which calls for access to support mechanisms to assist people with ADHD to experience positive mental health.

2.2.3 Positive Prospects

The previous sections explored some of the negative outcomes that people with ADHD are at risk of experiencing. Positive outcomes appeared less frequently within the literature demonstrating the under researched nature of this aspect. Sedgwick and colleagues (2019) sought to explore the positive aspects of ADHD through the positive psychology paradigm. Although their study involved participants who were recruited based on success and were all male, their findings were still able to highlight aspects not often affirmed in research explorations. Cognitive dynamism was a core theme identified in the study, referring to the ability to hyper-focus, think outside the box, be creative, and curious (Sedgewick et al., 2019). Courage was identified as the second theme, referring to the tendency to be non-conforming, adventurous, brave, persistent, and have integrity. Energy was identified as a third theme, referring to the “abundance of energy” and “capacity for action” as well as energy in domains of spirit, physical and psychological (Sedgewick et al., 2019, p. 245). The core theme Humanity referred to humour, social intelligence, recognition of feelings and self-acceptance. Resilience was another theme identified in relation to strategies adopted to cope with aspects of ADHD such as self-regulation and sublimation. Transcendence was identified as the final theme, applying to one participant in relation to appreciation of beauty and excellence through music. Sedgewick and colleagues (2019) argue that deficits are frequently discussed in narratives about ADHD, and that researchers should seek to explore and affirm positive aspects to promote well-being in people with ADHD.

Schippers and colleagues (2022) undertook a similar pursuit by exploring positive aspects of ADHD through self-reported open-ended questionnaires. Of the 206 responses from individuals with ADHD, five themes were identified. Creativity was identified as the first theme and was characterised by the ability to think outside the box in problem solving and coming up with ideas. Being dynamic was the second theme identified in the study and related to having high energy, positive attitude, and adventurousness. Flexibility was identified as the third theme characterised by being open, flexible, and spontaneous. Socio-affective skills was identified as the fourth theme in relation to experiencing strong emotions, being socially outgoing and empathic/prosocial. In this theme, their own strong emotions helped them to understand or have a sense of other people's emotions. The fifth theme “Higher-order cognitive skills” was characterised by quick thinking, analytical, attention to detail and increased focus when interested (Schippers et al., 2022, p. 8). The authors stated that positive aspects are common in the experiences of people with ADHD. In addition, Schippers and colleagues (2022) suggest that increasing awareness of the strengths associated with ADHD can support individuals in coping, accepting and/or embracing their diagnosis. However, the factors that contribute to positive aspects remained unknown and would be an area of research in need of exploration (Schippers et al., 2022). A common factor in both studies focusing on positive aspects of ADHD is that the participants were all diagnosed with ADHD and as such, were able to access support to help manage ADHD.

Sedgewick and colleagues (2019) stated that their participants were diagnosed and prescribed medication to support the management of their symptoms. In contrast, it was not stated whether the participants in the study conducted by Schippers and colleagues (2022) were medicated.

A small number of studies have sought to explore protective factors that contribute to positive outcomes or negate risk outcomes. A literature review conducted by Dvorsky and Langberg (2016) found social acceptance was a protective factor which negated depressive symptoms and poor academic performance. They also found positive parenting promoted positive outcomes in addition to individual factors of modest/positive self-perceptions of competence (Dvorsky & Langberg, 2016). Schei and colleagues (2015) found social competence, personal competence and better structured style were protective factors against emotional problems and supported better quality of life among adolescents with ADHD. Medical treatment was also identified as providing significant improvements to self-esteem and social functioning. Social resources and family cohesion protected against conduct and emotional problems and supported better quality of life (Schei et al., 2015).

The literature has largely highlighted life prospects as negative for people with ADHD painting a bleak picture. There are positive life prospects too, and while this seems lightly touched on, it is more of a reflection of where the greatest attention is paid in terms of ADHD research. It is important to highlight the positive prospects and to enquire about the supportive factors that activate these prospects. While the answers are limited, this section on life prospects has suggested that early identification of ADHD is crucial, providing an avenue for accessing support to manage and thrive with ADHD.

2.3 Diagnosis and Management

My research focuses on adults who receive a diagnosis of ADHD as an adult. To give context to this research it is important to understand the diagnostic process. It is also important to consider the impact of getting a diagnosis and missed diagnosis experiences. The diagnostic process occurs in a clinical context and is discussed in clinical terms which primarily focus on deficit and disorder.

2.3.1 Diagnosing ADHD

While the diagnostic process may vary in different countries as is the case for many health conditions, the World Federation of ADHD International Consensus Statement (Faraone et al., 2021) provided an overview of ADHD diagnosis. To receive a diagnosis of ADHD, an individual must be assessed by a licensed clinician who conducts an interview with the individual or parent/caregiver (if the individual is a child). ADHD cannot be detected solely through neuropsychological tests, rating scales, brain imaging or any other biological test (Faraone et al., 2021). The consensus statement outlined the following requirements for diagnosis:

1) *the presence of developmentally inappropriate levels of hyperactive-impulsive and/or inattentive symptoms for at least 6 months;*
2) *symptoms occurring in different settings (e.g., home and school);*

3) *symptoms that cause impairments in living;*
4) *some of the symptoms and impairments first occurred in early to mid-childhood; and 4) no other disorder better explains the symptoms. (Faraone et al., 2021, p. 5)*

The Updated European Consensus Statement on diagnosis and treatment of adult ADHD explained that ADHD diagnosis is based on two diagnostic manuals; these are "The Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Statistical Classification of Diseases and Related Health Problems (ICD)" (Kooij et al., 2019, p. 17-18) and are described in an earlier section. During the clinical interview, individuals self-report symptoms, which are evaluated for characteristic impairments and symptoms of ADHD outlined in the diagnostic manuals. Symptoms related to executive dysfunction are also noted, although not explicitly mentioned in the criteria, and include: "problems with organization, facing daily responsibilities, solving problems, managing time and self-regulating (inhibiting) behaviors" (Kooij et al., 2019, p. 18). A full description of the diagnostic criteria in the DSM-5 is presented in Table 1 followed by the diagnostic criteria in the ICD-11 presented in Table 2. Both criteria state that symptoms must have been present before the age of 12; must occur in multiple settings; not be attributed to other mental disorders and not a result of substance use (APA, 2013; World health Organisation, 2022).

2.3.2 The Impact of Diagnosis and Missed-Diagnosis

Diagnosing ADHD in accordance with current diagnostic guidelines requires an individual to be experiencing impairing aspects of ADHD which means the diagnostic process is heavily focused on negative aspects of ADHD. Receiving a diagnosis can sometimes carry stigma, with awareness of ADHD limited to the negative aspects outlined in the above paragraphs. For example, research examining caregivers' experiences of their children receiving ADHD diagnosis found that they experienced stigma towards ADHD medication in addition to stigma and social isolation towards their child with ADHD (DosReis et al., 2010). Other research found reflections on being diagnosed varied among young people with ADHD. On one hand, there was fear of being stereotyped and on the other hand, diagnosis provided a label for their struggles while others felt like their ADHD improved their abilities and life quality (Jones & Hesse, 2018).

In a London based study involving eight participants who had been diagnosed in adulthood, being diagnosed with ADHD triggered an emotional rollercoaster, beginning with relief and elation to have something to attribute their difficulties to (Young et al., 2008). Negative emotions followed such as anger and sadness for having struggled for so many years. Participants in the study considered the missed opportunities through reflecting on how their lives may have been different, more positive, and successful had they been diagnosed with ADHD earlier. Being diagnosed gave them self-acceptance but also concern for the future and the potential for stigma (Young et al., 2008). Interestingly, in an Aotearoa based study, participants diagnosed with ADHD in childhood reported that diagnosis had a negative effect on their self-confidence, whereas participants diagnosed in adulthood felt that diagnosis had a positive effect on their self-confidence, and participants from the adolescent group were divided in their reflections (Murray, 2021).

Table 1

DSM-5 Diagnostic Criteria for ADHD

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 nega-tively impacts directly on social and academic/occupational activities: Note: The symptoms are not solely a manifestation of oppositional behavior, defi-ance, hostility, or failure to understand tasks or instructions. For older adolescents and adults (age 17 and older), at least five symptoms are required.	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). b. Often has difficulty sustaining attention in tasks or play activities (e.g., has diffi-culty remaining focused during lectures, conversations, or lengthy reading). c. Often does not seem to listen when spoken to directly (e.g., mind seems else-where, even in the absence of any obvious distraction). 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 sidetracked). e. Often has difficulty organizing tasks and activities (e.g., difficulty managing se-quential tasks; difficulty keeping materials and belongings in order; messy, dis-organized work; has poor time management; fails to meet deadlines). 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). g. Often loses things necessary for tasks or activities (e.g., school materials, pen-cils, books, tools, wallets, keys, paperwork, eyeglasses, mobile telephones). h. Is often easily distracted by extraneous stimuli (for older adolescents and adults, may include unrelated thoughts). i. Is often forgetful in daily activities (e.g., doing chores, running errands; for older adolescents and adults, returning calls, paying bills, keeping appointments).
2. Hyperactivity and impulsivity: Six (or more) of the following symptoms have per-sisted 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: Note: The symptoms are not solely a manifestation of oppositional behavior, defi-ance, hostility, or a failure to understand tasks or instructions. For older adolescents and adults	a. Often fidgets with or taps hands or feet or squirms in seat. 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 runs about or climbs in situations where it is inappropriate. (Note: In ad-olescents or adults, may be limited to feeling restless.) d. Often unable to play or engage in leisure activities quietly. e. Is often "on the go," acting as if "driven by a motor" (e.g., is unable to be or un-comfortable 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 talks excessively. g. Often blurts out an answer before a question has been completed (e.g., com-pletes people's sentences; cannot wait for turn in conversation). h. Often has difficulty waiting his or her turn (e.g., while waiting in line).

(age 17 and older), at least five symptoms are required.	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 per-mission; for adolescents and adults, may intrude into or take over what others are doing).

Note. Adapted from the American Psychiatric Association (2013, pp. 59-60).

Table 2

ICD-11 Diagnostic Criteria for ADHD

A persistent pattern (e.g., at least 6 months) of inattention symptoms and/or a combination of hyperactivity and impulsivity symptoms that is outside the limits of normal variation expected for age and level of intellectual development. Symptoms vary according to chronological age and disorder severity.		
Inattention	Several symptoms of inattention that are persistent, and sufficiently severe that they have a direct negative impact on academic, occupational, or social functioning. Symptoms are typically from the following clusters:	• Difficulty sustaining attention to tasks that do not provide a high level of stimulation or reward or require sustained mental effort; lacking attention to detail; making careless mistakes in school or work assignments; not completing tasks. • Easily distracted by extraneous stimuli or thoughts not related to the task at hand; often does not seem to listen when spoken to directly; frequently appears to be daydreaming or to have mind elsewhere. • Loses things; is forgetful in daily activities; has difficulty remembering to complete upcoming daily tasks or activities; difficulty planning, managing and organizing schoolwork, tasks and other activities. ***Note:*** Inattention may not be evident when the individual is engaged in activities that provide intense stimulation and frequent rewards.
Hyperactivity impulsivity	Several symptoms of hyperactivity/impulsivity that are persistent, and sufficiently severe that they have a direct negative impact on academic, occupational, or social functioning. These tend to be most evident in structured situations that require behavioural self-control. Symptoms are typically from the following clusters:	• Excessive motor activity; leaves seat when expected to sit still; often runs about; has difficulty sitting still without fidgeting (younger children); feelings of physical restlessness, a sense of discomfort with being quiet or sitting still (adolescents and adults). • Difficulty engaging in activities quietly; talks too much. • Blurts out answers in school, comments at work; difficulty waiting turn in conversation, games, or activities; interrupts or intrudes on others conversations or games. • A tendency to act in response to immediate stimuli without deliberation or consideration of risks and consequences (e.g., engaging in behaviours with potential for physical injury; impulsive decisions; reckless driving)

Note: Adapted from World Health Organisation (2022, paras. 2-5).

Diagnosing ADHD provides individuals with the possibility of receiving support and self-acceptance; a clearly positive impact of diagnosis (Hamad et al., 2015; Lefler et al., 2016). Missing diagnosis in individuals with symptomatic ADHD denies them of this possibility. A systematic literature review conducted by Attoe and Climie (2023) to investigate the impact of undiagnosed ADHD in women and adult diagnosis found that missed diagnosis had negative impacts on the women's socio-emotional wellbeing, characterised by low self-esteem; difficulties in emotional control and social relations; "maladaptive coping strategies"; and regret towards not being diagnosed earlier (Attoe & Climie, 2023, p. 650). Difficulties in relationships were additionally identified with relation to entering and maintaining romantic relationships and feeling supported in family relationships. A lack of control was identified in aspects of women's lives with power and control attributed externally. The final finding related to how women felt after receiving a diagnosis in adulthood. Relief and self-acceptance were highlighted as the most common responses to receiving diagnosis. Being diagnosed provided the women with an explanation while also relieving negative emotions of guilt and shame, increasing self-acceptance (Attoe & Climie, 2023).

The literature presented in this section suggests that children may be more susceptible to stigma than adults, while adults are aware of the stigma, self-acceptance appears to override social acceptance in adulthood (Murray, 2021). A possible reason for this distinction could be due to developmental life stages. Adults have already formed their identities prior to diagnosis and may be relieved to learn that aspects that became part of their identity are explained by ADHD (Jones & Hesse, 2018). In contrast, children and adolescents diagnosed with ADHD experience the stigma of ADHD during identity formation and are unlikely to have had the choice to be assessed or not (Jones & Hesse, 2018). Similarly, undiagnosed ADHD in childhood contributes to identity formation in the sense that external negative comments become internalised and are carried into adulthood (Long & Coats, 2022). It has been suggested that early diagnosis should be accompanied by early understandings of how the ADHD brain works as natural support systems (for example, family) may not have accurate information (Murray, 2021). Supporting children to understand their ADHD may reduce the impact of stigmatisation on identity formation. Additionally, it is important to ensure the ongoing diagnosis of adults with ADHD as there are long lasting impacts on identity and self-esteem (Attoe & Climie, 2023).

2.3.3 Supported Management of ADHD

Diagnosis provides an avenue for individuals to access support to manage difficult aspects of ADHD. The literature refers to this support as 'treatment' as it is often discussed through a medical conceptualisation in which the provision of support is positioned as the treatment of a disorder. This type of positioning serves the clinical context where individuals are viewed narrowly as having disorders that need treatment but is detrimental to a holistic understanding. This is worth noting here as this section discusses the literature pertaining to supported management of ADHD and the terms used in the literature are reproduced here to avoid misrepresentation of research findings.

People with ADHD who receive treatment experience better outcomes than people with untreated ADHD (Hamad et al., 2015; Harpin et al., 2016). Treatment for ADHD includes a variety of options such as medication, behavioural interventions, cognitive therapies, stimulation devices, supplementary interventions, and interventions for mind and body (Nazarova et al., 2022). Treating ADHD with medication involves the prescription of stimulant or non-stimulant pharmaceuticals. Stimulant medications have been proven to be highly effective for the management of ADHD (Caye et al., 2019; Faraone et al., 2021). Medication is not a cure for ADHD but has been indicated as an effective treatment for 80% of people with ADHD (Brown, 2013). Medication has been found to mitigate risks of suicidality, substance use disorders, mood disorders, criminality, accidents, injuries, traumatic brain injury, car crashes, and academic difficulties (Boland et al., 2020).

Research has highlighted the positive impacts of stimulant medication as reported by adults diagnosed with ADHD in adulthood (Young et al., 2008). The reported impacts included feeling as though they could function in a way that aligned with “normal people” and reduced feelings of difference; improved social interactions; and hope for the future as their goals were more achievable (Young et al., 2008, p. 497). Adults in the study acknowledged that medication itself was not enough to manage ADHD. When medication wore off, it highlighted behaviours that the adults were previously unaware of which provided an opportunity to work on behaviours and a desire to seek additional support (Young et al., 2008). These findings describe therapeutic effect through supporting social conformity in addition to opportunity through insight.

Literature on the efficacy of non-medical management is mixed and complex due to the diverse range on offer and the lack of universally accepted methods (Caye et al., 2019; De Crescenzo et al., 2017; Faraone et al., 2021) and arguably, a prioritisation of medical research. Despite this, addressing psychological, behavioural, occupational, and educational needs has been recognised as essential in supporting adults with ADHD (De Crescenzo et al., 2017). Nazarova and colleagues (2022) suggested there was evidence indicating behavioural therapy alongside medication had significant effects on symptoms of ADHD. Non-medical supports that may be useful in treating ADHD include cognitive behavioural therapy (CBT), dialectical behavioural therapy (DBT), mindfulness therapy, and hypnotherapy (Nimmo-smith et al., 2020). The Updated European Consensus Statement on diagnosis and treatment of adult ADHD stated that treatment of ADHD should be multi-modal, consisting of pharmacotherapy, psychoeducation, and CBT or/and coaching (Kooij et al., 2019).

CBT is a therapeutic approach which involves restructuring cognitive processes to improve thought patterns and behaviours to reduce negative outcomes and promote positive outcomes (Fullen et al., 2020). CBT as a supported management approach for ADHD typically involves aspects including attainment of goals; coping skills; interpersonal skills; problem solving; managing distraction and motivation; planning; time management; and organisation (Fullen et al., 2020). DBT is an approach similar to CBT in that it challenges thought and behavioural patterns with the addition of principles of acceptance and mindfulness

(Fullen et al., 2020). ADHD coaching is an approach that has been suggested to be complimentary in addition to other supports and impactful as a stand-alone support (Kupik, 2010). Through ADHD coaching, a goal-driven partnership is formed between a client and a coach aiming to support the development of practical strategies that benefit daily life (Goldstein, 2005; Kupik, 2010). Coaching is a pragmatic approach, tailored to the individual and their needs and does not follow a prescribed process (Goldstein, 2005; Kupik, 2010). This approach first focuses on self-awareness as the foundation, unpacking the personal impact of ADHD to replace negative self-concepts with positive and capable self-concepts. Following this foundational step, focus then shifts to working together to develop specific goals (Kupik, 2010).

This section has discussed some of the supported management approaches that are commonly highlighted within the literature. Medication tends to be the frontline approach for the management of ADHD (Fullen et al., 2020) and while considered beneficial for those who respond well to medication, there is a desire for additional supports (Young et al., 2008).

2.4 Chapter summary

This chapter provided an overview of the literature pertaining to ADHD. To understand how ADHD has been framed in the literature, definitions were explored in the clinical context in addition to definitions and understandings present in the historical context. Contemporary understandings were then explored and discussed demonstrating an ongoing evolution of understanding. The literature relating to the life prospects associated with having ADHD were additionally reviewed and discussed in terms of concern, mental health, and positive prospects. Finally, attention was turned to the diagnostic process and treatment options.

Chapter 3: Methodology

This chapter provides an overview of the design implemented in this study to explore the lived experiences of adults who have been diagnosed with ADHD in Aotearoa as adults. The sections within this chapter outline the rationale of the research design and the methods employed to achieve the aim of this research.

3.1 Research design

Several methodological assumptions were identified as conducive to the aims of this study. Embarking on an exploration into the reality of access to assessment and support; and the impact of late diagnosis on adults with ADHD in Aotearoa, meant that I had assumed the existence of a reality. I assumed that the reality under study was influenced by social structures. These assumptions aligned with the Critical Theory paradigm, which posits that reality is "shaped by cultural, political, ethnic, gender and religious factors which interact with each other to create a social system" (Rehman & Alharthi, 2016, p. 57). A researcher situated in the Critical Theory Paradigm is committed to going a step further than producing an understanding about society by seeking to additionally challenge and/or change oppressive structures (Rehman & Alharthi, 2016).

Perhaps unconventional, the principles and assumptions underpinning this research fall within an additional paradigm of importance. The emerging neurodiversity paradigm is predicated on three principles (Walker, 2021). Firstly, neurodiversity is a form of human diversity that is natural and valuable. Secondly, the notion "there is one 'normal' or 'healthy' type of brain or mind" is socially constructed and matches the validity of "the idea that there is one 'normal' or 'right' ethnicity, gender, or culture"; and lastly, neurodiversity is impacted by social dynamics that impact different forms of diversity such as privilege, oppression, and inequality (Walker, 2021, p.15). The neurodiversity paradigm stems from critical race theory, feminist studies, and queer studies and is increasingly informing research in a range of fields including critical psychology, sociology, medical humanities, critical autism studies, and critical disability studies (Rosqvist et al., 2020a). Blending principles from both the critical theory and neurodiversity paradigms generated a research foundation of a critical neurodiversity paradigm. The blended paradigms directed the current study to develop an understanding of the social structures that influence the participants reality; challenge the oppressive structures; and explore the impact of social structures and social power inequalities.

To explore the phenomena of ADHD diagnoses in adulthood, it was imperative to seek understanding from individuals with lived experience to reduce the risk of further marginalisation through neurotypical framing (Rosqvist et al., 2020b). Hermeneutic phenomenology was identified as the appropriate epistemological framework due to its centring of lived experiences as the generator of knowledge (Dibley et al., 2020a; Laverty, 2003). Additionally, the acceptance and management of research preunderstandings contributed to perceived appropriateness given I have lived experience of ADHD. This means I carry preunderstandings of the research topic, however management of these are accommodated through reflexive practices wherein preunderstandings are acknowledged and navigated (Dibley et al., 2020b). Further to the reflexive practices of hermeneutic phenomenology, I was also guided by discussions among the 'insider research' epistemologists (outlined in section 3.1.2). Interpretive phenomenological analysis (IPA; outlined in section 3.4) was used to approach the data for its process of interpreting meaning from data, lending itself to hermeneutic phenomenology as interpretation is required to enact a hermeneutic circle (Smith et al., 2022).

3.1.1 Hermeneutic Phenomenology

This study utilised the philosophical underpinnings of hermeneutic phenomenology. Hermeneutic phenomenology is an approach that stems from phenomenology which describes a range of research approaches that focus on the nature and meaning of phenomena (Kafle, 2011). Furthermore, phenomenology focuses on the lived experience, and people's perceptions and meaning making of the world around them (Kafle, 2011). Hermeneutic phenomenology maintains the principles of phenomenology through creating understanding and meaning through interpretation and full description of the lived experience (Dibley et al., 2020a; Laverty, 2003; Mapp, 2008; Rapport, 2005). The epistemological position of hermeneutic phenomenology holds that the origin of knowledge lies within the lived human experience (Dibley et al., 2020a; Laverty, 2003). Therefore, only holders of lived experience can communicate the knowledge relevant to the phenomena of interest (Mapp, 2008). Additionally, the knowledge of those with lived experience is understood and interpreted through language, which constructs the reality or realities being examined (Laverty, 2003; Sloan & Bowe, 2014). Interpretive phenomenological analysis is an approach that allows the researcher to interpret the lived experience and meaning making of individuals experiencing a phenomenon (Smith et al., 2022). The epistemological position of hermeneutic phenomenology is useful for this study which seeks to understand the experiences of adults diagnosed with ADHD, and to centre their voices in line with neurodiversity paradigm (Rosqvist et al., 2020b).

A distinguishing factor of hermeneutic phenomenology is that it does not view reality as separate from the individual and rejects the separation of the researcher from their own pre-understandings and lived experiences (Kafle, 2011; Laverty, 2003; Mapp, 2008). Rather, pre-understandings are viewed as the basis of interpretation, and are questioned throughout the research process; enacting a hermeneutic circle where parts of the phenomena, and the phenomena as a whole inform each other (Dibley et al., 2020a). Reflexivity allows for the acknowledgement and navigation of pre-understandings and researcher influence, by assessing and revisiting the role of our prior understandings and experiences in all aspects of the research project (Dibley et al., 2020b). To reduce bias, the researcher must be self-reflective and transparent about preunderstandings that could obscure and illuminate the researcher's understanding of the studied phenomenon (Amour et al., 2009). This is referred to as intersubjectivity which allows the researcher to use their experience to understand participants' experiences (Armour et al., 2009).

3.1.2 Insider Research

Through the early stages of developing this research project, the question of bias was raised through the research ethics assessment phase. While Hermeneutic Phenomenology allowed space and offered process for acknowledging the elephant (bias/preunderstanding/lived experience) in the room; the necessity to defend this position became apparent and raised uncertainty within myself as the researcher. Subsequently, I turned to the literature to seek assurance that my embarkment was justified, and to identify additional considerations and strategies. Through this exploration, the epistemological standpoint of insider research was discovered. Insider research describes the relationship between the researcher and the phenomenon of interest, specifically with the researcher being a member of the population being studied (Dwyer & Buckle, 2009; Greene, 2014; Wilkinson & Kitzinger, 2013). Historically, the validity of insider research had been debated as there were opposing arguments related to the question of objectivity. Within the positivist paradigm, outsider status has been perceived as the objective ideal, in contrast to insider status (Chavez, 2008; Ross, 2017). Although the theory of 'insiders as contaminators of knowledge' had been debunked several decades ago, this notion is still perpetuated within the field of psychology and social sciences (Wilkinson & Kitzinger, 2013).

In grappling with the subject of insider research, Greene (2014) identified a series of pros and cons that can be associated with this type of research. Knowledge held by the insider researcher benefits the research process due to familiarity with the community being studied and reduced culture shock. During interviews, pre-existing knowledge enables insider researchers to ask meaningful questions and to pick up on non-verbal cues. Additionally, insider researchers can interact more naturally with participants and are less likely to stigmatise them or their communities. There is also easier access to participants/groups through pre-existing contacts and their acceptance of an insider. In terms of cons, Greene highlighted that critics have argued there is a risk of being 'too subjective'. This concern relates to the potential for analysis to be obscured by the insider researcher being normalized to the patterns and features within the data; they risk making assumptions in line with their pre-understandings. Secondly, Greene notes that critics claim that insider research is biased due to the insider researchers' preunderstandings, which influence the research design and findings. In response, Greene (2014) suggests that insider bias can provide opportunity, especially if insider researchers are aware of the bias and take measures to reduce undue effect. The risk of bias for outsider researchers can also not be underestimated. Greene explained:

> *The same warning may be made to outsider researchers, in that they may inadvertently hold preconceived and perhaps even incorrect perceptions of the social group or organization under study, and, thus, must make efforts to become aware of these and where a concern, alleviate the ill effects of such biases* (Greene, 2014, pp. 4-5).

Greene (2014) concluded with a strong recommendation that qualitative researchers recognise and acknowledge their biases and positionality. A reflexive account of positionality within qualitative research helps to ensure a fuller account of the research and ensures the voices of participants are heard (Greene, 2014). Similarly, the necessity of providing a reflexive account to communicate positionality has also been identified by Chavez (2008) and Ross (2017). In doing so, research data is enriched, and reliability and validity are strengthened (Chavez, 2008; Ross, 2017).

3.1.3 Positionality

Acknowledgement of preunderstandings within the phenomena of interest is paramount in hermeneutic phenomenological research. As the researcher of this study, I bring with me lived experience as an adult diagnosed with ADHD, who has engaged with assessment and support services in Aotearoa New Zealand. Through this journey and the search for support, I have spoken with many others in similar situations, and as such have borne witness to a multitude of realities that seek illumination. These discussions occurred through social connections in my community and through the 'ADHD NZ Community for Adults with ADHD' Facebook group. My experience of being diagnosed with ADHD as an adult, while hearing the stories of other adults trying to access the same services, created deep feelings of concern and despair for my community. The decision to embark on this research project was influenced by this increased awareness. Resultingly, in designing and conducting this research, I made sure that I held an open mind and avoided making assumptions about the lived experiences and realities of participants. However, my preunderstandings and my experiences through life formed the basis for the interpretation of the data within this research, and my interpretation provided the vehicle for which this research is presented.

It is important and valuable for lived experience to be central in this research to uphold the neurodiversity paradigm principle of centring neurodiverse voices. Thus, having lived experience leading the research reinforces this principle and is an expression of the "nothing about us, without us" disability rights mantra which calls for disabled people to be involved and prioritised in issues that impact us (Francis, 2018). Extending this mantra into research acknowledges lived experience as expertise (supporting the epistemological position of hermeneutic phenomenology), allows for more meaningful and relevant research, and challenges power imbalances that have "historically oppressed and exploited vulnerable populations" and violated the experiences of disabled people (Ahlers et al., 2021, p. 23; Dibley et al., 2020a; Oliver, 1992, as cited in Inckle et al., 2023).

3.2 Procedure

This section outlines the steps taken to conduct this study to achieve the aim of the research, including recruitment, participants, and data collection. The procedures undertaken sought to develop an understanding in response to the research questions outlined in Chapter one and presented below to recap:

1. How do adults in Aotearoa experience accessing assessment for ADHD and subsequent treatment/support?
2. How are adults in Aotearoa impacted by the current pathways to ADHD assessment and supports?

3. How are adults in Aotearoa impacted by late diagnosis, misdiagnosis and/or missed diagnosis of ADHD?

3.2.1 Recruitment

Purposive sampling was utilised in this study as it allowed for the selection of participants based on the crucial and specific information they could contribute relating to the research question (Liamputtong, 2020). The purposive approach to sampling was also conducive to IPA as it relates to a sample with information-rich homogeneity while appreciating the heterogeneity across the sample (Smith et al., 2022). The maximum variation technique was attempted to gain diversity within the sample by seeking heterogeneity across age (in adulthood), ethnicity/culture, gender, occupation, and geographical location (Liamputtong, 2020). Diversity within geographical location was an additional key consideration to acknowledge the disparities of healthcare provision across different regions, commonly referred to as 'post-code lottery' (Fraser et al., 2019; Donald Beasley Institute, 2022).

Recruitment occurred within a Facebook group titled "ADHD NZ community for Adults with ADHD" which at the time of recruitment consisted of 7,400 members. This approach is in line with purposive sampling principles where members of the group carry crucial and specific information relating to the research questions. The researcher had conducted a scanning exercise on this platform prior to this study to explore whether the community would find this research project beneficial, and if members would be interested in sharing their experiences. The outcome of the scanning exercise indicated that at least 25 members were interested in participating. The exercise demonstrated that recruiting the desired sample would be achievable through the Facebook group.

I posted an advertisement in the Facebook group which included an information sheet detailing the aims of the project and the role of participants (see Appendix A and Appendix B). Following moderator approval of the post, interested participants emailed the researcher and were then provided with a participant interest form consisting of demographic and criteria-based questions to determine eligibility (see Appendix C). Participants were additionally sent an informed consent form prior to the interview (see Appendix D). The small number of excess expressions of interest following the end of recruitment were provided with information about other research opportunities, and asked if they would like to receive a final copy of this report.

3.2.2 Participants

Qualitative inquiry requires researchers to focus on depth within a small sample as opposed to quantifying data found in larger samples as required by quantitative research (Liamputtong, 2020). An additional factor in opting for a small sample was the length of time allowed for conducting the study (12 months). As such, a sample size of 10 was considered appropriate for the proposed study. The inclusion criteria for participation required participants be:

1. Aged 18 and above.

2. Residing in Aotearoa New Zealand.
3. Diagnosed with ADHD in their adult life.
4. Diagnosis within Aotearoa New Zealand

Following recruitment, 10 participants provided their informed consent. All participants were given the option to check their transcripts for accuracy. A breakdown in communication occurred with one participant and their transcript was not released back to the researcher. Subsequently, continued consent could not be ascertained and therefore the participant's data was not used in the research. A description of participants is provided in Chapter four.

3.2.3 Data collection

In adherence to hermeneutic phenomenological principles, the study utilised in depth semi-structured interviews, to allow the in depth sharing of lived experience through language (Liamputtong, 2020). A Semi-structured approach allows participants flexibility to discuss what is important to them and to elaborate freely while allowing the researcher to ask questions that inform the research (Liamputtong, 2020). Such an approach enables a natural, conversational flow in dialogue between the researcher and the participant (Liamputtong, 2020).

The interviews were conducted by the researcher on Zoom, an online video call platform and were recorded using Zoom's recording capabilities (audio and video). The duration of interviews was between one hour to one hour and a half. Each interview commenced with rapport building, followed by a discussion relating to the purpose of the study and a broad question inviting the participant to start where they feel is best. Guiding questions were utilised to elicit information relevant to the research questions. During the end of the interviews, once the recorder had been switched off, participants were asked to confirm their postal addresses so they could be sent Prezzy Cards (vouchers) to compensate for the time participants contributed to this project. Participants were additionally asked if they would like to check their transcripts for accuracy once they had been transcribed. Interviews were then transcribed using Otter.ai, an online software. The researcher then went through each transcript while listening to the audio recording to ensure accuracy.

3.3 Research considerations

This section sets out the ethical considerations that were relevant in carrying out this research. An outline of the limitations of this research project will also be provided.

3.3.1 Ethical considerations

An essential aspect of designing this study was the careful ethical considerations. Researchers must ensure that the participants they include are protected from stress and harm (Cacciattolo, 2015). To ensure this study was ethically sound, I first read through the Code of Ethical Conduct for Research, Teaching and Evaluations Involving Human Participants endorsed by Massey University (2017). I also sought advice from the supervisor of this study to ensure I had correctly interpreted my responsibilities. This study involved human participants, and the researcher perceived a potential risk of distress for participants depending on the nature of their experiences. As such, full ethical approval was sought and granted from the Massey University Human Ethics Committee: Southern A (Application 22/49).

Informed Consent

Prior to interviews, participants were invited to provide informed consent. This process included providing information to the participants relating to the purpose of the study, the nature of their contribution and how their data was to be used. Acknowledging that consent is continuous and is not absolute, participants were reminded that they could withdraw their consent at any time prior to final reporting. Informed consent was obtained using a form emailed to participants to allow for their written consent. For participants who found the written consent form to be a barrier to their participation, verbal consent was accepted and recorded at the beginning of the virtual interview. All participants were provided the opportunity to check their transcripts for accuracy and privacy concerns and were informed that this was not compulsory. Participants who checked their transcript provided written consent through a transcript release form (see Appendix E). Participants who opted out of transcript review provided their consent verbally which was recorded at the end of the interview. One participant who opted to review their transcript (so they could ensure their anonymity and remove confidential information) did not respond or consent to the release of their transcript. The data associated with the participant was excluded as required by ethical obligations and in respect of continuous consent.

Safety of Participants and Anonymity

There was an identified potential for participants to experience distress in recalling uncomfortable or traumatic experiences in this study. Participants were informed prior to the interview that they could stop the interview at any time. The researcher was vigilant to the needs of the participant; distress, discomfort, or concern was not detected during any of the interviews. To ensure the wellbeing of participants, the researcher checked in with the participants via email following the interviews. Further to this, interviews were conducted online which further protected participants and the researcher from risks associated with the COVID-19 pandemic.

All identifying information was removed from transcripts to protect the privacy of participants including names of people, clinics, and employers. All data was contained securely on a password protected device, only accessible by the researcher.

Accessibility

To ensure the study was inclusive and accessible to all participants, they were asked whether they had any access requirements that may support their participation. In this study, the only accommodations requested were through the option of providing verbal consent. One participant highlighted a barrier within the recruitment process which concerned the forms participants were required to complete to take part in the study. Although the researcher had planned for this accommodation in the informed consent process, an alternative to the written interest form was not planned. The implications of this served as a lesson for future research in ensuring all elements of information and recruitment forms are provided in accessible formats and to avoid reliance on written forms. The researcher intends to develop a short plain English summary to be published alongside this final report to increase accessibility of findings.

Cultural Considerations

In Aotearoa, culturally safe research is underpinned by Te Tiriti o Waitangi (the Treaty of Waitangi; Massey University, 2017). This study maintained an adherence with Te Tiriti o Waitangi principles (protection, partnership, and participation) and a desire to conduct inclusive and safe research. This meant that I needed to ensure that the right for Māori to participate was accompanied by the right for Māori to have tino rangatiratanga, expressed by self-determination in their participation in the research process (Hudson & Russell, 2009). To promote tino rangatiratanga within this study, all participants were asked whether there were any tikanga / cultural protocols they would like adhered to within interactions and interviews. For example, participants may prefer that the interview opens and closes with a karakia, in which case the participant may prefer to give karakia or request that the researcher opens and closes with a karakia as the holder of the meeting. Asking the participants their preferences avoids imposing processes that could provoke discomfort and it allows participants from all cultures to determine the terms of their involvement. If cultural practices were requested, I could utilise cultural advisors at Massey University to obtain advice and guidance. I also read through the summary of Te Ara Tika provided by Massey University (n.d). Participants from different cultures to my own were included in the study however, none of the participants requested cultural accommodations during their involvement. While conducting this research, I remained open minded and flexible in navigating human diversity.

3.3.2 Limitations

The researcher identified several limitations within this research project. Firstly, as mentioned in the section on accessibility, the requirement of written forms and written information may have presented as a barrier to participation in this study. There were several individuals who showed interest in this study by contacting the researcher, however many did not complete the recruitment process. The implication of this limitation is that it is possible that some individuals were restricted from participating due to barriers in the process. While this limitation is confronting for the researcher, and perpetuates inequity in research engagement, it provides the opportunity of improving future research accessibility. To improve accessibility in research involving people with ADHD, ethical obligations should be reviewed and updated to prevent barriers to participation.

Secondly, most participants were diagnosed with ADHD a short period before their involvement in the research. While these perspectives were important to the research, it meant that the analysis was restricted to a short period of reflection following diagnosis. This limitation could be avoided if the research time frame was longer, allowing a follow-up interview with participants. Another potential cause for this limitation was the method of recruitment. It is possible that individuals who are recently diagnosed may be more active in the Facebook group, or alternatively, were more interested in speaking to the focus of this research with the experience still fresh in their minds.

Lastly, this research was open to participation from adults who had been diagnosed through both the public and private pathways. Despite this, all participants received diagnosis through the private pathway. This limitation means that perspectives of adults diagnosed with ADHD through the public pathway are missing from this study. It is possible that there may be less people from this cohort in the Facebook group where recruitment occurred. This could also be indicative of limited access to public diagnosis. Future research would need a more targeted approach to ensure this cohort is included.

3.4 Data analysis

This section provides an overview of the approach used and steps taken to analyse the data following the interviews.

3.4.1 Interpretive Phenomenological Analysis

The data obtained in this study was derived from the lived experiences of participants. Therefore, it was crucial to implement an approach that would appreciate and make sense of this type of data. Interpretive Phenomenological Analysis (IPA) met the criteria for appropriateness due to its allegiance to the principles of hermeneutic phenomenology. As explained by Smith and colleagues (2022), hermeneutic phenomenology is clearly expressed as an interpretive activity, and IPA is well suited as it is explicitly interpretive in nature. Data analysis in this study was conducted in line with the IPA approach suggested by Smith et al. (2022). IPA involves the process of analysing data case by case, which requires the researcher to engage in a series of steps for each transcript. Once the researcher has attended to each step in one transcript, they must begin the process again on the next transcript (case), leaving behind the ideas and interpretations of the previous case (Smith et al., 2022).

The first step involved approaching case one and engaging with the data by reading the data and reading the data again. This process centralised the voice of the participant and brought me into their world. In attending to this step, I found it useful to listen to the audio recording while reading through the transcript to locate the participant's tonal cues. The second step involved attending to the transcript while making exploratory notes of interest to expand familiarity and to begin to make sense of the participant's sense making. During this step, I attended to transcripts using Microsoft Word 360 and used the comment function to record my exploratory notes. Step three required the development of experiential statements as outlined by Smith et al., (2022). The purpose of this step is to begin to make sense of the experiences and their nuances by generating concise statements that focus on discrete portions of the transcript. To achieve this step, I transferred the parts of the transcript that had been noted on into an Excel spreadsheet with pieces of the transcript in one column, exploratory notes in the next column, and crafted the experiential statements in the third column. Step four required the researcher to search "for connections across experiential statements"

(Smith et al., 2022, p. 90). This step required the organising of experiential statements into clusters of meaning and connection. To achieve this step, the authors recommended printing the statements and cutting them up so they can be moved around. Due to my lack of owning a printer, I utilised an online tool called Miro. This allowed me to copy all the experiential statements from excel into Miro which presented each statement on a sticky note. I then began to organise the sticky notes into clusters, often reshuffling them to remain open to different possibilities. Step five involved naming each of the clusters to describe their characteristics and evolving the clusters into Personal Experiential Themes (PETs) with subthemes. Each PET was then inserted into a table using Excel, subthemes, experiential statements, and associated quotes were included in the PET table.

The next step of the analysis process involved engaging in step one through to step five again with a new transcript. Vital to this step was ensuring that each transcript was attended to as an individual case and avoiding the reproduction of ideas from the previous case. This step seemed to be straight forward in its expectations, however, once most cases had been processed, it became increasingly difficult to let go of previous ideas as they would be triggered when coming across certain aspects of data. For example, an unexpected repetition of a certain phrase or feature. As described by Smith et al. (2022, p. 99), it is inevitable that what has already been found will have an influence due to the changing of my "fore-structures". With the awareness of these fore-structures, I found myself often questioning the emerging features to avoid missing new features. The Final step in the process involved working across all cases to develop Group Experiential Themes (GETs) to identify similarities and differences. This process occurred similarly to step four; it was an intimidating task due to the significant amount of data. However, once coming to terms with the task, I took to Miro again to organise and reshuffle the PETs and experiential statements to develop the GETs. The GETs and their subthemes are presented in Chapter four.

3.4.2 Reflexivity

Earlier, I discussed my positionality and how my preunderstandings and experiences influenced the design of this research. In this section, I revisit the role of my preunderstandings in interpreting the lived experiences shared by participants. This illuminates the hermeneutic circle whereby each lived experience as expressed by participants formed a part, in addition to my own preunderstandings which also formed a part, and my new interpretation which created the whole (Dibley et al., 2020a). This also contributes to rigour by making intersubjectivity transparent (Armour et al., 2009).

Throughout all processes in this research, I was able to reflect frequently with my supervisor to navigate emotions that arose and in addition to challenges posed by my beliefs or the beliefs expressed by participants. This proved helpful when navigating this interpretive pursuit as a novice to IPA. One of the challenges of interpreting the lived experiences in this study was maintaining awareness of my own experiences and as well as maintaining awareness of aspects that were not within my experience. An easy mistake for an insider researcher could be highlighting aspects that aligned with the researchers experience and missing other important elements. However, this challenge appeared salient prior to the analysis while researching the process of IPA and I questioned my thinking often with this in mind. For example, when participants independently raised the notion of privilege when describing how it felt to have received a diagnosis, I felt a sense of vigilance to this, probing further to understand why privilege was associated with diagnosis. My interest in this association was due to my own experience of accessing diagnosis and feeling a sense of privilege. I felt privileged because I was very aware of the multitude of people who could not receive this service and despite my struggles, I had a good job and was able to pay to access diagnosis. I found the connection between fundamental healthcare and privilege interesting and disconcerting. While experiencing this thought process, I began to question the focus I had put into the notion of privilege and as such, brought this to my supervisors' attention. It was beneficial to interrogate this aspect of interpretation because it highlighted another potential risk in doing insider research – going further than questioning interpretation by experiencing apprehension of interpretation.

I was surprised at some points in the analysis when interpreting experiences that related to the impact of being late diagnosed with ADHD. I was aware from exploring the literature that people with ADHD are more likely to experience poor mental health than those without ADHD. I assumed mental health would be a topic that participants talked about, but I had assumed this would be due to emotional dysregulation as I had put my own experiences of poor mental health down to emotional dysregulation (once diagnosed with ADHD). I was surprised because in conducting the final stages of analysis, and writing up the findings, I realised that the treatment of others and social norms had a more significant impact. Sitting with findings like these opened my eyes to the reality of participants but also to a deeper understanding of my own reality. This also highlighted another aspect of insider researcher that I was cautioning against, the effect of preunderstandings and prior assumptions on the research. This meant that while I did indeed carry preunderstandings and prior assumptions into this research, having awareness and an open mind meant that the research had impacted my understanding in a transformative way by also changing my perception of my own experiences.

Chapter 4: Findings

This research project sought to explore the lived experiences of adults who have been diagnosed with ADHD in Aotearoa as adults. The two main focuses were access to assessment and supports, and the impact of late diagnosis. However, the impact of late diagnosis emerged as a dominant feature across the data corpus. The findings of this research project are set out in the following four sections of this chapter and are summarised in Table 3.

Table 3

Group Experiential Themes with Sub-themes

Theme	Sub-theme
Undiagnosed and struggling	Undiagnosed and misunderstood in childhood and adolescence
	Undiagnosed ADHD, an occupational hazard
	Catalysts to realisation
Seeking help	Two-tier health system
	Access takes privilege
	Bumps in the road
	In need of support
Coming to terms with late diagnosis	It wasn't picked up
	Emotional processing
	What could have been
Structural flaws	Ableism
	Misconceptions
	Systemic issues

In total, the experiences of nine adults were included in this study from several regions across Aotearoa. Seven participants identified as female, one participant identified as agender and, one participant identified as male. The age of participants ranged from 22 years of age to 41 years of age; with an average of 31.4 years of age. All participants were diagnosed with ADHD as an adult. The time between receiving a diagnosis and being interviewed for this study ranged from one month to three years. Eight out of nine participants had been diagnosed for less than 12 months. For these participants, the experience of going through the assessment process was fresh in their minds. It was initially thought that these participants may not have had enough time to experience the impact of late diagnosis, however, this was not the case. All participants provided a rich account of their experiences through the assessment process in addition to their reflections of delayed diagnosis. The age of participants at the time of diagnosis ranged from 22 years of age to 40 years of age with an average of 29.8 years of age. Of the nine participants, six were Pākehā; one was Māori and Pākehā; one was Indian; and one identified as White American. Demographic information is presented below in Table 4.

Table 4

Participant Demographic Information

Participant	Ethnicity	Gender	Region	Age	Age of Diagnosis
1	Pākehā	Female	Central	29	29
2	Indian	Male	Northern	32	29
3	Māori / Pākeha	Agender	Te Waipounamu	29	29
4	Pākehā	Female	Te Waipounamu	32	32
5	Pākehā	Female	Te Waipounamu	25	24
7	White American	Female	Central	22	22
8	Pākehā	Female	Central	41	40
9	Pākehā	Female	Northern	31	30
10	Pākehā	Female	Te Waipounamu	33	33
Average				31.4	29.8

Note. The four regions of Te Whatu Ora (Health New Zealand) are used to represent the geographical location of participants to protect their identities.

4.1 Undiagnosed and Struggling

This theme sets out the experiences of participants in relation to their lives before diagnosis, from childhood to the point that they realised ADHD may be the reason for their difficulties throughout life. Three subthemes are present within this section, they include: misunderstood in childhood and adolescence; undiagnosed ADHD, an occupational hazard; and catalysts to realisation.

4.1.1 Misunderstood in Childhood and Adolescence

All of the participants in this study remained undiagnosed for the duration of their childhood and adolescent stages of life. Many participants described difficulties moving through their early years. Reflecting back on these early years, all participants described feeling misunderstood, not fitting in, or a sense of difference that was continually reinforced by others including parents, teachers, and peers. This theme outlines how the misunderstanding presented, how they felt, in what situations, and the consequences of being misunderstood.

One of the common struggles during this period was the result of external perspectives where expectations placed on participants were unmet, and their behaviour misunderstood. As articulated by Participant 10, being misunderstood was difficult: "*And I guess it's hard like growing up, and your parents just being like, 'Oh, you're just lazy, just get up and do the thing.' And it's just like, but I'm trying but it's not working*". On reflecting on her younger years, Participant 9 described a similar experience of behaviour:

> *"People, I guess from an outside perspective, [...], people would have described me as like, quite naughty; naughty or oppositional. Like I was always kind of like, I think that was probably a way I masked difficulties and like, I kind of had quite like a difficult life growing up. (#9)"*

For Participant 9, the consequence of being misunderstood meant that judgement was cast on to them for not meeting the expected norms; "*having that unknown of like, What the fuck is wrong with you? Why is this an issue? It was really threatening and was really... Yeah, and was really shame inducing*". This type of judgement is ableist in nature, as it condescends a person who does not fit the mould of perfection, of able mind and body – the corporeal standard (Campbell, 2001, as cited in Francis, 2018).

Several participants described difficulties with social connection when they were younger. For Participant 3, their difficulties related to fitting in with peers "*I was always a bit of a misfit at school*". In contrast, other participants struggled with maintaining relationships due to the expectations and assumed requirements associated within the social contract of friendship. For the following two participants, this included remembering to maintain communication, and having the patience or perhaps the ability to maintain interest within the friendship.

> *"I found it really hard to sort of make friends and keep friends. Purely because I'm really bad at keeping in touch with people, like messaging people, remembering to message people back and things like that." (#5)*

> *"So a lot of my relationships, that affected my friendships, I just didn't have the patience. I just wanted to move on, to move on, to move on. And relationships are tricky. They require patience and knowing. You know, I just didn't have the patience for that." (#2)*

While pondering this period of life, Participant 2 also reflected a yearning to experience the consistency present in the lives of those around him: "*I just wish I had something normal, like something predictable that, you know, like one pathway to get me through life. But gosh, it was never that for me*". This reflection highlights an internal struggle present within many of the experiences of participants where their difficulties to conform to expectations were not for lack of awareness or wanting. At this early stage of life, they were not only misunderstood by the people around them, but also by themselves.

There is a tension highlighted here that points to a nuanced understanding of ADHD, that challenges the stereotypical notions of a lack of self-awareness or awareness of difference. This difference was constantly being reinforced by others, but the awareness meant this feeling of being misunderstood and not fitting in was hurtful and had long term consequences for the participants.

4.1.2 Undiagnosed ADHD, an Occupational Hazard

In reflecting on their experiences of life prior to diagnosis, participants also described their experiences as students and employees. Unidentified and undiagnosed ADHD grossly impacted the wellbeing of many participants as they attempted to fulfil their education and employment obligations and expectations. Experiences within the education system left some participants feeling like they had let themselves down due to the constant reinforcement that they were capable but not living up to potential (and at the time not really knowing why this was the case).

> *"My school reports were constantly talking about how she is a bright kid, but she needs to focus and she's very talkative and distracted. So, I did reasonably well in school. But I always felt like I could have done better. And I was letting myself down". (#1)*

> *"I found school really hard as well. I didn't finish school; actually dropped out early, so I never finished it. But I feel like I could have achieved more." (#5)*

For Participant 9, the constant struggle of surviving the education system meant their self-perception was distorted "*It wasn't till seventh forum that I realised I was actually kind of good at a few things like my whole education, I just thought I was really stupid.*" School has consistently been shown to be difficult for individuals with ADHD (Kendall, 2016; Loe & Feldman, 2007; Taneja Johansson, 2021). This research shows a type of presentation as evident in the classic ADHD school report card that many participants talked about:

> *"all my [...] school reports, so classic ADHD stuff, like can't stay on task. It's out of seat; talks too much with friends. But also, that I wasn't fulfilling my potential". (#4)*

Although it was not explicitly highlighted by participants, it is clear that the feedback provided in school reports had an impact on the self-perceptions of participants. This occurred through the adoption of negative self-descriptions and inferior self-concepts. The link between ADHD and low self-esteem in childhood and adolescence has been identified in several studies (Capelatto et al., 2014; Klimkeit et al., 2006; Mazzone et al., 2013). Further to this, Harpin and colleagues (2016) found an association between untreated ADHD and lower long-term self-esteem across childhood and adulthood.

Participant 10 experienced punitive responses to behaviours characteristic of ADHD while at school, demonstrating further misunderstanding.

> *"I remember, have vague memories of always getting in trouble at school for having a really messy desk. And forgetting to bring, like pencil cases, and books and sports gear and all that just accidentally leaving it at home all the time and being late." (#10)*

These experiences bring the awareness of teachers into question. Teachers often highlighted behaviours consistent with ADHD symptoms within the school reports of participants, however, the identification did not lead to further investigations. Similarly, a study in Ireland found that teachers often mentioned inattentive behaviour on student report cards to encourage self-correction but failed to identify the behaviour as symptomatic of ADHD in girls (Lynch & Davison, 2022). It was suggested that this tendency was due to a lack of professional development regarding the presentation of ADHD in girls (Lynch & Davison, 2022).

In terms of work environments and jobs, a few participants described difficulty in maintaining employment, while others described difficulty in staying in a job long term.

> *I jumped through a lot of different jobs. I think my longest job has been about nine months. And there's just been, yeah, just lots of different jobs; different areas of the jobs. (#1)*

Carrying out job tasks or maintaining interest and engagement were mentioned as common struggles for participants who were trying to remain employed.

> *And I just wasn't paying attention, I'd make mistakes. I, you know, my performance wasn't the best at the end of the day. Yeah, disengagement was definitely one of the challenges and the other one was complete restlessness. I think restlessness in terms of, you know, lack of patience. (#2)*

The occupational hazard of undiagnosed ADHD exists through the impact on self-perception, self-belief, and access to meaningful employment. During these periods, participants did not identify ADHD within themselves; ADHD was also not identified by educators or employers. When there was no consideration of ADHD by themselves or their workplaces, their issues then became seen as an internal problem (something wrong with them) as opposed to any form of structural issue.

4.1.3 Catalysts to Realisation

> *"I started realising the little things that gave me trouble in life, all came back to being ADHD." (#3)*

For all participants, it was not until they reached their adult years that the realisation occurred that they may have ADHD. The journey to this realisation took many forms for the participants. For some participants, exploring the possibility of an ADHD diagnosis was triggered by the awareness of other family members who had been diagnosed at some point in their lives. As was the case for Participant 2, "*I ended up getting diagnosed with ADHD, just because I have a family history.*" Other participants were encouraged by family members who had been diagnosed and had identified similar struggles.

> *I didn't even sort of realise that I might have ADHD until a few months before that. But my brother also has ADHD, and he's the one who sort of pushed me to look into it a bit more and be like, 'Hey, you should get diagnosed'. (#10)*

> *…my biological mother who I'm close with, she just got diagnosed with ADHD. And she was like, you should look into it. It's genetic. (#4)*

Friends were also instrumental in coming to the realisation for many participants. It was common for these conversations to arise out of shared experiences of battling with mental health and being impacted by periods of distress.

> *"But I think the kicker was him saying about his depression, anxiety. And me, having been at that point, like maybe a year out from having had this big depression, I was like, why would I not check?" (#8)*

Participant 9 described their distress as "spiralling". It was clear that their mental wellbeing and self-perception were being impacted by the effects of undiagnosed and untreated ADHD. An assessment was suggested by a friend with an understanding of ADHD.

> *…but they were like, 'Hey, why don't you go and get an assessment of ADHD', because it was just, I was spiralling and like, just a lot of shame about why I was having difficulties and I guess just still trying to make sense of what was going on and blaming myself and had like a really negative self-concept.*" (#9)

Relating to content published on social media by people with ADHD was another avenue through which participants came to the realisation that their difficulties aligned with the symptoms of ADHD. For example, Participant 5 explained the following:

> *"So on social media, like TikTok and Instagram, all these posts of sort of kept coming up about just like traits and things like that, that people had or like, things about other people's experience And I was like, 'Wow, this feels really specific. Like, I get those'." (#5)*

Whether it was through family, friends or social media – participants were only able to identify the possibility of having ADHD through the lived experience of those they were exposed to. Awareness of how ADHD presents and how to identify it was not something that participants had prior to drawing from their social connections outlined above. Participant 4 articulated their transition of understanding that had previously been in line with common misconceptions of ADHD:

> *"And I kind of like, did a quick Google, and I was like I don't have ADHD because I guess I just kind of had that idea of that sort of, hyperactive, boy kind of you know how, like you. That's how you, I guess it's kind of seen." (#4)*

As she began to search further, the realization arrived and along with it came intense emotions:

> *"Just one day, I was like, just felt I needed to google it again. And I just listened to a TED talk. And it was like, the woman's story was exactly like mine, and then it hit me. And then I was like, holy shit. Then I'd like cried like I'd never cried before. That was like the strangest sensation, that was like, my*

> *reality just was like, totally shifted. And yeah, so that, and then I was like I think I have ADHD." (#4)*

Several participants were met with a catalyst, where they felt they were experiencing the wheels falling off, or burn out, characterised by a reduced ability to maintain participation in realms of their life. This took effect when they could no longer push through their struggles due to the distressing impact on their mental health.

> *"I mean, it was really hard; [...] I had a giant mix of anxiety and depression. And just I was unable to focus or concentrate. My Social Life was so up and down and all over the place as well." (#3)*
>
> *"I had proper, proper burnout from there and got really depressed. You know, that whole just can't stop crying all the time, but went on antidepressants, etc, which is so easy to get compared to an ADHD diagnosis. So yeah, I think that was a bit of a catalyst for me to change the way I do things and kind of demand more, but I feel like I've always known something. I've always been looking for the answer, to what, not what's wrong with me, but why I'm a bit different." (#8)*

In summary, the experiences outlined in this theme highlighted the difficulties of being misunderstood throughout their younger years through the perceptions of the people in their lives. Participants experienced difficulties in education and employment which impacted their self-perceptions. Negative self-perceptions developed into mental distress for many participants who remained undiagnosed and unaware of the potential presence of ADHD until they confided in their social supports.

4.2 Seeking Help

After the catalyst, all participants then embarked on a journey to seek answers and help. This theme sets out the experiences of participants through their process of seeking diagnosis and subsequently, their process of seeking support. Four subthemes were identified within this theme: two-tier heath system; access takes privilege; bumps in the road; and in need of support.

4.2.1 Two-tier Health System

Participants learnt that the services they required operated within a two-tier system, comprised of public and private pathways. The public system is accessed through government funding and the private system is accessed through self-funding. None of the participants in this study were able to access publicly funded assessments despite many participants trying or being open to getting assessed through the public system. Participant 5 summarised the public system as *"non-existent, unless you're in crisis."* This statement was supported by the experiences of many participants. For example, Participant 3 did not meet the threshold of severity for a funded assessment *"I got my GP to try and refer me through the public system. But because I wasn't bad enough, they declined to assess me."*

The first step in the process to obtaining a diagnosis was to have an appointment with their General Practitioner (GP). For most participants, this appointment was where they learned that they would not have access to public funding. A common theme among these experiences was the GP's awareness that the public system was effectively hopeless.

> *"And [the GP] said, There's no way that she can refer me to anyone down here, there's no way that I'm going to end up getting through the public system." (#5)*
>
> *"My GP was really nice about it. And basically, you know, asked me to explain myself on why I think I have ADHD and what I'd like to do about it, and he went on to say that, basically, public isn't accepting referrals for adult ADHD anymore. And so, if I want medication, I need to go private." (#10)*

One key difference in the experiences shared by participants presented itself through Participant 2 who did not realise there was a publicly funded option.

> *"I think my general practitioner, [...] she told me you should go private straightaway. She didn't even tell me to, you know, yeah, she just, I mean I didn't even realise there was a public." (#2)*

The enigma of the public system was something that participants had only heard stories about. Whether it was from their GP or their online communities, the stories were enough to evoke fear.

> *"The process of getting diagnosed in New Zealand looks really scary. Just because I've yeah, heard lots of stories because I didn't have money to go through private, going through public looked really scary." (#7)*

Within the two-tier approach to service provision, the public system appeared to be crisis-based and inaccessible. Participants were left with two options: go private or remain undiagnosed. Accessing the public system involves being referred to Adult Mental Health and Addiction services (Ministry of Health, 2022b). In Aotearoa, the mental health system has been widely referred to as a sector in crisis (Mulder et al., 2022). Adult Mental Health and Addiction services respond to those with the highest level of need and the Ministry of Health (2022b) has acknowledged that people with ADHD are often not considered to be within this threshold.

4.2.2 Access Takes Privilege

"I have the privilege of being able to afford it." (#8)

To access assessment, participants were required to self-fund their appointments through the private system. It was acknowledged that the amount of money required to undergo this process was exorbitant. When describing the reality of being in the position to meet these costs, participants commonly reflected on feeling a sense of privilege which for some participants, was associated with negative emotions. Participant 9 commented, *"it's sort of sad that it takes so much financial privilege. And like, it's just so not an inclusive system."* Delving deeper into the experience of privilege, Participant 2 provided the following insight *"But I'm sitting here and reflecting on how privilege is something that is learned, in the sense that you can very easily, unless this is brought to your attention, you won't necessarily know about it."* Privilege in this context was identified by participants comparatively through their awareness that there were many other people who would not have the means to access assessment through this avenue regardless of need.

> *“[…] There's some people in the groups and stuff who […] seem like they don't have a life at all. Because of the ADHD, and they're the ones that can't get help. And that seems horrible.” (#8)*

For participants who were not able to meet the costs themselves, privilege and luck was acknowledged in relation to accessing the financial resources required through other means. Participant 10 reflected on the privilege of having a supportive and resourced family member that enabled her to access assessment:

> *“I was very, I realise how privileged and lucky I am that [my brother] was very kind enough to pay for that for me, because it's very expensive. And he works at [employer removed]. So he has lots of money, which is very lucky. But if he wasn't able to pay for that for me, we can't afford $700, $800 just for the initial appointment, and then another $250 or $300 for the follow ups and things like that. So yeah, if I wasn't able to get him to pay for it, like we, I wouldn't be diagnosed now. I'd be trying to save up and save up.” (#10)*

In some cases, being able to meet the costs of an assessment came down to the timing of receiving a one-off payment that was not part of their typical income.

> *"The fact that it's so expensive to get diagnosed, is ridiculous. I mean, the only reason I could afford it was because Studylink screwed up and had to back pay me half a year. Not everyone can afford $560 for a 40 minute appointment." (#3)*

> *"I know that I come from an extremely privileged position because of the resources that I had, and simply that tax refund, because otherwise, I would have been begging family and friends for a couple of thousand to see someone." (#1)*

In both scenarios, whether it was through family or non-typical income, the understanding of their privileged position was heightened in comparison to other participants as they had come close to being part of the undiagnosed population who would not be able to consider the private pathway and subsequently remain stranded.

> *“So it's just kind of like, either you pay all this money or you just don't get diagnosed, and then you self-medicate, which is like caffeine or other avenues. Not that I’d ever go down those avenues.” (#5)*

The experiences of participants within the private system were varied, the challenges of which will be described in the following section. The positives ranged from being offered the ability to email questions to going through a quick and smooth process.

> *" And within 40 minutes, he was like, okay, yes, you have ADHD. Here is some medication, email me if you have any questions, and we have a med review in February." (#3)*

> *"So, it did obviously, cost a lot and we purposely decided to go private. And it was much faster, the experience was smooth. So, it wasn't the best experience. But yes, I think from a systemic perspective, you know, I was diagnosed and I went to pick up my medication and boom that's it." (#2)*

This theme highlighted self-perceived privilege as a key ingredient for access to assessment services. This finding compounds the reality presented in the previous theme and raises a salient issue - for privilege to be a qualifying factor, socioeconomic inequity must be present. The notion of privilege is characterised by a special advantage that is not universal or common (Black & Stone, 2005).

4.2.3 Bumps in the Road

Although some participants experienced a quick and smooth process of assessment as described in a previous section, other participants were faced with challenges at different points in the process. Participant 3 described navigating an array of emotions while experiencing a lengthy wait time, *"like it did take… it was a five month wait from when I started, from the referral to the appointment and it was exciting and nerve wracking and frustrating"*. For Participant 5, the challenge they faced was in relation to identifying a clinic that had availability:

> *"So it took me a couple of weeks to sort of look around and find somewhere that was able to do a virtual consult, because no one in [region removed] was taking, like patients for assessments." (#5)*

General aspects of the process were found to be challenging for some participants who suggested there were additional barriers to access including administrative confusion from unclear requirements to confirm appointments; the requirement to navigate and complete numerous forms; and maintaining prescriptions and medication review appointments. Managing these barriers can be particularly difficult for people with ADHD who may struggle with organisation, motivation, and memory.

> *"it's ridiculous that even just the path to getting medication is not ADHD friendly at all. Like having to remember all these appointments and things and do this on this time and pick up this at this time." (#10)*

The challenges faced by one participant had a significant impact on them in relation to the distress she experienced through the treatment of her psychiatrist. Typically, when an assessment is conducted by a psychiatrist, diagnosed individuals are provided a prescription for medication to manage symptoms of ADHD during their initial appointment. For Participant 4, it was this part of the appointment that was the most challenging.

> *"I told him about the times I've taken recreational drugs before and I've never had a drug addiction. And I wouldn't say a drug problem but I've tried recreational drugs but that didn't sit well with him and so he actually said it went against regulations to prescribe me stimulant medication because I think he thought I was like after drugs and yeah" (#4)*

The denial of medication due to the psychiatrists' assumptions of drug seeking could be considered a rights violation under Article 25(f) of the UNCRPD due to "discriminatory denial of health care" (United Nations, 2006, p. 16). The New Zealand Government has an obligation to ensure policies do not violate rights under the convention. This experience had a profound effect on Participant 4, to the extent that her physical health was impacted:

> *"Yeah, it was just extremely distressing. I actually got my period early for only the second time in my life, like the level of stress. [...] I really believe it was like, a health right, being denied and discrimination" (#4)*

The assumptions of the psychiatrist are likely informed by concerns pertaining to the risk of abuse associated with stimulant medication, often highlighted among college students (Clemow & Walker, 2004). However, research suggests that there is no increased risk of stimulant medication abuse for people who are prescribed it, and that stimulant medication actually protects against substance abuse (Chang et al., 2014). This experience highlights the harm that can be caused by these assumptions.

4.2.4 In Need of Support

The typical assumption when engaging with healthcare is that support is what follows diagnosis. Referrals are made, a plan is in place and hope is instilled that the struggles leading to this point may become a distant memory, or at least manageable. The reality for participants was a contrast to that assumption. Following diagnosis, the treatment plan for most participants was solely the provision of prescribed medication. Maintaining prescriptions relied on the organisation skills of participants to order the script every month; pick the prescription up; and keep up with appointments and charges.

> *"And then there's expecting people who have trouble making, planning, keeping appointments, to remember to do all of that. You literally just diagnosed us at being bad at that." (#3)*

The efficacy of medication varied among participants as seen in the following excerpts:

> *"And it has been helping, not as like, not as much as I, well consistently as I'd like, but I think that's just getting used to the meds." (#3)*
>
> *"Like I didn't feel like I was any better than if I didn't take my meds like I forgot to take them some days because it literally, like made no difference to me." (#5)*
>
> *"I forgot to grab this thing. I'm halfway down the driveway, but I forgot to put a school bag in the car. It's gotten a bit better so far, a little bit now that I'm on medication, but yeah, it's always been fun." (#10)*

The medical approach to treatment left many participants wanting. As articulated by Participant 2, medication alone was not sufficient and taking the medication came with further challenges. The absence of additional, non-medical support on offer meant Participant 2 was tasked with finding his own support.

> *"I had to go through it on my own. I had to go seek some help. Obviously, things are bad. I mean, on medication, you know, the mood swings, and the side effects, obviously had an impact on my relationship with my wife. And so, I was at a point where I had to go seek some help." (#2)*

Aside from pharmaceutical offerings, participants were themselves required to respond to their own necessity and find a path to support. As described by Participant 4, "*I haven't been offered any support. But I've asked for support and have had to like Google and research and stuff.*"; and similarly expressed by Participant 5, *"I feel like it's very, it's very, very, very self-driven. Like, I kind of have to do everything and push everything myself."*

Once support options had been identified by participants, they were again met with financial hurdles when considering how or if they could afford to meet the costs of these supports. For example, ADHD coaching was a service commonly mentioned by participants as a preferred support. ADHD coaching is a form of intervention which focuses on cognitive, behavioural and emotional outcomes with an aim of building life skills and changing negative beliefs and outcomes (Kubik, 2010). However, participants faced a barrier to receiving this type of support.

> *"like, I would like to do some sort of coaching or something. I know that that's a thing that you can give ADHD, but I can't afford to pay $130 an hour or whatever, for an ADHD coach." (#10)*
>
> *"And I'll definitely do more coaching in the future. I'm just [...] currently not working. I don't have the income. That's the factor at the moment." (#4)*

Having access to these supports once again came down to financial privilege as articulated by Participant 2: *"So interestingly enough, the more you throw money at this problem, the better your support systems."* Outside of conventional supports, participants found support through social media platforms. The support that came through this vehicle took the form of advice and hacks for ADHD dilemmas as well as relatable insights into ADHD life.

> *"I could almost just search on TikTok, like I'm having X problem. What's an ADHD hack? And it will probably come up on there." (#8)*

Through accessing this type of support, some participants described feeling a sense of community through shared experiences. This experience demonstrates a sense of belonging, mitigating feelings of difference that are often experienced by people with ADHD (Redshaw & McCormack, 2022).

> *"I've learned more about ADHD from Instagram, and memes. And just like for the first time in my life, kind of really having a sense of community of people who really struggle with the same things and kind of sharing those with friends." (#9)*
>
> *"And I think that, you know, things like this Facebook group are really good." (#7)*

In summary, the experiences outlined in this theme highlighted a two-tiered system where assessments were accessible to those in the "severe" category (public) or those in the "privileged" (private) category. Even though participants accessed the private system, some still faced challenges in navigating it. Once diagnosed, medication was offered as the sole treatment to manage ADHD (in most cases), leaving participants to embark on a support seeking journey themselves.

4.3 Coming to Terms with Late Diagnosis

This theme sets out the experiences of participants as they navigated the internal processing of receiving an ADHD diagnosis as an adult. Three sub-themes were identified within this theme, these include: it wasn't picked up; emotional processing; and what could have been.

4.3.1 It Wasn't Picked Up

Equipped with a diagnosis, an increasing understanding of ADHD, and hindsight, many participants recalled what they considered to be early signs. Despite exhibiting behaviour consistent with characteristics of ADHD, the possibility was not identified until later in life when participants were able to identify it themselves.

> *"I was super hyper as a child. This is a common one that my mom and dad keep telling me I would never sit still, abundance of energy. I mean, I remember a time when my mom was narrating this to me quite recently, she said, you know, the more you get tired, the more hyper you'd get. " (#2)*

This reality left participants attempting to make sense of how their difficulties managed to remain undetected for a large portion of their lives.

> *"I would have been a terror. But like, I also feel sad for me that it was never, nobody ever, like looked any deeper." (#9)*

For Participant 2, it was not difficult to understand how his parents had not figured it out, "*I don't blame my parents [...], they weren't even aware that such a thing existed*." Other participants made sense of their missed diagnosis though awareness of gender differences in ADHD presentation. In childhood and adolescence, ADHD is more likely to be identified in boys due to the presence of externalised symptoms, while girls exhibit a higher level of inattention symptoms. Externalised symptoms in male children mean that they are identified and assessed earlier than female children (De Rossi et al., 2022).

> *"And I guess they didn't really pick it up. But it was more common, I guess, back then it was sort of more common for boys to be diagnosed, but not so much girls." (#5)*

> *"And being female and inattentive means that it might not have been picked up regardless."*

Participant 8 made sense of her delayed diagnosis through considering her own personality traits and nature which, she assumed to be the reason her difficulties remained unidentified.

> *"I was smart and because I was a very compliant child. Very people pleasing, wanting to do the right thing, never wanting to break a rule. Obviously, nobody ever saw ADHD in me at all". (#8)*

For Participant 9, unsuccessful attempts to mitigate difficulties in the classroom led them to draw their own conclusions about why they experienced those difficulties. The impact of these conclusions resulted in negative self-perception, which continued to follow them into later life.

> *"I guess that was where the narrative started that I was really stupid. And I was in remedial reading when actually, I think I had glasses for a period, but I actually think it was just inattentive symptoms." (#9)*

Many participants experienced mental health difficulties while their ADHD remained undetected. Some participants described these difficulties as a symptom of ADHD, while others described their mental health issues as a result of undiagnosed ADHD.

> *"like that dysfunction, kind of like, became a big part of my life in a way. That was really hard on my mental health, because I didn't have any context or language or anything for it. And I just, what the hell [...], I'm like, why am I so lazy? Like, what happened to me? Yeah, by myself for a lot of it. And I think that really did a number on my mental health." (#7)*

> *"I can be so different each day, like my moods can be sort of really volatile, almost, it's better now that I am medicated, but it was kind of bad. And just like I could be super reactive, and really, really emotional for no reason" (#5)*

Participants made sense of why or how ADHD wasn't picked up through a variety of ways. Missed diagnosis took a toll on participants and impacted their mental health. Having undiagnosed ADHD also impacted identity formation, due to the unexplained difficulties and negative comments that became internalised and part of their identity (Long & Coats, 2022).

4.3.2 Emotional Processing

Receiving an ADHD diagnosis in adulthood was a lot to process for many participants. Coming to terms with this new information about themselves evoked a range of emotions while they attempted to make sense of the ADHD diagnosis, and the delay in which it came. Some participants described experiencing positive emotions resulting from finally receiving a diagnosis that explained their difficulties. Participant 4 summarised the new information as positive *"because it just makes everything make sense. You know, and it's like, holy shit."* For these participants, diagnosis enabled them to make sense of themselves and their struggles and challenge their previous self-perceptions. One of the most consistent reactions among participants was the feeling of relief:

> *"very relieved to just have that confirmation that I'm, I'm not crazy. Like, there's a reason for all these things." (#7)*

> *"it was sort of like a relief to be able to, like, know that there is something different and that I can now understand it a little bit more." (#5)*

> *" when he said the words, something, something ADHD, which I think you have, I almost started crying out of just the relief." (#3)*

For some participants, the news was followed by anger and grief at having struggled for so many years without any suggestion or inquiry into their struggles.

> *"I was angry, because how did no one see this? Why did my teachers say I had potential that I wasn't living up to but not ask why I wasn't living up to it?" (#1)*

> *"I generally don't, I don't label. I avoid all groups that, you know, as I know, some people find it liberating, I suppose, is there's still a lot of anger in terms of coming to terms with it. And you know, I'm seeking some help for it. So I go to a psychotherapist, I mean, obviously, we're working through it." (#2)*

Some participants expressed a sense of hope, in that having a diagnosis meant there were now opportunities to address and communicate some of their struggles. There is a term that they can now use which encompasses relevant areas of difficulty. This provides participants with an avenue to explore resources online:

> *"And I looked up a couple of things. And it was essentially how to get motivated. And I found someone on YouTube who was talking about, you know, their struggles with ADHD and how they get motivated and what's blocking them." (#1)*

In addition, this also enabled participants to find their community as articulated by Participant 5: "*And it is a whole group of people that pretty much have the same experience, I guess*."

For many participants, the positives of being diagnosed had practical implications, such as the potential for medication to assist in the management of ADHD:

> *"and now I am medicated, which has been amazing but not like, it [...] wasn't like an electrical bolt or wasn't like a sudden thing. It's a bit more subtle with me and mostly that I'm not exhausted all the time." (#8)*

> *"Now, it's like, Oh, my God, like I can – I've got these, you know, even just getting the diagnosis, processing that and receiving medication. Absolutely life changing." (#4)*

Processing diagnosis in adulthood after living a large portion of life undiagnosed was an emotional rollercoaster for many participants. Young and colleagues (2008) reported similar findings in their study of late diagnosis where emotional processing included relief, elation, anger, and sadness.

4.3.3 What Could Have Been

One of the most consistent themes within the experiences of participants emerged as they reflected on what it meant to be diagnosed late in life. Grappling with the unknown of "what could have been" was identified as the most common impact on participants. The years before diagnosis were emotionally damaging for many participants.

> *"So it feels difficult, and I feel sad kind of talking about, you know, what could have been or how it could have been different but in a lot of senses like yeah, I feel really stoked about where I am. But it was it was a really difficult school experience you know, I was cast as a problem on daily report and getting in trouble when actually yeah, it was, I was bored" (#9)*

> *"I was quite, I got, I don't want to say depressed because it probably wasn't as bad as like actual depression, but like quite depressed in that it made me sort of think back. And if it got picked up when I was at the start of high school, what my life would look like now. [...] I guess it's grief and sort of just being like, what if, what would be different?" (#10)*

Self-castigation appeared as a response to being chastised by others for their inability to regulate their behaviours to the standard of their peers. Self-castigation was identified when participants reflected on their previous self-perceptions. As highlighted in a previous section, missed opportunities to identify ADHD earlier in life can have a long-term impact on self-esteem.

> "*I thought I'm just a terrible shitty person who can't keep your house clean and tidy. And I'm always late for things*." (#10)

> *"so yeah feeling for 10 years like there's just something well my whole life feeling like there's something wrong with me but not knowing what yeah, that was pretty depressing. Confusing." (#3)*

> *"through my teenage years and stuff, like it was very hard to sort of understand why it was harder for me during those times, but if I was diagnosed, I wouldn't have had such a terrible experience." (#5)*

It is possible that the mental distress participants experienced at various times in their life could have been prevented if they had access to treatment and gained self-understanding earlier. Participants reflected on how their life outcomes may have been different had they had the opportunity to have their difficulties seen, heard, understood, and supported.

> *"I wish I had [been diagnosed earlier], because I would have done, I would have had the support. And I would have probably taken steps to change a lot of things that, you know, I've been forced to do so now." (#2)*

> *"And if I'd had access to treatment, both like talk therapy and medication. I wouldn't be where I am now. I mean, I might have finished a uni degree, I might be a clinical psychologist by now. I might have. I might not have burned myself out to the point of getting chronic fatigue syndrome. " (#3)*

In summary, participants experienced a period of reflection following their diagnosis. Reflecting on the years that came before diagnosis, participants attempted to make sense of how and why they were not suspected as having ADHD in their earlier years when they could identify their differences themselves in hindsight. Finally receiving a diagnosis brought relief for participants as it allowed them to make sense of themselves and find connection with others who have shared experiences; and grief for the difficulties they had to overcome prior to receiving recognition. As an extension of the grief participants experienced, participants found themselves pondering the unknown: what would life have been like if they were diagnosed earlier in life?

4.4 Structural Flaws

Across the lifespan, participants were impacted by their social environments. This theme sets out the experiences of participants as they navigate the impacts of societal influences and the impacts of systemic gaps while offering suggestions for improvement. Three sub-themes were interpreted within this theme including ableism; misconceptions; and systemic issues.

4.4.1 Ableism

In the social worlds of participants, ADHD was not well understood. The behaviours associated with ADHD deviate from the conventions of social norms. When ADHD is not well understood, deviations are viewed as character flaws. According to Gappmayer (2021, p. 105), ableism is the social norm in which people are expected to possess certain skill levels and abilities to be "a fully acknowledged human in society". A social misunderstanding of ADHD was evident in the experiences of participants as they described the ways they had been perceived by others when unable to conform to social norms.

> *"But also just I've always been seen as lazy like, even by my parents and things like that, just because I'd never sort of get stuff done or didn't want to do it. Which, I guess was sort of hard because I never saw it as like lazy. I just couldn't do things." (#5)*

> *"Or if you look at a child who's you know, is obviously struggling with emotional dysregulation? You know, a lot of my friends or just people that I've known who just say, this guy's throwing a tantrum, or the parents are terrible. They haven't taught the child this. You know? So, we've got a long way to go." (#2)*

For Participant 8, behavioural expectations within social norms conditioned her to believe that her behavioural tendencies made her inferior. With this understanding, she developed a method to compensate for difficulties with regulation.

> *"Well, society taught me to, right?. Like, if you're late, or you interrupt, you're just not a good person. Or I think I had been working on myself for so many years too like, I will often monitor how much I've said in a conversation, be like you haven't, you haven't asked any questions. You need to ask some questions, you know." (#8)*

Some participants found navigating these societal beliefs difficult, particularly regarding the people closest to them. Despite having an official diagnosis, family members remained dismissive and subservient to societal expectations.

> *“I haven't told my parents about my diagnosis or anything, because growing up, even when [my brother] got diagnosed and put on medication, it was just ‘Our son is just lazy. What even is ADHD, there's not even a thing’, even though he's taking medication for it, and obviously a psychiatrist diagnosed him. And things like so, if your parents can't even, you know, accept it, how is other people who don't have anything to do with it even supposed to understand.” (#10)*

> *“I just can't get to the stuff I need to get to and can't like, organise my day and think about it takes a lot of my brain power to do that. And she was like, ‘You just need to be less lazy’. Like those words came out of her mouth. I was like, Mom, I have been diagnosed as having a brain that works differently.” (#8)*

For Participant 7, in contrast to the above experiences, acceptance was obtained from the people closest to her. She attributed this to luck in recognition of the lack of understanding in wider society.

> *“but I also do feel really lucky to have like, my husband and I do have some close friends who have taken the time to understand.” (#7)*

The societal attitudes surrounding participants were often explicit regarding how they should be acting, feeling, and behaving. This type of ableism also resembles neuronormativity, characterised by a preference for neurotypical or ‘normal’ cognition and behaviour which marginalises those who deviate (Bolton, 2023; Chapman, 2020).

4.4.2 Misconceptions

Participants described widely held beliefs within society that contradicted the factual reality of ADHD. McAfee and Hoffman (2021, p. 1) define misconceptions as “unjustified beliefs, or beliefs explicitly contradicted by scientific evidence”. A common misconception highlighted by participants was the stereotypical assumption that ADHD can only be associated with hyperactive male children. This assumption only accounts for a certain presentation of ADHD and leads to the general unawareness that ADHD can encompass many other features, can present without the feature of hyperactivity, and can change over time.

> *"most people just think it's the stereotypical stuff which we all know is not right. Cis white boy, hyperactivity. So yeah, no, I don't think it's understood in wider society at all" (#3)*

> *“It's not at all understood in society. And you really have to fight to have it understood. It's understood if you're a hyperactive eight-year-old boy” (#8)*

The dominance of this stereotypical assumption was also acknowledged by some participants as being consistent with their own understandings prior to learning more about ADHD. The lack of awareness meant they were unable to identify it within themselves until becoming more aware.

> *“I kind of discovered all of this a couple years ago, and kind of thought of it as like, like a hyperactive four-year-old boy. Yeah, so it was kind of a surprise to discover what it actually is.” (#7)*

> *"I mean, before I was diagnosed and learned a bit more, but when someone's had ADHD, just think of the little hyperactive boy running around and getting into trouble and doing naughty things. And I don't know that's always been how I've sort of, I've been thinking about it, but to know that there's like the inattentive stuff as well. And how it can look completely different in girls and things." (#10)*

It was clear that general understandings among society were limited. There were elements of ADHD that were not in alignment with public discourse; creating a feedback loop where lack of awareness perpetuates lack of awareness. An example of the limited awareness and discourse is provided by Participant 8.

> *"But I think one of the other big ones for me, and it's not talked about as much, and it's not as much in the criteria, but the emotional dysregulation thing and just feeling down in that hole not wanting to get out of bed in the morning thing, like, because whenever you read about that, that's depression, right? That's what depression is. But my meds helped with it". (#8)*

The stereotypical young hyperactive boy remained the most consistently mentioned stereotype but there remained misconceptions about what ADHD is and what issues it can cause requiring a new level of education and learning from the participants. Being diagnosed as an adult for some did little to change misconceptions for others in their lives.

4.4.3 Systemic Issues

> *"I don't want anyone else to have to go through what I just did." (#4)*

Participants described being impacted by systems and policies that were infelicitous to their realities. One such area involved systemic gaps that were identified as detrimental to mental health. Several participants expressed concern for people with ADHD who had not been diagnosed; either because they had not identified it or could not access assessment and treatment.

> *"I feel like there are some people that have had enough of the struggles. And, you know, I reached a point, before I realised that I had ADHD that, you know, I had really, really dark thoughts. So, I can only imagine how many other people out there who haven't reached this, this conclusion basically, that do make that decision and do take that action." (#1)*

> *"I think there are people in this country at risk because we can't access medication. Or, like information, people or the health practitioners don't have that information." (#4)*

Participants were right to be concerned about the risks for people with ADHD who remain unsupported. Studies have found adults with ADHD are more likely to attempt suicide (Fuller-Thomson et al., 2022); experience suicidal ideation (Giupponi et al., 2020); and have an elevated risk of completed suicide (Balazs & Kereszteny, 2017). As highlighted by Participant 5, the impact of current pathways to assessment and suppoprt call for prompt address.

> *"But I think it is a really important matter that should be fast tracked, because it contributes to so many mental health problems, like the amount of people that I've talked to that just ended up in an*

> *insane depression, because of having undiagnosed ADHD is like, quite significant, but they can't go and they still can't go get diagnosed or anything." (#5)*

Participant 1 described a crisis-based system, where the provision of support is reliant on a certain level of crisis which was evident in participants' experiences of access discussed in section 4.2.1.

> *"because of where I worked, I understood that, unfortunately, through the DHB's [District Health Boards], the mental health services are an ambulance at the bottom of the cliff. And I was on the edge, but I wasn't falling down it at that point." (#1)*

Some participants found it difficult to understand why the health system allowed for an easier process to be diagnosed with depression compared to ADHD. Particularly when there may be other conditions responsible for depressive symptoms. The criteria for diagnosing Major Depressive Disorder (commonly referred to as depression) is that the symptoms must not be caused by any other medical condition (American Psychiatric Association, 2022b). The ease of anti-depressant provision was likened to handing out candy:

> *"I think it should be easier to do. And I really think that like GP's shouldn't be giving out antidepressants like candy when it could be, nothing against antidepressants. They really helped me but the comparison of how easily you can get an antidepressant versus how hard it is to get the ADHD diagnosis, like how quickly you can be diagnosed with depression versus how quick that you can be diagnosed with ADHD. Like blows my mind." (#8)*

> *"And they hand out, the GP's and doctors handout antidepressants like it's candy, like, it is very easy to be prescribed that and it's kind of like that doesn't treat the main issue." (#5)*

Another systemic issue identified by some participants was in relation to the education system. In the education system, participants expressed concern over the way students with unconventional behaviour or learning needs are being treated. Punitive approaches were described as opposed to looking into the root causes.

> *"I think so much in our schooling system. We see kind of a naughty kid, as like someone to expel or get kicked out. That never happened to me. But like, [...] actually naughtiness is a sign of intelligence in some way. And we're not kind of asked, we're not doing learning assessments. We're not trying to get to know how to meet people's needs, we'd actually just try and get them out." (#9)*

Within the education system, there is an opportunity to combat delayed diagnoses and negative education experiences for students. However, teachers need to be supported and educated to identify difficulties associated with ADHD to set in motion processes toward assessment and support.

> *"So yeah, if it's picked up earlier in children, that's ideal, but it needs education and expansions to, to education. I guess sorry. It's educating teachers as to how to pick it up sooner, because again, like I said, in the school reports, the bright student who's distracted constantly. If someone had said*

> *something to my parents sooner, it might have been investigated a bit further and nothing might have come of it." (#1)*

> *"I think we need to seriously look at both our education system, but how we're treating neurodiverse people, and the judgments that are laid on to them. Because I only just feel like now that's lifting, and that's only because I've been able to access all these really expensive things." (#9)*

In relation to service delivery, a specialist deficit was highlighted by several participants as an inadequate feature of impact. Many participants detailed experiences of being unable to access assessment specialists in their area. For some, this was due to local specialists not having the capacity to take on more clients and for others, there were no specialists in their area.

> *"I told him I wanted to do telehealth, because at the time there was no one in [Location removed]." (#4)*

> *"I couldn't even see someone in [my region] I had a, it was online because the doctor was in Auckland" (#3)*

Some participants described having to wait long periods of time for their appointments once they had identified a service that had the capacity to assess them.

> *"I was like I can't even get a diagnosis like this is going to be at least at least two months. You know, that's the best case scenario. The other ones were like six months, January. one gave me a date of next October. Like it was like, you know, come on." (#4)*

The process for accessing assessment was an additional area needing revision as identified by participants. Through their own experiences of getting diagnosed, participants had learnt that the public system was dysfunctional and in need of increased resources.

> *"But what really needs to happen is to make diagnosis and just like the special authority appointments and things that you need to have every couple of years, they need to be more accessible, because like I said, I'm very, very fortunate that my brother was able to pay for it for me, but so many people aren't able to do that. And to have to try and rely on the public system when we were told that there's not even, it's so underfunded and so overstretched that they're not even taking adult ADHD cases anymore." (#10).*

Participant 4 suggested revising the policies which restrict diagnostic capability to psychiatrists and clinical psychologists.

> *"I think there needs to be more access, like, availability for the public system, where you don't have to sort of go through like crisis teams and things like that, to be eligible for any sort of assessment, or at least some funding towards private, so that people are able to access it at a lower cost." (#4)*

The process of Special Authority was identified by several participants as an unnecessary procedure that is accompanied with an additional financial burden. Special Authority approval is required by PHARMAC, the government agency in New Zealand which manages the funding of medications. This process is due to the 'controlled drug' classification of stimulant medication prescribed to treat ADHD (PHARMAC, 2023). Special Authority is provided when an individual is first diagnosed with ADHD, and then expires after 24 months (Ministry of Health, 2023). Individuals with ADHD are required to undergo another appointment with a specialist to assess whether they continue to meet the criteria of Special Authority.

> *"So it's just like, having to get reassessed every two years, it's just ridiculous. And again, costly" (#5)*
>
> *"having to get your scripts looked at every couple of years and renewed. Yeah, I don't know if that's just because I don't understand the reasoning why, but that definitely seems like something that should be changed in my mind. Because if you've been diagnosed, you know, you have an issue and you need those things, especially after being on them for a couple of years." (#7)*

As suggested by Participant 1, the requirement for Special Authority renewal is an unnecessary drain on the capacity of a system that is already under resourced. Removing this requirement may result in increased capacity.

> *"I think if we removed or changed the way we did special authority, so that people don't have to go to a psychiatrist every two years, using that resource for something that isn't really necessary, frees up that psychiatrist to see other people and diagnose them. I think that's weird. And it doesn't make complete sense that you have to go back to a psychiatrist after two years, because it's not like your ADHD is going away." (#1)*

For Participant 5, increasing the variety of medications available to treat ADHD was a necessary improvement, particularly for individuals who find the current available medications ineffective:

> *"we don't have enough med options available here." (#5)*

Participant 2 perceived the current approach to support as an area for improvement, he suggested a form of wraparound support:

> *"but where I do see an opportunity is the after diagnosis report? You know, there could be a database or registry of people with diagnoses, and you know, there could be a counsellor, you know, sort of just reaching out checking on what other support you could use or whether you know, and giving you a whole bunch of resources, perhaps?" (#2)*

Lastly, access to information about ADHD and the process to get support was an aspect that was perceived as in need of improvement. Relying on information from GP's was considered to be insufficient particularly as it required GP's to hold relevant up to date information.

> *"I think more information would help like more awareness of what ADHD actually is. Because you tell.. people's doctors don't even understand ADHD." (#3)*

> *"I couldn't find much information about the process. [...] It was just like, Yeah, I think it's like, I guess, ultimately, educational information might be necessary." (#4)*

When reflecting on these aspects of the system that needed attention, most participants described a positive aspect of the current system. Chloe Swarbrick, a member of New Zealand Parliament, was described as a vessel of hope for participants due to Chloe's openness about living with ADHD and her efforts to push ADHD matters forward in Government.

> *"Chloe Swarbrick is doing a great job. Great to have an ADHD advocate in politician and politics." (#3)*

> *"I feel like she's almost taken this fight on in a very public manner. And she doesn't have a lot of support, in a sense. She's one person who's very loud and doing a fantastic job with it. But we need more people being loud and talking about how this is a struggle, how to fix them how it's a problem, just the diagnosis in general, as well as the things lacking in our system. We need more voices out there talking about it." (#1)*

In summary, many participants felt misunderstood by society due to the lack of awareness and the expectation to meet social conventions. Participants experienced their difficulties being attributed to negative characteristics. The expectation on ADHD people to not exhibit ADHD behaviour demonstrated ableist belief systems within society. Participants also felt that the reality of ADHD was not well understood, and general awareness was full of misconceptions. A range of systemic issues were identified as in need of repair, due to their detrimental effects and lack of suitability for the population.

Chapter 5: Discussion

The aim of this study was to explore access to ADHD assessment and supports for adults in Aotearoa and to develop an understanding of the impact of receiving a diagnosis in adulthood. This was achieved through interpreting the sense-making of adults with lived experience. My own lived experience provided the lens in which interpretation occurred which is paramount for IPA (Smith et al., 2022). The knowledge generated by this study is centred on lived experience, an expression of the 'nothing about us, without us' disability rights slogan and part of disability policies here in Aotearoa (Office for Disability Issues, 2016b). The imperative for this study was borne out of access concerns raised in news articles, an online community for adults with ADHD in Aotearoa expressing frustration and in some cases helplessness at policies that make it difficult for adults to seek a diagnosis, and a lack of research out of Aotearoa in this area. The findings of this study illuminate a reality that begs for attention and address. This chapter provides an exploration of the findings of this study and the implications of this research.

5.1 Summary of Findings

The participants in this study lived the entirety of their childhood and adolescence with undiagnosed ADHD. All participants struggled with being misunderstood during their younger years by others including their peers, teachers, and parents. Feedback provided in school reports had an impact on the self-perceptions of participants. This occurred through the adoption of negative self-descriptions and inferior self-concepts. The link between ADHD and low self-esteem in childhood and adolescence has been identified in several studies (Capelatto et al., 2014; Klimkeit et al., 2006; Mazzone et al., 2013). Further to this, Harpin and colleagues (2016) found an association between untreated ADHD and lower long-term self-esteem across childhood and adulthood. Difficulties were also experienced in employment settings. Within the work environment, participants went from job to job and struggled with engagement. This support other research that suggests people with ADHD are more likely to experience employment difficulties such as job searching, participating in interviews, and job performance (Zalsman & Shilton, 2016; Gordon & Fabiano, 2019) and that employment challenges also arise for individuals with ADHD through being unable to meet their own standards, even though performance evaluations were not negative (Fuermaier et al., 2021). These difficulties with work and education had long lasting impacts on participants' self-perceptions. Negative self-perceptions were common, which further developed into mental distress for many participants which has been highlighted in other research (Faraone et al., 2021, Zalsman & Shilton, 2016). Once reaching a catalyst, and following a newfound awareness of ADHD, participants embarked on a help-seeking journey.

All participants were unable to access assessment through the public health system (even though assessment pathway was not an eligibility factor for this study). Access to assessment through the public health system was only provided in the most severe cases forcing participants to engage with private specialists. The private pathway was expensive and having access came with a sense of privilege for those who could afford it, and luck for those who were able to obtain the financial resources through other means.

This has been shown in some other research (e.g. Best, 2022; McCarthy, 2021). For some, even the private system was challenging to navigate. The expense and getting a referral remain significant barriers for adults seeking a diagnosis.

Once diagnosed, participants grappled with a range of emotions while they processed the lack of identification earlier in life. While diagnosis brought relief and self-understanding, it also came with grief for the years of difficulties they had experienced. The most common impact of being diagnosed late in life was grief for ‘what could have been’. This supports the findings of Young and colleagues (2008) in relation to the emotional processing of adult diagnosis. There were positives to getting a diagnosis for these participants including a sense of relief and a level of sense making and re-creating an identity with a new sense of purpose as found by Sedgwick and colleagues (2019). What was universally mentioned was the systemic barriers to diagnosis including stigma, health (including mental health systems), lack of education for professionals and within the community. The participants made sense of their experiences through their personal journeys, their interactions with others and their interactions with the world at different times and life stages. ADHD was considered misunderstood in society through limited awareness of ADHD, misconceptions, and ableist ideologies (Jones & Heiss, 2018). Participants were expected to demonstrate neurotypical behaviour, which exposed ableist belief systems within society. A range of systemic issues impacted participants and there was concern for how these issues may affect others in the community.

5.2 The Impact of Late Diagnosis

One of the fundamental questions underpinning this research related to the impact of being diagnosed later in life with ADHD. Being diagnosed in adulthood meant that there was a significant period where participants experienced life undiagnosed. The findings demonstrated a nuanced intersecting system of factors that impacted the adults in this study. The participants made sense of their journey from interactions with friends, families, schools, peers, and then with health providers (including mental health) in dynamic and intersecting ways. All these factors contributed to their sense making of their identity prior to diagnosis and after diagnosis (Jones & Heiss, 2018; Long & Coats, 2022; Murray, 2021). Being undiagnosed meant that participants were not understood by others or themselves which impacted self-esteem (Attoe & Climie, 2023). The way participants were perceived fed into their own self-perceptions. Neuronormativity and ableism were the basis for the on-going struggle with self as participants made sense of themselves in relation to social, community, health, and educational norms and expectations.

This research found that inadequate awareness and education regarding ADHD contributes to delays in diagnosis for many people with ADHD. These delays are leading to distress, problems with identity and life-long impacts which are compounded by neurotypical norms and expectations. If changes are to be made, then addressing the issues through the lens of ableism allows us to challenge these norms. Not getting a diagnosis and support is dis-abling.

5.2.1 Ableism, Neuronormativity, and The Self

The findings of this study highlight the existence of ableism in the lifeworld of people with ADHD prior to, during and after diagnosis. The expectation to participate in society and demonstrate a preferred type of human form is an expression of ableist ideology. Ableism is a belief system based on social norms that grants acceptance to conventional ability (Gappmayer, 2021). Displaying conventional behaviours and skills is the ideal, falling outside of social convention reduces the recognition of human status (Gappmayer, 2021). A succinct definition posited ableism as:

> a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human (Campbell, 2001, p. 44).

For the participants prior to diagnosis, from childhood they were expected to meet social conventions and display the skills and behaviours of other children based on a set of neurotypical norms. Through the lens of the neurodiversity paradigm, these social norms have been referred to as neurocognitive norms and describe outliers as "neuro-minorities' marginalised by a 'neuronormative' organisation of society in favour of the 'neurotypical" (Chapman, 2020, p. 58). Neuronormativity describes a belief system that idealises neurotypical ("normal") cognition and considers neurotypicality to be correct and natural (Bolton, 2023). For the participants when these standards were not met, negative characteristics were attributed to the child and in this context, being a good child is associated with being 'able' and being 'able' requires the absence of ADHD. This sense of not measuring up had long-lasting impacts on self-concept, self-esteem, and well-being.

The self-awareness presented here supports the findings of Klimkeit and colleagues (2006) that children with ADHD have self-awareness. It is possible that the self-awareness of children with ADHD paired with social persecution contributed to the negative conclusions of self highlighted in the findings of this study. The link between ADHD and low self-esteem has been well established in the literature (Attoe & Climie, 2023; Capelatto et al., 2014; Klimkeit et al., 2006; Mazzone et al., 2013). This research suggests that ableism is a significant factor in the development of low self-esteem among individuals with ADHD. Diagnosis may mitigate this impact for two reasons, 1) diagnosis provides self-acceptance as highlighted in this research and other studies (Hamad et al., 2015; Lefler et al., 2016); and 2) adults with diagnosed ADHD were found to have better self-esteem than adults with undiagnosed ADHD (Pawaskar et al., 2020).

This pattern of expectation of neuronormativity continued throughout the lives of participants within social, educational and employment settings. In all these settings, differences had been identified by others through pointing out the skills and abilities that participants should be exhibiting, yet ADHD had not been identified by others or the participants. Thus, the participants had no way of understanding the difficulties they were experiencing but they were certainly aware they were not meeting expectations. Receiving a diagnosis provided partial respite to the participants as it gave them self-acceptance which meant they could begin to unpack the neuronormativity that had become internalised and the ways in which ableism had impacted them across their life. However, they still faced neuronormativity in the world around them expressed through a perpetuation of expectations and ignorance towards ADHD.

The impact of receiving a late diagnosis is compounded by ableism and neuronormativity within society. The findings of this study highlighted negative self-perceptions as an impact of being undiagnosed. Additionally, the findings demonstrated that negative self-perceptions are an impact of ableist, neuronormative attitudes. The social environment of participants idealised perfect behaviours, when participants were unable to meet these standards despite trying, they began to believe they were inherently bad, or inadequate. This presents as an expression of internalised ableism through desperate aspiration to meet social norms (Jóhannsdóttir et al., 2022). Participants highlighted how over time their self-perceptions had developed into mental health issues. An impact of late diagnosis was being disabled by the views of others – an expression of the social model of disability which posits societal barriers as disablers (Office for Disability Issues, 2016). In this view, ADHD is not a disability, but rather people with ADHD are disabled by societal barriers which in this context include ableist, neuronormative attitudes.

5.3 Access to Assessment and Support

This study was underpinned by an additional two questions which related to assessment and support. Particularly, how adults accessed these services, and how adults were affected by current access pathways in Aotearoa. During recruitment for this study, it was expected that adults who had accessed different pathways would participate and provide insights on the experiences of the available options. However, registration of interest was only received from adults who had accessed assessment through the private system. This provided an initial suggestion that the alternative publicly funded pathway was less prevalent, which was supported by the findings of this study. Further research is needed to quantify the rates of diagnosis through both the public and private pathways.

5.3.1 ADHD Healthcare

Given prior suggestions in the grey literature and anecdotal interactions, it was not surprising that significant barriers impacted access to assessment and support for adults with suspected ADHD. The findings suggested access to assessment is based on either privilege or crisis. To undergo an ADHD assessment, individuals must either be in a state of crisis to a level of severity deemed eligible for access through the public system; or have the financial means to self-fund assessment through the private system. Participants indicated that initial appointments through the private system were unaffordable and could cost between \$560.00 - \$800.00. To contextualise this significant cost, 32.2 percent of households in Aotearoa reported insufficient or only just enough income to cover daily needs in data from 2022 (Stats NZ, 2023). The cost of private assessment would be out of reach for at least one third of the population in Aotearoa. Participants recognised this and many felt a sense of privilege, while some participants attributed luck to meeting these costs due to support of family or a sudden windfall. This finding of diagnosis determined by privilege supports findings of another Aotearoa based study exploring the experiences of women with ADHD (Best, 2022). The feeling of privilege was something I personally related to through my own experience in being diagnosed with ADHD as an adult. In our online community, the cost of assessment and the desperation for support are common cries and as such, became a driving force for this study. I wondered if the health system knew about this or knew about us and the plight of having undiagnosed ADHD.

5.3.2 The Ambulance at the Bottom of the Cliff

There are several salient concerns with the current assessment systems. Firstly, a public system which responds to severity rather than need operates through an ambulance at the bottom of the cliff approach. Jones and colleagues (2009) suggested the "cliff analogy" as a model for understanding levels of health intervention. The ambulance at the bottom of the cliff represents acute medical care responding to those who have fallen. The problem with sole reliance on the ambulance at the bottom of the cliff is that there is harm caused in falling off the cliff and there may not be enough ambulances to respond in a timely manner. In the Aotearoa context, the ambulance is Adult Mental Health and Addiction Services which "are funded to support people with the highest mental health and addiction needs, and often people experiencing ADHD do not meet the high threshold for access" (Ministry of Health, 2022b, p. 3). Within the cliff analogy, nets and trampolines could be placed halfway down the cliff to reduce harm for those who have fallen, representing secondary prevention. Preventing people from falling off the cliff would reduce harm and so a sturdy fence could be placed at the top of the cliff representing primary prevention. People will need to be moved away from the edge of the cliff to prevent overcrowding the fence, which represents "addressing the social determinants of health" (Jones et al., 2009, p.3). The levels of health intervention for ADHD in Aotearoa consist of too few ambulances at the bottom of the cliff (publicly funded mental health and addiction services) and a private helicopter (private services) which may take a while to arrive due to high demand and limited capacity and has a high cost for the individual. There are no nets, trampolines, or fences which places pressure on both ambulances and private helicopters.

Limited intervention strategies expose the second concern, what level of severity is severe enough? Will the required level of severity inflate with increasing demand? What happens when severity or level of need is perceived incorrectly by health practitioners? What happens to those left at the bottom of the cliff? The risk of poor mental health has been identified in a multitude of studies (Faraone et al., 2021; Ogrodnik et al., 2023; Zalsman & Shilton, 2016) in addition to high rates of co-occurring mental health conditions (Balazs & Kereszteny, 2017; Diallo et al., 2022; Rucklidge et al., 2014). Higher rates of suicidality have also been identified in previous studies (Balazs & Kereszteny, 2017; Fuller-Thomson et al., 2022; Giupponi et al., 2020; Sultan et al., 2021). The ambulance at the bottom of the cliff approach is grossly inadequate and misguided considering the evidence of risk. This research has shown the lifelong impact of getting a late diagnosis and has illuminated the need for current policies to be revised in consultation with the ADHD community. This would be in line with disability policies and mental health policies to include people with lived experience in all levels of decisions. This is incredibly important to address the issues raised in the this and the previous section.

5.3.3 In Breach of the UNCRPD

In signing and ratifying the UNCRPD, the New Zealand Government committed to take up obligations and legal rights set out in the Convention. As stated in Chapter 1 of this report, disabled people have a "right to the enjoyment of the highest attainable standard of health" (United Nations, 2006, p. 16). The findings of this study suggest that adults with ADHD in Aotearoa are being denied this right. The ambulance at the bottom of the cliff approach means that it is not possible for early identification and intervention to occur creating a risk of further disability through its level of severity criteria. This finding suggests a potential breach of Article 25(b)[6] of the UNCRPD. The alternative pathway to identification and intervention occurs through the private system which is financially inaccessible for a larger portion of the population and is also hampered by excessive wait-list times. Reliance on the financially inaccessible pathway would seem to breach Article 25(a)[7] of the UNCRPD.

5.4 Changing the System

In response to an evidently problematic system, participants identified a range of issues that affected them and recommendations to improve ADHD healthcare for themselves and for other people seeking support. The systemic issues and recommendations suggested by the participants in this study are set out in Table 5.

5.4.1 Promised Change

At the same time as this study was being conducted, a petition was presented to parliament on the 10th of August 2022 carrying 2890 signatures. The petition was created by Laura Williams and asked the New Zealand Government to increase funding for ADHD diagnoses to address financial inaccessibility and to investigate barriers to access and prioritise early intervention. The Health Committee considered the petition and accepted submissions prior to responding to the petitioner. While acknowledging the importance of the matter, the Health Committee concluded their response by explaining:

> *We were pleased to hear that health agencies and other stakeholders are working together to improve outcomes and reduce barriers for people with ADHD or who suspect they have ADHD. We also acknowledge that work is being done to develop a nationally consistent pathway for assessing and treating ADHD.* (Health Committee, 2023, p. 6)

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[6] Article 25(b) "Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons" (United Nations, 2006, p. 16)

[7] Article 25(a) "Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes" (United Nations, 2006, p. 16).

Table 5

Summary of Systemic Issues and Recommendations

Issues	Recommendations
The risk to mental health from struggling with unidentified and undiagnosed ADHD	Fast track improvement of access to assessment
Being treated for depression rather than ADHD	Health practitioners should investigate all possible causes for mental health concerns.
Punitive treatment and exclusion of non-typical behaviour in the education system	Educate and support teachers to identify difficulties that are symptomatic of ADHD so children can be supported and understood and so ADHD can be identified early in life. Improve the education system so it is accessible and safe for neurodivergent people.
Lack of specialists providing ADHD assessments	Revise the policies which restrict diagnostic capability to psychiatrists and clinical psychologists
Lack of access to assessment	Increase funding for ADHD Healthcare through the public system and provide funding toward access through the private system.
Special Authority requirement is expensive and places additional pressure on the system	Remove this requirement to reduce the financial burden on people with ADHD and to increase the capacity of assessment services.
Limited options for ADHD medication which impacts people who do not respond to the current available medications	Increase the medication options available in Aotearoa.
Lack of non-medical support following diagnosis	Develop a wraparound approach to support
Lack of information about the assessment process and lack of awareness of ADHD	Increase public information about ADHD healthcare and increase the awareness of ADHD among health practitioners.

The collaboration identified by the Health Committee was the Arorerétini Programme Reference Group (APRG) involving ADHD NZ, members from a variety of government agencies and ministries and with support from Member of Parliament, Chloe Swarbrick. The APRG met in August 2022 to discuss initiatives to address the issues faced by the ADHD community when attempting to access diagnosis and support. The APRG agreed to the six initiatives presented in Table 6.

Since work on these initiatives begun, changes to the Misuse of Drugs Act 1975 have been made to allow three-month prescriptions of ADHD medication, meaning individuals with ADHD will no longer have to order a prescription every month (Ministry of Health, 2023b). However, this new change is only applicable through electronic prescribing which private clinics are still now allowed to use. It is understood that many of the initiatives will take a considerable amount of time to progress (Health Committee, 2023).

Table 6

Summary of Initiatives to Improve Access to Diagnosis and Support

Initiatives	Resulting Outcomes/Actions
1. Improving access to ADHD medicine by addressing issues with special authority renewal and considering new medicines not currently available in NZ.	Pharmac and the Ministry of Health have agreed to look at changes to special authority rules. Pharmac, with input from RANZCP, will investigate access to new medicines
2. Increasing the understanding of ADHD in Aotearoa through better data and research at both a macro and micro level.	
3. Building a consistent model of service for supporting those with ADHD across Aotearoa as part of the health sector reforms.	Te Whatu Ora has agreed to collaborate with providers to develop a consistent and quality model of service for assessment and support for ADHD as part of the health sector reforms.
4. Adopting new medical practice guidelines for ADHD.	The RNZCGP, NZCCP and RANZCP will investigate endorsing the Australian ADHD Professionals Association (AADPA) guidelines in the interim with a view to tailoring for our local context – especially in terms of Te Tiriti recognition. Australia's guidelines were developed in consultation with RANZCP and ADHD NZ believes these guidelines are world leading.
5. Establishing an ADHD reference group with representation from government agencies, medical professionals and ADHD NZ to improve collaboration and information sharing and support the implementation of this programme of improvements.	ADHD NZ has taken responsibility for this action point. Without this central point of collaboration there is a risk that the proposed actions will lose momentum and will fail to achieve the intended outcomes. Also it is important that all of these actions are connected and developed within the context of a wider health system.
6. Delivering quality ADHD training for healthcare practitioners Including GPs, clinical psychologists, paediatricians and psychiatrists to ensure their understanding of ADHD remains up to date.	Each of the colleges will begin upskilling their workforces with ADHD specific training – possibly drawing on AADPA training. This will be consistent across all colleges.

Note. Adapted from documents released by the Ministry of Health as requested under the Official Information Act 1982 (Ministry of Health, 2023b, p. 4).

5.5 Implications

This research found adults face barriers when attempting to access ADHD diagnosis. In addition, non-medical support (psychological support) was almost absent and relied on adults with suspected ADHD sourcing their own supports. Access to assessment was predicated on severity or privilege due to a two-tier health system which consists of a public pathway and a private pathway. The public pathway operates from an ambulance at the bottom of the cliff approach. The implications of this approach put people with ADHD at risk, given the increased risk mental health issues, suicidality, and co-occurring mental health conditions. The participants in this study were resoundingly clear in identifying this risk and communicated the importance of changing current approaches. Reliance on the ambulance at the bottom of the cliff may result in preventable casualties, although this is not empirically evident. In a country like Aotearoa that takes pride in a public health system, public healthcare must be extended to people with suspected ADHD. By the Ministry of Health’s own admission, people who suspect they have ADHD are often not eligible for access through the public system due to significant pressure on these services. It is clear this is an area that requires prioritising in terms of resourcing. None of the participants of this study were able to access the public pathway and so embarked on the private pathway to diagnosis. The private sector is also under resourced and financially inaccessible resulting in long wait times and often requiring telehealth consultations as opposed to in person.

These findings suggest that the New Zealand Government may be in breach of their obligations under the UNCRPD regarding people with ADHD and their right to early identification and intervention. Having ratified the convention in Aotearoa, the New Zealand Government have actioned a commitment to realising, promoting, and protecting the rights of disabled people. However, the unfortunate reality seems that people with ADHD or suspected ADHD are left wanting. The New Zealand Government has communicated intentions to address some of the systemic issues faced by people with ADHD in Aotearoa. The findings of this study suggest recommendations for improvement from the perspective of adults with ADHD, and an imperative to make these changes happen.

This research uncovered an interesting and concerning intersecting impact of being diagnosed in adulthood, through providing an insight of undiagnosed ADHD. Experiences of undiagnosed ADHD exposed ableist and neuronormative societal attitudes which ostracised individuals with ADHD for the inability to conform to social expectations. The constant reinforcement of difference and failure developed into negative self-perceptions and for many participants, developed further into mental distress and mental health conditions. Participants expressed this through describing the psychological harm they experienced as a result. An implication of these findings is the effect of neuronormativity on the wellbeing of people with ADHD. Additionally, this research highlights the importance of early identification and intervention of ADHD to prevent the development of negative self-perceptions and preventable mental distress and to support self-acceptance and the potential for support. Further research could investigate whether early diagnosis mitigates neuronormative expectations and punitive treatment through exploring experiences of late diagnosed adults and adults diagnosed in childhood.

While the findings relating to access to ADHD healthcare were unsurprising and will come as no surprise to the ADHD community, it is hoped that they will provide insight to government agencies embarking on initiatives to improve service provision for people with ADHD. Additionally, the findings contribute to the growing field of ADHD research which prioritises the voice of people with ADHD in an expression of the disability rights movement call – Nothing about us, without us.

5.6 Conclusion

In Aotearoa, adults with ADHD/suspected ADHD face barriers when attempting to access assessment and supports for ADHD. None of the participants in this study were eligible for publicly funded assessment due to a lack of capacity and priority given to the most severe cases. The findings demonstrated an ambulance at the bottom of the cliff approach to health care. Participants were diagnosed through self-funded private specialists, they acknowledged that this pathway is expensive and is inhibited by wait lists, and many others are unable to access private specialists. The participants in this study described a health system that was not serving them as it should. The findings highlighted a concerning reality for those who are undiagnosed but suspect their life trajectory has been impacted by neurodivergence and cannot afford private assessment and cannot access publicly funded assessment.

This research contributes to the emerging neurodiversity paradigm through the suggested impact of neuronormativity on people who grow up with undiagnosed ADHD. Negative self-perceptions were developed in response to constant demands to fit the mould, and to operate within neuronormative expectations. Negative self-perceptions were exacerbated by reinforcement by others of their failure to comply. Mental distress and the development of mental health conditions were common among participants due to exposure to ableist and neuronormative attitudes and the absence of early diagnosis, preventing the opportunity for self-understanding and connection with others of a similar neurotype.

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Appendices

Appendix A: Advertisement

Research project exploring access to ADHD assessment and support/treatment

Kia ora koutou,

My name is Eden, and I'm studying a Master of Arts through Massey University, majoring in Psychology. A while ago I posted in this group when I was considering a thesis topic, wondering if anyone would be interested in sharing their experiences of getting diagnosed with ADHD in adulthood and experiences of seeking support. A lot of you were interested so I've put in the mahi to get this project started.

My thesis will explore the experience of accessing ADHD specific assessment and support/treatment in adulthood in Aotearoa; the impacts of the current pathways and the impacts of late diagnosis, misdiagnosis and/or missed diagnosis of ADHD.

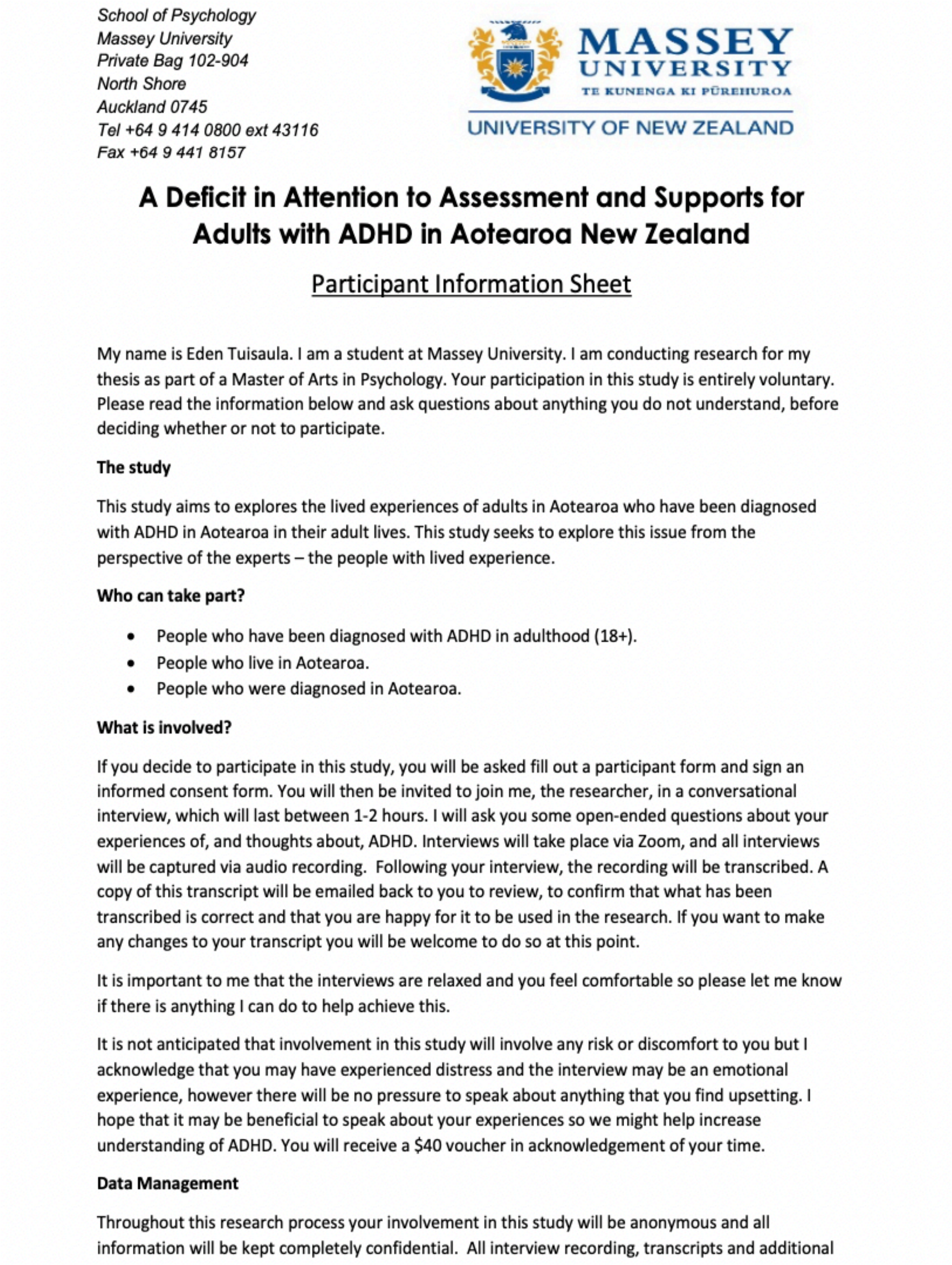
As this is a thesis, I am limited by time and resources as to how big this project can be so at this time I am only able to hear from people who have been diagnosed as adults (18+) in Aotearoa and who live in Aotearoa.

I recognise that there are so many valid experiences that may not be able to be included in this project and there will be an opportunity in the future to conduct a bigger project, inclusive of these experiences.

If you are an someone who has been diagnosed with ADHD in adulthood and in Aotearoa, and you would like to share your experiences to inform this research, please check out the attached file for more information and my contact details.

Ngā mihi nui, thank you!

Appendix B: Participant Information Sheet



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A Deficit in Attention to Assessment and Supports for Adults with ADHD in Aotearoa New Zealand

Participant Information Sheet

My name is Eden Tuisaula. I am a student at Massey University. I am conducting research for my thesis as part of a Master of Arts in Psychology. Your participation in this study is entirely voluntary. Please read the information below and ask questions about anything you do not understand, before deciding whether or not to participate.

The study

This study aims to explores the lived experiences of adults in Aotearoa who have been diagnosed with ADHD in Aotearoa in their adult lives. This study seeks to explore this issue from the perspective of the experts – the people with lived experience.

Who can take part?

- People who have been diagnosed with ADHD in adulthood (18+).
- People who live in Aotearoa.
- People who were diagnosed in Aotearoa.

What is involved?

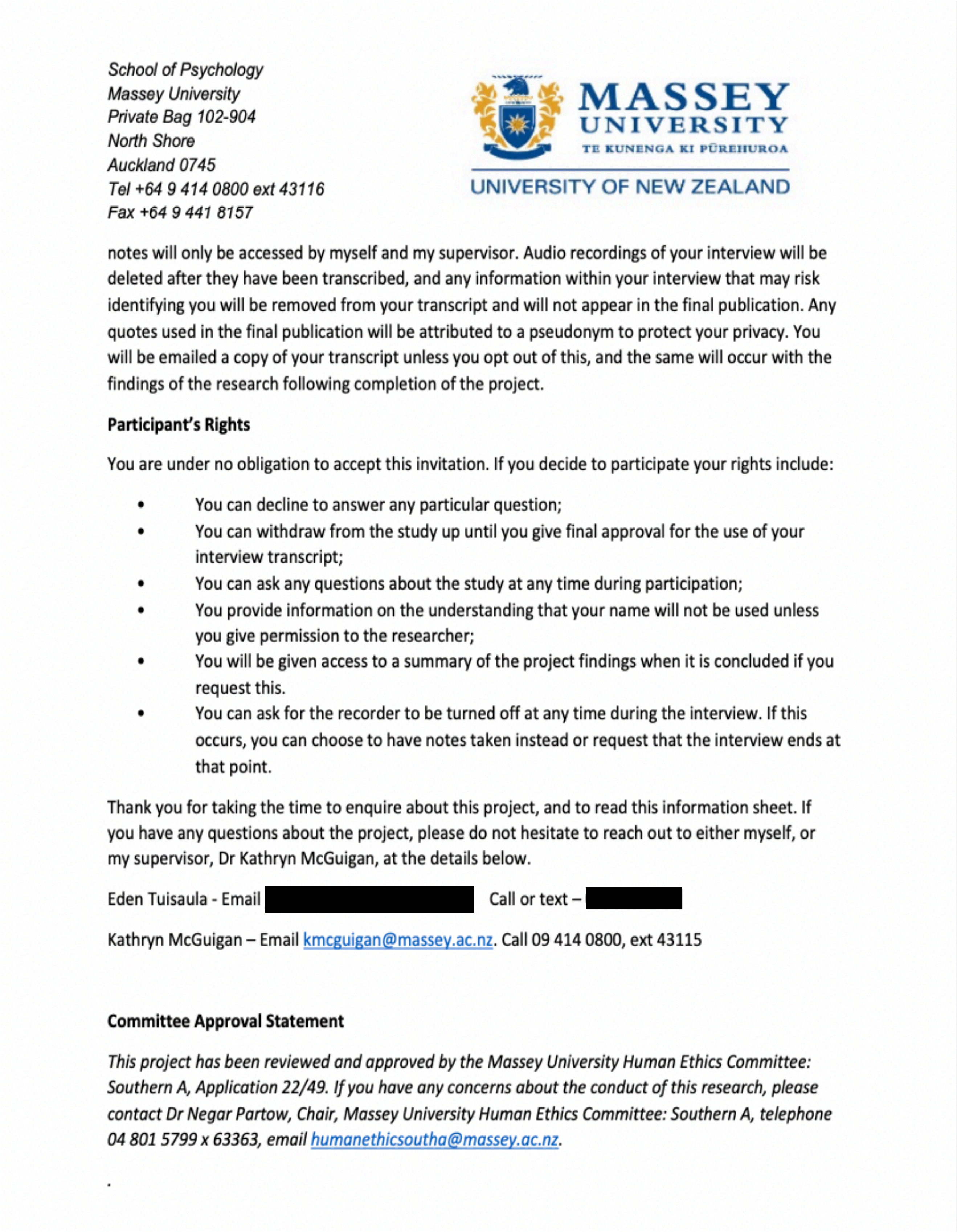
If you decide to participate in this study, you will be asked fill out a participant form and sign an informed consent form. You will then be invited to join me, the researcher, in a conversational interview, which will last between 1-2 hours. I will ask you some open-ended questions about your experiences of, and thoughts about, ADHD. Interviews will take place via Zoom, and all interviews will be captured via audio recording. Following your interview, the recording will be transcribed. A copy of this transcript will be emailed back to you to review, to confirm that what has been transcribed is correct and that you are happy for it to be used in the research. If you want to make any changes to your transcript you will be welcome to do so at this point.

It is important to me that the interviews are relaxed and you feel comfortable so please let me know if there is anything I can do to help achieve this.

It is not anticipated that involvement in this study will involve any risk or discomfort to you but I acknowledge that you may have experienced distress and the interview may be an emotional experience, however there will be no pressure to speak about anything that you find upsetting. I hope that it may be beneficial to speak about your experiences so we might help increase understanding of ADHD. You will receive a $40 voucher in acknowledgement of your time.

Data Management

Throughout this research process your involvement in this study will be anonymous and all information will be kept completely confidential. All interview recording, transcripts and additional



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notes will only be accessed by myself and my supervisor. Audio recordings of your interview will be deleted after they have been transcribed, and any information within your interview that may risk identifying you will be removed from your transcript and will not appear in the final publication. Any quotes used in the final publication will be attributed to a pseudonym to protect your privacy. You will be emailed a copy of your transcript unless you opt out of this, and the same will occur with the findings of the research following completion of the project.

Participant's Rights

You are under no obligation to accept this invitation. If you decide to participate your rights include:

- You can decline to answer any particular question;
- You can withdraw from the study up until you give final approval for the use of your interview transcript;
- You can ask any questions about the study at any time during participation;
- You provide information on the understanding that your name will not be used unless you give permission to the researcher;
- You will be given access to a summary of the project findings when it is concluded if you request this.
- You can ask for the recorder to be turned off at any time during the interview. If this occurs, you can choose to have notes taken instead or request that the interview ends at that point.

Thank you for taking the time to enquire about this project, and to read this information sheet. If you have any questions about the project, please do not hesitate to reach out to either myself, or my supervisor, Dr Kathryn McGuigan, at the details below.

Eden Tuisaula - Email [redacted] Call or text – [redacted]

Kathryn McGuigan – Email kmcguigan@massey.ac.nz. Call 09 414 0800, ext 43115

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 22/49. If you have any concerns about the conduct of this research, please contact Dr Negar Partow, Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63363, email humanethicsoutha@massey.ac.nz.

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Appendix C: Participant Interest Form

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A Deficit in Attention to Assessment and Supports for Adults with ADHD in Aotearoa New Zealand

Participant Interest Form

Full Name: ____

Address: ____

____

Email: ____

Phone: ______________________

Gender: ______________________ Pronouns: _____________________________

Age: ______

Ethnicity: ____

Have you been diagnosed with ADHD in Aotearoa? Yes/No

What age were you when you were diagnosed with ADHD? ______

Do you have any accessibility requirements you would like me to know about?

____

Do you have any cultural protocols you would like followed during our interviews?

____

Appendix D: Informed Consent Form

Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

A Deficit in Attention to Assessment
and Supports for Adults with ADHD in Aotearoa New Zealand

Please tick to indicate you consent to the following:

I have read, or have had read to me, and I understand the Participant Information Sheet.		
I have been given sufficient time to consider whether or not to participate in this study.		
I have had the opportunity to have whānau/ family support or a friend to help me ask questions and understand the study.		
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.		
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting me in any way.		
I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
I consent to my interview being recorded.	Yes ☐	No ☐
I know who to contact if I have any questions about the study in general.		
I understand my responsibilities as a study participant.		
I wish to receive a summary of the results from the study.	Yes ☐	No ☐

Declaration by participant:
I hereby consent to take part in this study.

Participant's name: ______________________________

Signature: ______________________ Date: ______________

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

Appendix E: Transcript Release Form

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AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: .... **Date:** ....

Full Name - printed ....