Whānau Māori and Their Experiences of Attention-Deficit/Hyperactivity Disorder: Implications for Clinical Practice

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Abstract

Health care in New Zealand (NZ) is based on the ideal of universal health coverage for all. However, for many Māori health inequities exist in health outcomes and in access to services which adequately meet the needs of whānau Māori. Researchers have considered explanations (and solutions) for this situation, including whether health services are able to meet the cultural needs of Māori clients through a more holistic approach. Rather than considering this generally for all services, this research considers this specifically in relation to Attention-Deficit Hyperactivity Disorder (ADHD). Alongside core symptoms of hyperactivity, impulsivity, and inattention, for there to be a diagnosis of ADHD there must be associated functional impairment and diffuse impact of behavioural symptoms in multiple domains of a person's life. This means that ADHD is well suited to the application of holistic understandings of wellbeing, such as those that exist in mātauranga Māori. A lack of research about ADHD among Māori highlights a need for research which explores the experiences of tamariki Māori and their whānau as they navigate ADHD diagnosis and treatment. This research used a Māori-centred framework and throughout, was guided by He Awa Whiria (Gillon & Macfarlane, 2017) which emphasises the importance of drawing together cultural and clinical knowledge. There were three main objectives: to understand the experiences of whānau Māori with a child assessed and treated for ADHD; to describe how whānau understood and accommodated ADHD behaviours before diagnosis; and to identify any barriers or facilitators for whānau Māori in accessing assessment and/or treatment. Semi-structured interviews took place with 10 whānau members, representing 13 young people who had been diagnosed with ADHD. The interview responses were analysed using (codebook) thematic analysis. The main findings revealed firstly that there were different levels of knowledge about ADHD among caregivers and some whānau struggled to know where to begin, to get support; secondly, it was difficult to access the service, and there was a lack of ongoing support available other than medication; and thirdly, while in all cases medication was offered as treatment, whānau found this a difficult decision to make for their child, preferring a more holistic approach. Most whānau were not asked about their cultural background or beliefs during assessment and half of the participants would have accessed a kaupapa Māori service if available. The implications of the findings for clinical practice are discussed with recommendations for how to blend cultural and clinical knowledge to ultimately benefit whānau Māori and achieve the best possible outcomes.

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Taumārere herehere i te riri

Te rere i Tiria

Te puna i Keteriki

Keteriki, kete tangariki

Ko Ngāti Hine pukepukerau

This whakatauākī is attributed to Hineamaru, te tupuna o Ngāti Hine iwi and a leader of great mana. It references the sacred Taumārere river and the many tributaries which flow through the pukepukerau ('one hundred hills') of Ngāti Hine. This kōrero speaks of tuna (eels) and their journey upstream as tangariki (elvers or juvenile eels), where they eventually come to a waterfall at a place called Otiria. The local people would gather the tangariki up in kete and keteriki (kits or baskets) and lift them to the top of the waterfall to help them on their journey.

To the iwi of Ngāti Hine, of whom I belong, this whakatauākī means significantly more than the direct translation of its component parts. Instead, as a kupu whakarite used by Ngāti Hine, this kōrero urges the people to work together in the interests of the greater good. This kōrero also represents pakeke (adults) supporting rangatahi (youth) and is thus, a kupu whakarite for this rangahau (research). This epitomises my goal of expanding and improving the options we have available to uplift our young people during challenging times; to ultimately support te iwi Māori to flourish.

This thesis would not have eventuated without the whānau who chose to share their experiences with me, and I have done my best to accurately represent their stories with their tamariki. The whānau who participated did this to support other whānau on their journeys and all of them at some stage talked about hoping for change. Nā reira, tēnei te mihi ki a koutou katoa, ngā whānau i kōrero mai ki ahau mō aku rangahau me te pēhea i pā ai ki a rātou aroreretini, tēnā koutou katoa. The experiences we have as whānau Māori navigating uncomfortable spaces and speaking up when they don’t adjust and fit around us; those are the voices I tried to represent here. That was the most important part of my rangahau, and I have given my best effort in the service of those whānau, in return for their trust and openness. Nau ahau i whakakipakipa.

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Ko Charlene Mereana Tipene tōku ingoa

Nō Mōtatau ahau

Tihei wā mauriora!

Māori Glossary

Aku	The cross beams of a two-hulled waka
Aotearoa	Māori name for New Zealand
'Aroha ki te tangata'	Respect for the people you are working with
Hapū	Kinship group; sub tribe; to be pregnant
Hauora	Wellbeing; health; spirit of life; vigour
Hui	Meeting; gathering
Iwi	Tribal grouping; extended kinship group; nation
Kaimahi	Worker; employee; staff
Kaitiaki	Guardian; custodian; keeper; caregiver
'Kanohi kitea'	'The seen face'; face-to-face
Karakia	Incantation; prayer; blessing
Kāwanatanga	Authority; governorship
Kaupapa	Topic; policy; plan; agenda; subject
Kaupapa Māori	Māori approach, Māori topic, Māori customary practice
Koha	Contribution; gift; donation
Kōhanga Reo	Māori language preschool; Māori language nests
Kōrero	Narrative; account; discussion; conversation
Kura kaupapa	Primary school operating under Māori and using te reo Māori as medium of instruction
Mahi tahi	To work together, collaborate, cooperate
Mana	Prestige, authority, control, power, influence, status, spiritual power, charisma; mana is a supernatural force within a person, place, or object
Mana Māori	Māori authority or power
Mana whenua	Regional authority by local iwi or hapū; customary title over land

Mātauranga Māori	Māori worldview; Māori knowledge; traditional knowledge; wisdom
Mātua whāngai	Foster parents; adoptive parents
Mauri	‘Spark of life’; the active component which indicates a person is alive; the source of emotions
Mihi	Greeting; pay tribute, acknowledge; thank
Mirimiri	Massage
Mokopuna	Grandchild; descendant
Ora	Alive; well, in health; safe
Pākehā	New Zealander of European descent
Pēpi	Baby, infant
Poroporoaki	Formal farewell
Rangatahi	Youth; adolescent; younger generation
Rangatiratanga	Chieftainship; authority; right to exercise authority; chiefly autonomy; chiefly authority
Rongoā	Remedy; medicine; treatment
Taitamaiti	Child (singular) of either gender
Tamariki	Children (plural)
Tamariki whāngai	Adopted children; foster children
Tamatāne	Son; boy
Tāne	Male; men
Tāngata whenua	‘People of the land’; home people
Taonga	Gift; treasure; anything which is prized or valued
Tautoko	To support; verify; agree
Te Ao Māori	‘The Māori world’; Māori cultural resources
Te reo Māori/te reo	The Māori language
Te reo me ona tikanga	Māori language and custom

Tikanga Māori	Protocols; correct procedure; custom, manner and practice, pertaining to Māori
Tino rangatiratanga	The fullest expression of rangatiratanga; autonomy; self-determination; sovereignty; self-government
‘Titiro, whakarongo, kōrero’	‘Observe, listen, speak’
Tohunga	Cultural expert; expert in traditional Māori healing approaches
Tūpuna	Ancestors; grandparents
Tūmanako pai	Hope, positivity
Tūrangawaewae	Place where one has rights of belonging through kinship and whakapapa; place where one has the right to stand
Wāhine	Female; women
Waka hourua	Two-hulled waka
Wānanga	Conference, forum, educational seminar
Whakamā	Embarrassment; shame
Whakapapa	Genealogy; connection to ancestors
Whakataukī	Proverb, significant saying (where the person who said it first is unknown)
Whakawhanaungatanga	Establishing connections and relationships
Whanaungatanga	Close connection between people; kinship
Whānau	Family and extended family; to be born; to give birth
Whāngai	Foster; adopt; nourish; nourish; raise
Whare	House

Introduction

Introduction to the research

As the Indigenous people of Aotearoa New Zealand (NZ), Māori have well-established knowledge systems and cultural practices; referred to in te reo Māori as mātauranga Māori and tikanga Māori respectively. As with other Indigenous cultures around the world, the ongoing process of colonisation has undermined mātauranga and tikanga Māori (Ashton-Martyn & O'Connell Rapira, 2018). One of the ways in which this manifests is in disparate and inequitable health and mental health outcomes for Māori (as compared with non-Māori) (Boulton & Gifford, 2014). Although these inequities are well documented in the literature and relevant health statistics, less is known about how best to rectify this situation. Māori have long sought autonomy and self-determination for their own health and wellbeing (Came et al., 2020). However, the reality is that Māori negotiate a healthcare system where most doctors and clinicians are from a different cultural background. Therefore, in identifying Māori-led solutions to rectify inequitable health outcomes, there is a need to consider how these solutions are then implemented in clinical practice by non-Māori clinicians.

In mātauranga Māori, health is holistic; being well and healthy is more than good physical health. Through a Māori lens, when there is a health or mental health concern and a strictly biomedical model is applied to treating this, this only deals with a limited aspect of wellbeing. As health inequities are also seen in reduced access to health services by Māori (relative to need) (Cunningham et al., 2018; McClintock et al., 2016), previous research has focused on Māori experiences of these health services to better understand some of the factors which contribute to service engagement. The NZ government has also undertaken recent nationwide reviews of the mental health, and health and disability sectors and sought Māori consumer perspectives as part of their inquiries (Health and Disability System Review, 2020; Paterson et al., 2018). Based on this information, one of the proposed explanations for reduced service access (and there were several) is that healthcare services do not adequately meet the expectations of Māori about how health issues are best treated (Paterson et al., 2018). This prior research broadly considered service access in general for any health concern and this produced general recommendations to consider when working with Māori clients. The question which was unanswered was how clinicians could incorporate this information in a meaningful way, into their practice.

With inequitable health outcomes and service access in mind, the current research explored the experiences of whānau Māori who were supporting a young person with Attention-Deficit/Hyperactivity Disorder (ADHD). The objectives were: to describe how whānau understood and accommodated the ADHD-related behaviours prior to diagnosis; to understand how these experiences impacted service engagement; and to identify barriers and facilitators for whānau Māori in the assessment and treatment of ADHD. The reasoning was that focusing on ADHD as a specific concern might produce more nuanced and specific insights into how clinicians could be more effective when working alongside whānau Māori.

ADHD is currently very topical, with social media renewing interest in ADHD in the media, as a research topic and as a diagnosis which people are familiar with (Boseley, 2021; Yeung et al., 2022). ADHD also has a contentious history mostly around concerns that ADHD can be misdiagnosed and used to medicalise and medicate deviant childhood behaviour (Kazda et al., 2021; Langager, 2014; Levy, 2013; Taylor, 2017). Consequently, ADHD is one of the most researched conditions of childhood. Yet only a minimal amount of this research has been done in NZ or with a focus on local considerations with regards to the diagnosis and treatment of ADHD. In addition, Māori-centred research which considers the needs of Māori experiencing ADHD is lacking and points to a gap in the literature which needs addressing.

Positioning the researcher

While the topic of this research is the experience of ADHD for whānau Māori, from a personal perspective this thesis is also about my work as a Māori clinical psychologist. As a Māori in a clinical psychology training programme, my career and research goals are to foster mental health services which are responsive to the needs of whānau Māori. This is what Durie (2011) describes as working at the cultural-clinical interface where Māori views of health and wellbeing are integrated with clinical assessment and treatment practices. As clinical psychology is informed by a scientist-practitioner model, I could not conclude I knew what the needs of Māori were without adequate research to support (or not support) my intuition and personal experience. And so, I researched an area which I identified as a gap in my training. I wanted to know how to move from general ideas about how best to work with Māori while being culturally sensitive, to specifics on how I could enact this in my practice as a Māori clinician.

I have Māori whakapapa and my upbringing was in a Māori family. I also have experience of raising a child who has ADHD. While my own experiences were helpful when conducting research with whānau Māori, I would certainly not call myself an expert on mātauranga and tikanga Māori. Therefore, as I carried out this research I have relied as much on conversations about the research topic with kaumatua, Māori colleagues, peers, supervisors, and my own whānau and friends, as I have on the writings and teachings of other researchers.

Thesis Outline

As motivation for this thesis two major topics were introduced; namely the background to the status of Māori health in NZ; and an explanation of ADHD and how this affects families in NZ. A review of the literature related to these topics is presented in chapters one through five. Chapter one gives an overview of the health system in NZ and discusses the disparate health and mental health outcomes experienced by Māori within this system. Chapter two presents historical factors which have contributed to inequities and discusses the role of Māori health frameworks in Māori self-determination and health promotion. Together, chapters one and two indicate that although health service access issues are well established as contributing to health inequities for Māori, there is no clearly identified resolution. Chapter three therefore considers the implications of this situation for clinical practice within health and mental health and the significance of blending cultural and clinical knowledge. Chapter four focuses specifically on ADHD and clinical best practice guidelines for the assessment and treatment of ADHD. Chapter five discusses the relationship between culture and ADHD, and how ADHD is managed in the NZ context.

The research objectives and questions this thesis set out to answer are introduced in chapter six, and the methodology for approaching these questions is outlined in chapter seven. The seven themes which were derived from interview data with whānau Māori are discussed in chapter eight. Finally, chapter nine discusses the information from this study in the context of existing literature, and the implications of the findings for clinical practice. This includes suggestions based on the findings for how current guidelines could be improved. This concludes with limitations of the current study, and suggested directions for future research.

Chapter One: The Status of Health Services in New Zealand

To foreground discussion of the context in which ADHD is assessed and treated, the current chapter commences with an overview of the health system in NZ. This includes an explanation of how mental health services (MHS) feature in the overall health system. The well-established concern about health disparities for Māori is then presented, followed by a discussion of the status of available public health services. The chapter concludes with an overview of proposed facilitators and barriers to Māori accessing MHS in general. This is relevant as one of the objectives of the current research is to identify similar factors which impede or support whānau Māori to access available support for ADHD. How inequitable health outcomes have contributed to recent (July 2022) health reforms is outlined in more detail in chapter two.

1.1. Introduction to the Healthcare System in New Zealand

NZ is said to provide universal health coverage for all citizens, as the healthcare system is mostly publicly funded, with a combination of free and subsidised care (Gauld, 2020). In NZ the government dominates all aspects of health care. This includes setting the health policy agenda, defining regulations, determining service requirements, monitoring compliance, and making decisions on the publicly funded annual health budget (Gauld, 2020).

Services covered by the public health system include inpatient, outpatient, mental health, and long-term care, as well as prescription drugs. Some specific services such as optometry, adult dental services, orthodontics, and physiotherapy are not typically covered by the public system. There is a co-payment for some services, which includes general practitioner (GP) consultations and prescriptions. People on low incomes can reduce these co-payments by applying for an income-tested Community Services card (Manatū Hauora, 2022a). However, as an example, over a 12-month period 17% of people reported not visiting a GP due to cost and 8% said cost had stopped them from collecting a prescription (Health Quality and Safety Commission, 2021a). In addition, 1.45 million New

Zealanders (around 29% of the population) opt to have private health insurance; this covers co-payments, elective treatments in private hospitals and care outside of the public healthcare system (Financial Services Council NZ, 2022). Private health coverage can typically ensure faster access to treatment (Gauld, 2020).

1.1.1. ***District Health Boards***

Until July 2022, the delivery of healthcare was managed regionally through 20 District Health Boards (DHBs). The DHBs were fiscally responsible for decisions about healthcare in their regions and for planning, purchasing, and providing health services at the local level (Gauld, 2020). Gauld explains that the role of the DHBs was to pursue government objectives and targets through the operation of government-owned hospitals and health centres, as well as to provide community-based health services. To achieve this, the DHBs supported primary health organisations (PHOs), and funded non-government organisations (NGOs) and private providers to deliver community-based services. Māori and Pacific service providers for example, are often NGOs subcontracted to the DHBs.

1.1.2. Primary Healthcare Services

PHOs are in effect umbrella organisations for primary care service providers and general practices. The PHOs operate regionally and provide primary healthcare either directly or through contracted providers (Manatū Hauora, 2022b)**.** Patients enrol with a general practice of their choice, and PHOs are allocated money through Manatū Hauora to subsidise healthcare for their enrolled patients (Manatū Hauora, 2022b). In smaller communities, choice about which GP practice to enrol with is often limited. While patient registration is not mandatory, GPs and PHOs must have a registered patient list to be eligible for government subsidies (Gauld, 2020). This means patients who are not registered with a general practice may have to pay the full unsubsidised cost for consultation. As Gauld explains, about half of a GP’s income comes from the capitated, government subsidies (paid through the PHOs), patient co-payments and payments from the Accident Compensation Corporation account for the rest. Patient co-payments are set by individual GPs and vary between medical practices. In most instances patients interact with the health system through their GP. Therefore, primary care is the gateway to the rest of the healthcare system and GPs act as referrers to specialist care for health and mental health (Cunningham et al., 2018; Gauld, 2020; Lawrence, 2017).

1.1.3. Mental Health Services (MHS) in New Zealand

DHBs fund and provide a range of MHS, including secondary care, through a mix of inpatient, hospital, and community-based services. Funding for MHS in hospitals is directed toward the most unwell 3% of the population with mental health concerns (Ministry of Health, 2016). Therefore, these services often have restrictive criteria and people have (until recently when primary care options have been made more available) needed to be in significant distress to gain access to publicly funded support. As mental health support is a restricted commodity, secondary services (in the face of increasing demand), arguably work towards their own sustainability at the expense of individual service user need (Cunningham et al., 2018). If people do not meet criteria for a particular service (despite clear need), gaps appear when there is no other support available. In NZ, assessment for a neurodevelopmental condition such as autism or ADHD (for young people 18 years and under) is usually through a paediatric child development service, or through a Child and Adolescent MHS (CAMHS). As the demand for CAMHS far exceeds the available resource (Paterson et al., 2018), for a child to be assessed for ADHD through CAMHS they would also need to have significant mental distress or co-occurring mental health concerns (Mental Health Foundation, 2022).

People with mild to moderate mental health concerns are often first seen in primary care and general practice settings as their first point of contact with the mental health system (Dowell et al., 2009). They gain access to support through their GP who offers treatment and/or coordinates referrals to primary care MHS or to the specialist MHS and addiction services provided by DHBs or NGOs (Gauld, 2020). According to Manatū Hauora (2022) referrals to mental health and addiction teams were most likely to come from 'self or relative referral' (28%), or 'general practitioner' (17%). Importantly, because of the cost to see a GP, access to MHS is compromised through this pathway if people cannot afford to access primary care (Lawrence, 2017).

Primary mental health care encompasses promotion, prevention, early intervention and ongoing treatment; all of which ideally should be universally accessible to people in the community (Dowell et al., 2009). Although primary care MHS have only recently become more readily available, being able to access brief psychological therapies through the GP may fill a large unmet need and increase access to therapy for treatment of mild to moderate mental health issues (Dowell et al., 2009). Therefore, primary mental health care contributes to the overall function and sustainability of the mental health system in NZ. Accessing MHS through the GP or general practice also blurs the distinction between physical and mental health (which are inextricably linked) which normalises a holistic understanding of mental health and mental distress.

1.2. Disparate Health Outcomes for Māori

Published in 2006, Te Rau Hinengaro: The NZ Mental Health Survey was the first survey in NZ to measure the prevalence of mental disorders in a nationally representative sample (Baxter et al., 2006); this remains the most comprehensive data compiled on mental distress and addiction in NZ to date. As well as asking about the experience of mental disorder, Te Rau Hinengaro questioned participants about service use in response to mental health concerns. Overall, the 12-month prevalence of any mental disorder was highest for Māori, while relative to need Māori were less likely than non-Māori to have contact with support services (other than Pacific people who had even less contact) (Baxter et al., 2006). This confirmed disparities in Māori mental health and service access to be a significant public health issue.

According to Kingi (2017a) comparatively high rates of mental illness for Māori are a recent phenomenon. Since the 1980s there has been a significant increase in the number of Māori people accessing mental health facilities, as well as increasing numbers of Māori who are treated under compulsion through legislation (Kingi, 2017a). There are higher rates of suicide amongst Māori (than non-Māori) particularly for those aged 15-24 years, with the same pattern seen with intentional self-harm (Yeh et al., 2015). Recent figures from Manatū Hauora (2022), indicate Māori represent 29% of people accessing secondary MHS through specialist inpatient and community mental health (CMH) and addiction services. These services are funded by Manatū Hauora and in theory, are universally available (Gauld, 2020). In practice however, access to these services is determined by the service and based on level of need, so the figure above does not capture those people who were not eligible or did not access available services (Ministry of Health, 2022).

Unmet need is also seen in access to treatment where a diagnosis has been confirmed. Māori are almost one-and-a-half times as likely as non-Māori to report having an anxiety or mood disorder (Yeh et al., 2015). However, based on data from pharmacies for subsidised dispensing, Māori were less likely to be prescribed antidepressants than non-Māori (Health Quality and Safety Commission, 2021b). Whether this was because clinicians were less likely to prescribe to Māori patients or if Māori people chose not to have medication, was not clear. What is clear is that the lower use of medication was not compensated with alternative treatment (Health Quality and Safety Commission, 2021b). In addition, the HQSC reported 8,200 children aged 0-14 were regularly (i.e., in three or four quarters in a year) dispensed a central nervous system stimulant in 2018; with rates of dispensing much lower for Māori tamariki and rangatahi. The data used by HQSC (2021b) does not describe if dispensing was appropriate, if people took the medication, and does not capture if prescriptions are not dispensed.

Disparate outcomes are also seen in health and disability statistics for Māori, with disproportionately higher rates for Māori across the board. To summarise in brief, the following information is based on data from Tatau Kahukura: Māori Health Chart Book 2015 (Yeh et al., 2015). At all ages and stages of life, Māori have higher rates of disability. Diabetes features as one of the top five causes of death for Māori, which is not the case for non-Māori. The cardiovascular disease mortality rate is twice as high amongst Māori than non-Māori. The mortality and hospitalisation rates for stroke are both about one-and-a-half times higher for Māori than non-Māori. While total cancer registration rates are higher for Māori, for many specific cancers registration rates for Māori are less than or comparable to rates for non-Māori. However, the mortality rates for cancer are higher for Māori which suggests that Māori with cancer are more likely to die from their cancer than non-Māori.

Māori people are more like to be affected by respiratory disease including asthma and chronic obstructive pulmonary disease. Māori are also disproportionately affected by infectious disease.

As Durie (1998) explains there are varied and complex factors which influence Māori health status and to consider the above statistics in basic cause and effect terms would be overly simplistic and misleading. While disparate and inequitable health outcomes certainly exist, this does not indicate that overall Māori health has reached a desperate state (Durie, 1998; Kingi, 2017a). The Māori population is larger than ever and living longer than ever before and by that measure, has never been healthier (Durie, 1998; Kingi, 2017a). These figures do not represent that all Māori have poor health and can expect poor outcomes if they are unwell; they signify that there are multiple, systemic, ongoing inequitable outcomes which Māori face within the NZ health care system. This sets the scene that it is necessary to address Māori health and health equity from both a rights-based and needs-based position (Medical Council of New Zealand (MCNZ), 2019a) and this is discussed further in chapter two.

1.3. Status of Mental Health Services

In general, MHS in NZ are under pressure, fragmented, poorly funded and struggling to meet current demand with the available staff and funding (Allan, 2020; Cunningham et al., 2018; Elliot & ActionStation, 2018). In Te Huringa, the latest MHS and Addiction Service Monitoring Report, the government acknowledges the MH system is incomplete and lacks a full continuum of care and support when people require help (Mental Health and Wellbeing Commission, 2022). The burden is then placed on secondary MHS to support people when they are in severe distress. Excessive demand as compared to available resources means there are long wait times and clients needing to be in crisis to access services (Elliot & ActionStation, 2018). In addition, the DHBs have different processes for assessing acute referrals based on urgency or crisis which assumes the public know how and when to access these services (Lawrence, 2017). Service users have reported problems of access into MHS, excessive wait times, not meeting the threshold for treatment, gaps in services, and a system that is difficult to navigate (Elliot & ActionStation, 2018; Paterson et al., 2018).

1.3.1. He Ara Oranga

In response to concerns about MHS, in 2018 the government initiated a nationwide Mental Health and Addictions Inquiry (Paterson et al., 2018). A key purpose of the Inquiry was to summarise NZ's current mental health response, including service user responses about whether MHS are meeting the needs of people experiencing mental distress and mental illness. Primary considerations were how mental health issues might be prevented, opportunities for service improvements, and how to move towards a wellbeing approach to recovery (Paterson et al., 2018). The Inquiry was multifaceted in both scope and sources of information, and sought submissions from the community, people with lived experience of mental health and addiction problems, their whānau and families, and service providers. He Ara Oranga (Paterson et al., 2018), the report generated from the Inquiry, highlighted a number of communities as not equitably served by MHS, including Māori and Pasifika peoples, refugee and migrant populations, LGBTQ+ communities, trans people, disabled people, rural communities, veterans, people in prison, older people, young people and children in state care (Mental Health and Wellbeing Commission, 2022).

He Ara Oranga reiterated significant mental health inequities exist for Māori and outcomes for Māori continue to be worse than for the general population. The report also indicated Māori disproportionately experience issues that negatively impact on wellbeing and health including income inequality, child poverty, homelessness, unemployment, family violence and abuse, and stressed that, "disadvantage on all those measures is incompatible with the promises in the Treaty of Waitangi[1]" (Paterson et al., 2018, p. 66). As He Ara Oranga emphasises, these factors are compounding as there is a complex relationship between socioeconomic status (SES), social exclusion, and mental distress.

He Ara Oranga (Paterson et al., 2018) also indicated escalating demand for specialist MHS, particularly for infant, child and adolescent services. This increased pressure means services are operating at capacity and consequently instigate restrictive criteria to manage demand. Even when

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[1] An overview of the Treaty of Waitangi is presented in chapter two.

young people are seen through these services, there are waiting lists at times when families need to access support quickly. DHB targets are 80% of people referred for non-urgent mental health and addiction services are seen within three weeks and 95% within eight weeks; in 2020/21 65% of young people 19 and under were seen within three weeks of referral, and 87% within eight weeks (Mental Health and Wellbeing Commission, 2022). As mentioned, CAMHS are one of the main publicly funded services which assess and treat children for ADHD. Issues relating to access to these services for ADHD specifically, are discussed in more detail in chapter five.

Those who contributed to He Ara Oranga collectively put forward their narratives and expectations about how the mental health system should work for all New Zealanders. This included wanting increased access to MHS; decreased wait times; more treatment options and choice, particularly for people with mild to moderate, and moderate to severe needs; an emphasis on wellbeing; more investment in prevention and early intervention; whānau- and community-based services; and collaboration with communities on future service design (Paterson et al., 2018). Furthermore, Māori wanted more kaupapa Māori services, a strong Māori mental health workforce, and many Māori wanted to determine how services would be commissioned, delivered and evaluated (Paterson et al., 2018).

He Ara Oranga identified transformation of the mental health system as key to meaningful improvement (Mental Health and Wellbeing Commission, 2022). Subsequently, in the 2019 Budget the government dedicated a $1.9 billion package towards supporting mental wellbeing. Allan (2020) describes this shift as a need for transformational change, moving from a MHS to a wellbeing oriented system. Allan explains this will require an all-of government and community response where there is a shared agenda, collaboration, strong leadership, partnership with Māori and collective action.

To that end, Kia Manawanui was released in 2021 and establishes the framework for how the government will support mental wellbeing over the next 10 years (Manatū Hauora, 2021a). In Kia Manawanui, Manatū Hauora acknowledges He Ara Oranga set a “mandate for change” and provides the foundation for the future direction of MHS. There are five interconnected focus areas in Kia

Manawanui which indicate the pathway forward to improve mental wellbeing for all New Zealanders while addressing inequities faced by specific population groups (Manatū Hauora, 2021a, pp. 71–72):

1. Build the social, cultural, environmental, and economic foundations of wellbeing.
2. Equip individuals and whānau to look after their mental wellbeing.
3. Foster community-led solutions.
4. Expand primary mental wellbeing supports in communities.
5. Strengthen specialist services.

As these focus areas can be directly linked to recommendations from He Ara Oranga, these have in effect been informed by the people and communities of NZ. This shows initial promise of what He Ara Oranga and other community-led solutions might achieve. This also indicated a similar qualitative design could be beneficial in the current research and produce the information needed to address the research questions (the research questions and methodology are discussed in chapters six and seven).

1.4. Service Use Amongst Māori

The current status of Māori mental health is complex because while Māori are overrepresented in prevalence rates for mental health disorders, in general Māori simultaneously underutilise MHS (Baxter et al., 2006; Cunningham et al., 2018; McClintock et al., 2016). As noted by Ellison-Loschmann and Pearce (2006), much of the excess mortality for Māori comes from disease for which there is effective health care and evidence suggests there are differences between Māori and non-Māori in access to primary and secondary healthcare services. Therefore, improved access to care is fundamental to addressing health disparities (Ellison-Loschmann & Pearce, 2006). They suggest two approaches might support access to and quality of health care for Māori: increasing the number of Māori health care service providers and increasing access to cultural safety training for all service providers.

The reality for many Māori (and for people from other minority groups) is they will likely be treated by a GP or specialist who does not share their ethnic or cultural background. A significant proportion of registered doctors in NZ were trained overseas, with 42.1% gaining their medical degrees in countries other than NZ (MCNZ, 2022). The representation of Māori and Pasifika doctors is still relatively low in terms of the whole workforce. For example, Māori make up just 4% of doctors working as GPs. Notably, the proportion of Māori and Pasifika doctors is increasing amongst those more recently qualified. Of those students beginning medical school between 2015 and 2019, 15.3% identified as Māori and 3.6% identified as Pasifika (MCNZ, 2022).

Even with increased numbers of Māori and Pasifika doctors for example, cultural competency training will remain a necessary (and ongoing) aspect of clinical practice for all practitioners (cultural competence is discussed in chapter three). However, the extent to which different clinicians are willing, or feel able to demonstrate culturally competent practice varies, and is also difficult to observe. Additional impetus for the present research was the researcher’s honours project (Tipene, 2018) in which clinicians were interviewed about their experiences of working with children with ADHD in NZ. Clinicians were asked their perspectives of culture as a factor in the diagnosis and treatment of ADHD, and whether their cultural competency training and ongoing professional development supported them to work effectively with Māori clients and whānau. As a brief overview, findings included:

- While culture was not a key component of ADHD diagnostic criteria, most interviewed clinicians thought it was an important feature of assessment.
- Clinicians’ perceptions were that culture (of the client) affected how ADHD-associated behaviours were interpreted and managed by whānau.
- Clinicians also perceived whānau Māori as less willing to accept medication as treatment, preferring other treatment options first.
- Most clinicians also said they felt they enacted cultural competency in their interactions with Māori clients.

Clinicians’ experiences gave an important (yet limited) view of ADHD in NZ and indicated a fuller account of cultural considerations relevant to ADHD was needed - from a Māori service user perspective. This includes an understanding of how ADHD-related behaviours are understood from a whānau Māori perspective and how whānau experience the assessment and treatment process. This information is required to understand how whānau experiences of assessment influence service use and treatment decisions.

Other researchers have similarly questioned whether MHS work with Māori clients in culturally appropriate ways. For example, a study by Hatcher et al., (2016) considered whether a culturally informed intervention would improve outcomes for Māori presenting to the hospital emergency department, following intentional self-harm. They found improvements at 3 months post-intervention, which were not maintained at 12 months. However, the researchers suggested further understanding was needed of the role of cultural attitudes and knowledge at initial assessment, to generate ideas about where to focus intervention efforts and encourage client engagement with MHS.

Another NZ study sought to understand why there is high unmet need for CAMHS for ethnic minority and Indigenous populations. McClintock et al., (2016) reviewed the existing literature on how to improve MHS delivery for these populations. They found supporting evidence for culturally relevant services as a means of increasing engagement with and commitment to treatment programmes. Other barriers to accessing services for young people have previously been identified, including concerns about confidentiality, lack of knowledge about mental disorders and MHS, concern about the attitude of clinicians to their difficulties and a lack of access due to the geographical location of services or associated costs (Hetrick et al., 2017).

Concerns from Māori in He Ara Oranga included how (due to privacy issues) MHS often alienated whānau from the service user (Paterson et al., 2018). As one whānau member explained, isolating people from their family and community is both ineffective and inappropriate for collectivist cultures, such as Māori. In addition, psychiatric assessment did not recognise the significance to Māori of ties to whānau, hapū, and iwi, nor how these ties contribute to wellbeing, and are a potential pathway back to wellness (Kumar & Oakley Browne, 2008). He Ara Oranga emphasised a strong consensus that a Māori worldview, Māori health beliefs, Māori knowledge, whānau, hapū, iwi, and te reo me ona tikanga, were essential aspects of wellbeing for Māori. Understandably, these elements should therefore form the basis for meaningful and successful assessment, treatment planning and interventions delivered by MHS. Notably, some of these concerns were not limited to Māori, and similar health inequities exist for other communities and cultures in NZ, particularly for Pasifika peoples (Manatū Hauora, 2021c). Just as these concerns were not unique, the aspirations of Māori and Pasifika peoples for a more holistic approach to wellbeing (Sopoaga, 2011) are also relevant for many New Zealanders affected by mental illness.

Multiple submissions to the Mental Health and Addictions Inquiry expressed concern about limited publicly funded services for those with mild to moderate mental health needs. Until the introduction of Primary Mental Health Initiatives between 2005 and 2007, there was no public funding to specifically support primary mental health care (Dowell et al., 2009). Psychological treatment available in the community was provided by private providers thus restricting treatment to those who could afford it (Dowell et al., 2009).

Framing disparate health outcomes solely in terms of service utilisation is complicated when there is a lack of available services overall; are services available and not used or are there barriers to accessing available services? Supporting Māori to flourish relies as much on having improved access to services, as it does on delivering MHS which are aligned with a Māori worldview (Durie, 2011). A future challenge for MHS is how to blend cultural and clinical perspectives to best support Māori (Durie, 2011; Macfarlane et al., 2011). To enhance clinical practice, research is needed which demonstrates how MHS can affirm and incorporate the cultural values, experiences, and aspirations of Māori clients and their whānau into assessment and treatment. Thus, one of the research questions in this study was whether the support which was available to whānau was culturally appropriate and relevant, and did this influence engagement with services for ADHD? Durie (2017) says although health approaches have been transformed in the past forty years to a more responsive health system, this has yet to address growing inequities. Indeed, these patterns demonstrate a need for innovative and culturally inspired solutions (Kingi, 2017a).

1.5. Chapter Summary

This chapter provided a broad overview of the universal healthcare system in NZ. The ideal of this system is to provide accessible care which meets the health care needs of all New Zealanders which the current system does not. This is evident in the ongoing inequitable health and mental health outcomes Māori people have experienced within this system. In a general sense, MHS are under pressure to meet demand and there are significant access issues and unmet need for these services. This includes CAMHS services, which are involved in ADHD treatment for children and youth. Service access issues have been brought to the forefront recently through community-driven, service-user led reviews such as the Mental Health and Addictions Inquiry. He Ara Oranga again emphasised several communities are not equitably served by MHS in NZ, including Māori and their whānau. The impact of reports like He Ara Oranga, has meant consumers are empowered to contribute to meaningful change; this model of effecting change by seeking a consumer perspective contributed to the qualitative approach in the current research. Access to services is just one of the barriers experienced by Māori. Other considerations are whether services are culturally appropriate and responsive when working with whānau Māori. The following chapter provides context for the disparate outcomes discussed here, by providing a brief overview of the historical background of Māori in NZ

Chapter Two: Māori and the New Zealand Context

Chapter two presents a more detailed discussion of Māori as the Indigenous people of NZ as context for why the current research focused on experiences of whānau and tamariki Māori affected by ADHD. This includes a summary of the Treaty of Waitangi as the founding document that enabled British settlers to establish government in NZ. Based on the underlying principles of the Treaty, this has afforded Māori certain rights which continue to bear weight in present day policy and legislation. Therefore, how those same principles and rights are applicable to health inequities for Māori is discussed; this enhances the observation in chapter one that Māori have needs- and rights-based reasons to expect good health. When working alongside Māori in partnership, it is important to establish a shared meaning of what good health means; therefore, the significance of Māori models of health to Māori self-determination and health promotion is introduced. Finally, the chapter concludes with a discussion of “diverse Māori realities” (Durie, 1995) and how this is conceptualised in the current research.

2.1. Te Tiriti o Waitangi: An Overview

“Because of the Treaty, Māori believe right to this day that they are equal partners and yet they know from experience that is not so.” (Sir James Henare, 1988)

Though there are differing accounts, the use of the term Māori is thought to have arisen following Pākehā contact to distinguish between people of Māori descent and the colonising British settlers (Baker, 1945). During the time of early NZ settlement, Māori were largely living within their hapū and iwi (Boulton et al., 2013), and it was these distinctions which Māori used to identify themselves rather than the singular term Māori. Māori is now commonly accepted to describe the tangata whenua or Indigenous people of NZ, in terms of both culture and ethnicity.

Signed in 1840, Te Tiriti o Waitangi (the Treaty of Waitangi) was an agreement between Māori and the British Crown and is the founding document of contemporary NZ society. Te Tiriti allowed the

Crown to establish government over British settlers in NZ, while affirming Māori sovereignty, and granting Māori people the same rights and privileges as British subjects (Orange, 2021). This also allowed for the rapid immigration of British settlers from 1840 onwards and the ongoing process of colonisation has had a profound impact on Māori ways of life.

Te Tiriti has three articles which are briefly outlined, as summarised by Orange (2021). In Article One Māori acceded *kāwanatanga* or governance of NZ to the Crown, which assured Māori they were one of two Treaty partners who would share responsibility for shaping the future of NZ. Article Two guaranteed the Crown would uphold *tino rangatiratanga* (or chieftainship) of Māori over their lands, villages, *me o rātou taonga katoa* (and their other taonga) (Henare, 2006). Finally, Article Three assured Māori they would have the same rights and protection afforded to British subjects.

Problems have arisen based on different interpretations of Te Tiriti between the Māori and English translations. In short, the Crown asserted the signing of the Treaty meant Māori ceded sovereignty to the Crown (Pomare, 2015). However, the word kāwanatanga which was used to indicate “sovereignty” was more akin to governance in the Māori language (Berghan et al., 2017). Thus, Māori understood they were allowing government of their lands while still managing their own affairs. Tino rangatiratanga in the Māori text also guaranteed Māori retained full authority over their people, resources and taonga; and *taonga* has a broad definition so that what is precious or of value to Māori, extends beyond the tangible (Henare, 2006; Mead, 2016). In accordance with international treaty law, *contra proferentem* states that where there is conflict over treaty interpretation, this should be interpreted against those who drafted or proposed the treaty (Waitangi Tribunal, 2016); therefore the Māori text should be the recognised version.

2.1.1. Principles of The Treaty of Waitangi

Compromise between these interpretations has been reached by attending to the principles of Te Tiriti (Durie, 1998), and these principles have guided much of the recent public policy in relation to Māori (Boulton et al., 2013). The Royal Commission on Social Policy (1988) recognised three principles derived from the underlying intent of Te Tiriti o Waitangi which are: partnership, participation, and protection. These principles can be readily applied to Māori health promotion: 'Partnership' is working together with Māori communities to develop applicable healthcare strategies; 'Participation' requires Māori are involved at all levels of the decision-making, planning and delivery of healthcare services; and 'Protection' aims to ensure Māori have at least the same level of health as non-Māori, and that Māori health practices, and knowledge systems are protected.

2.2. The Waitangi Tribunal

As has been the case for many Indigenous cultures, the process of colonisation has eroded Māori identity, culture, language, resources and land, and created systems which have diminished the place of tikanga Māori (Ashton-Martyn & O'Connell Rapira, 2018). Legislation has previously been used which denied Māori their connection to their whenua, and undermined Māori health and ways of living (Ashton-Martyn & O'Connell Rapira, 2018; Bennett, 2017). For example, as part of the government's policy to assimilate Māori into Pākehā society, the Native Schools Act 1867 established primary schools in Māori communities where instruction was conducted entirely in English (Walker, 2016). Children who spoke te reo Māori at school were punished. Another example was the Tohunga Suppression Act 1907 which effectively outlawed traditional Māori healing practices to displace these approaches with medical practices (Bennett, 2017). The cumulative effect of policies like these has been the marginalisation of traditional Māori knowledge systems.

These actions, in the name of colonisation, are clear breaches of Te Tiriti o Waitangi on behalf of the Crown. In response, there is an extensive history of Māori leadership which has sought redress and reparation through political, legal and diplomatic means (Came et al., 2020). In 1975, the Treaty of Waitangi Act established the Waitangi Tribunal as an entity to investigate alleged breaches of Te Tiriti (Orange, 2021). Taking into account the Treaty principles, the Tribunal considers claims where Māori interests have been "prejudicially affected" (2021, p. 175) and thereby makes recommendations regarding appropriate action. Notably, the Tribunal has no power to enforce their recommendations and the Tribunal does not determine the process for negotiating settlement (where this applies). However, as Durie (1998) explains, the Tribunal's sweeping revisions of NZ's history and unfair legislation put pressure on the government to consider all aspects of social policy from a Treaty perspective. Thus, Māori philosophies have increasingly been recognised in legislation, education and social service delivery and the Waitangi Tribunal continues to profile Māori concerns to NZ (Kingi, 2017b).

2.2.1. Te Reo Māori Claim

In 1985 a claim was lodged with the Waitangi Tribunal which sought recognition and protection of te reo Māori as an official language of NZ (Waitangi Tribunal, 1989). This claim was an important milestone as this was the first Tribunal hearing which considered an intangible aspect of Māori culture as a taonga. The Waitangi Tribunal upheld the claim and agreed the Crown had failed to protect te reo Māori as guaranteed by Article Two of the Treaty (Waitangi Tribunal, 1989).

Based on the Tribunal's recommendations, the Māori Language Act 1987 recognised te reo Māori as an official language of NZ and established Te Taura Whiri i te Reo Māori (the Māori Language Commission) (Orange, 2021). Through this claim it became clear that the work of the Waitangi Tribunal could affect change for all NZ society; Māori and non-Māori alike (Orange, 2021). While the Tribunal also recommended Māori be taught in schools, they did not think te reo should be a compulsory subject, which had been a concern for some non-Māori opponents of the claim (Waitangi Tribunal, 1989). The Tribunal viewed the claim as an opportunity to promote te reo Māori, rather than impose it.

The te reo Māori claim was one aspect of a growing movement in the later decades of the 1900s which saw Māori reaffirming their cultural identity and te reo me ona tikanga. Another aspect of this movement was the emphasis on active Māori participation in health care (Durie, 2017c). Māori were clear; they wanted greater autonomy and flexibility in how health care was delivered (Goodyear-Smith & Ashton, 2019), in ways which were meaningful, effective, and culturally-appropriate for Māori.

2.3. How can the Treaty of Waitangi Support Māori Wellbeing?

The impact of colonisation continues to manifest among whānau Māori to this day, with health inequities being a clear example (Boulton & Gifford, 2014). Health inequities exist in relation to health outcomes and health care (Whitehead, 1991). In health care, inequities appear in accessibility and quality of health services, where those most in need of care are least likely to receive a high standard of service. Whitehead explains, “Above all, on humanitarian grounds national health policies designed for an entire population cannot claim to be concerned about the health of all the people if the heavier burden of ill health carried by the most vulnerable sections of society is not addressed” (1991, p. 218).

Based on Whitehead’s (1991) definition, the term *inequity* implies there are differences which are unnecessary and avoidable and from a moral and ethical sense, these differences are unfair and unjust. Therefore, to determine this requires that possible causes for health inequities are identified and then judged as unfair in the context of NZ society. For this reason, Te Tiriti o Waitangi is a mechanism whereby Māori are assured they will be supported to achieve at least the same level of health as non-Māori (Royal Commission on Social Policy, 1988).

How health care is practiced in NZ should thus be fundamentally informed by the Treaty principles (Whitinui, 2011). In their latest report, the Mental Health and Wellbeing Commission (2022) maintain Te Tiriti o Waitangi is central to transformation of the mental health and addiction system. They stated funding should be prioritised toward supports which reflect whānau, hapū, and iwi aspirations. As Margrain and Macfarlane (2011) explain, overall Te Tiriti promises partnership, power-sharing and self-determination for Māori and Pākehā populations. Resultantly, the government has statutory obligations to work in partnership with Māori, and in support of Māori in improving Māori health outcomes. Whitinui (2011) discusses how this is beneficial for Māori, as ideally Te Tiriti supports the move from a model of “treating” Māori, to Māori achieving good health equally with non-Māori Treaty partners. Te Tiriti has a role in how Māori navigate and negotiate the kind of health Māori want to achieve on behalf of whānau, hapū and iwi (Whitinui, 2011).

As Māori health systems constitute a form of mātauranga Māori, Māori health is a taonga protected under Article Two of the Treaty of Waitangi (as was established for te reo Māori) (Pomare, 2015). Issues around Māori health are therefore within the remit of the Waitangi Tribunal (Came et al., 2020). In 2016, the Health Services and Outcomes Kaupapa Inquiry (known as WAI 2575) was opened by the Waitangi Tribunal. The purpose of which was to investigate potential breaches of Te Tiriti by the health sector which have contributed to persistent health disparities (Came et al., 2020). Specifically, WAI 2575 is considering: whether the way the healthcare system has been legislated, administered, funded, and monitored by the Crown since the passing of the NZ Public Health and Disability Act 2000 (NZPHDA), has been adequate to address existing inequities; and if not, whether this constitutes a breach of Treaty obligations. The complexity of WAI 2575 has meant the Tribunal will hear the evidence in three stages: stage one focuses on systemic issues and the primary healthcare sector; stage two will look at nationally significant issues including mental health, disabilities, alcohol, tobacco and substance abuse; and stage three will consider any remaining issues and historical matters (Waitangi Tribunal, 2019).

The Waitangi Tribunal’s stage one report was released in 2019 and their findings foremost reaffirmed persistent Māori health inequities which have not improved despite the reforms of the NZPHDA nearly 20 years ago (Waitangi Tribunal, 2019). The Tribunal found that the legislative framework for the health system does not consistently state a commitment to achieving equity for Māori. They also argued that commitment to the Treaty should not be limited to a specific Māori health strategy but incorporated throughout the entire framework. Overall, the Tribunal said there was inadequate funding for the primary health care system to operate sustainably, including for the four Māori PHOs and contracted Māori health providers. The report noted $200 billion NZD was spent on health since 2012, with $167 million NZD allocated to primary care for Māori and only $28.7 million NZD going to Māori PHOs during this period (Came et al., 2020). In general, the Tribunal noted issues with the funding system which disadvantage PHOs which serve high-needs populations. There was also ineffective monitoring of the primary health sector and inadequate data collection to monitor performance in relation to Māori health. The Tribunal also reported a lack of partnership with mana whenua and other Māori communities in planning and implementation of primary health service delivery, and ongoing underrepresentation of Māori in the health sector.

In their recommendations, the Waitangi Tribunal said that legislative and policy changes were needed which better reflected the Crown's commitment to Te Tiriti, the health system and to Māori health (Waitangi Tribunal, 2019). The Tribunal also called for an urgent and thorough review of funding for the primary health care system. In aid of protecting the right of Māori to choose to follow their way of life according to traditions and their cultural worldview, the Tribunal reminded the government this meant protecting the availability and viability of kaupapa Māori services and mainstream services which support Māori. The reality is most Māori access treatment and support through mainstream services (Kingi, 2017b); therefore, as well having a choice, Māori people should not be disadvantaged by their choice. The Tribunal also made an interim recommendation for the establishment of an independent Māori Health Authority. The Hauora Report was released in 2019 so recommendations could be considered as part of the Health and Disability System Review (see section 2.3.2 on Health Reforms).

As Tiriti obligations have a clear relationship to health (Cunningham et al., 2018), this is crucial to improving health outcomes (Boulton et al., 2013). However, as King et al. (2018) assert, addressing inequities in health for Māori is not only about meeting a needs-based right. They say suggesting this right is only afforded to Māori to meet Treaty obligations, once again undermines Māori authority and self-determination. Māori have tangata whenua rights to expect both good health and the right to live "as Māori" (Berghan et al., 2017).

2.3.1. The Goal of Health Equity

The ideal of a universal health system is that all New Zealanders have equal access to the same standard of treatment (Goodyear-Smith & Ashton, 2019). In their review of the NZ health system, Goodyear-Smith and Ashton noted that despite stating a long-standing commitment to health equity, the continued focus has been on individual-level secondary services instead of addressing issues though community-based health promotion, prevention, and primary care. With the goal of health equity in mind, they recommend resources need to be better aligned with need, Māori service provision needs to be expanded, and the government needs to strengthen population-based approaches which address drivers of health status. Durie (2017b) agrees that health equity will increasingly require environmental and social determinants to be addressed together. Targeting the social determinants of health is an important prevention approach and requires more than the isolated intervention of individual organisations (Allan, 2020; Cunningham et al., 2018). Continuing to focus on health in isolation and expecting a different outcome does not make sense, and there have been attempts by government to address this.

The Whānau Ora programme was launched in 2010 as an innovative, collaborative approach to enabling families (Māori and non-Māori) toward wellbeing (Te Puni Kōkiri, 2022). Whānau Ora takes a whānau-centred, holistic approach where whānau identify what they would like to achieve, and these aspirations indicate how best to integrate social and health supports for the particular whānau (Cunningham et al., 2018; Te Puni Kōkiri, 2022). In response there is a coordinated, collaborative approach across government, community- and whānau-based organisations. Where health providers deliver health services using a Whānau Ora approach, this can enable both individual and whānau resilience (Boulton & Gifford, 2014). Outcomes for many individuals and whānau, Māori and non-Māori, are often best achieved when self-determination is the focus of support. Whānau Ora has increasingly featured across government policies, including in the health sector (with varied success) (Manatū Hauora, 2014).

He Korowai Oranga, the government’s Māori health strategy builds on the holistic approach of Whānau Ora (Manatū Hauora, 2014). He Korowai Oranga outlines how the health system intends to respond to achieve equitable health outcomes for Māori. He Korowai Oranga was revised in 2014 to include Pae Ora: a vision of healthy futures (Manatū Hauora, 2014). Pae Ora incorporates three broad dimensions; in addition to Whānau Ora, this includes Mauri Ora (Healthy Lives) and Wai Ora (Healthy Environments). This shift was recognition of the need to further extend the focus for Māori health to environmental predisposing factors while improving and empowering individual and whānau wellbeing (Durie, 2017a). Kia Manawanui (as previously described) is the framework for transforming the mental health system and is centred towards Pae Ora. Moving forward, progress toward health equity now requires genuine commitment to these policies which integrate promotion, prevention and recovery for individual and whānau wellbeing (Cunningham et al., 2018).

2.3.2. Health Reforms in 2022

The health sector has been through several major reforms since the 1980s, prior to which the hospital system and primary health care had developed independently of one another (Boulton et al., 2013; Goodyear-Smith & Ashton, 2019). The reforms have been in aid of improved efficiencies and to develop a system for which it was evident funding was making a difference to outcomes (Boulton et al., 2013). However, these series of restructures did not result in expected efficiency gains and consequently, substantial changes to the health system were introduced by the NZPHDA in 2000 (Goodyear-Smith & Ashton, 2019).

The NZPHDA set the structure and function of the public healthcare system (Manatū Hauora, 2022b), and several operational policies and strategies developed from the Act to describe how specific aspects of health care would be delivered. The NZPHDA established the DHB system and was followed thereafter by the Primary Health Care Strategy in 2001 and the original He Korowai Oranga strategy in 2002. The expectation was the NZPHDA would better integrate primary and secondary health services (Goodyear-Smith & Ashton, 2019). Part of the stated purpose of the NZPHDA was a focus on equity for Māori and other underserved communities (Waitangi Tribunal, 2019). Over the period of these reforms Māori had been calling for greater autonomy in health care decision-making which affected Māori; MHS providers and practitioners were especially vocal (Kingi, 2017b). The development of PHOs did create greater opportunities for community-driven care, which included kaupapa Māori services. However, as the WAI 2575 claim highlights, the potential gains from these changes have yet to be realised.

In 2018 the government announced a review of the entire health and disability system (Health and Disability System Review, 2020). The goal of the review was to recommend system-level changes to the government which would lead to improved and more equitable outcomes for all New Zealanders (Health and Disability System Review, 2020). The Review's final report was released in 2020 and put forward a range of detailed proposals which suggested the health and disability system needed to be simplified; in how it was managed, how services were delivered, and how easily consumers could access services when they needed them. The review panel acknowledged that Te Tiriti principles should be embedded throughout health care legislation; they agreed an independent Māori health authority should be established, and that there should be collaboration between different parts of the system at primary and secondary levels (Health and Disability System Review, 2020).

In response to the proposals of the Health and Disability System Review, in July 2022 NZ moved to a new national health system. The government's stated goal is to transform the health system into "a more equitable, accessible, cohesive and people-centred system" (Department of the Prime Minister and Cabinet, 2022c). The NZ health system is now essentially made up of three entities: Manatū Hauora (the Ministry of Health), and the newly established Te Whatu Ora (Health NZ), and Te Aka Whai Ora (Māori Health Authority). The system has been designed so that health planning is managed nationally, and then regionally delivered based on local requirements (Department of the Prime Minister and Cabinet, 2022c). The 20 DHBs have been disestablished and Te Whatu Ora coordinates health care across the country and manages the regional delivery of hospital, primary and community health services (Department of the Prime Minister and Cabinet, 2022b). In theory the new system will mean there is more funding for delivery of services and the cost of managing the health system, as this will be dealt with nationally as opposed to regionally through DHBs.

Te Aka Whai Ora will work in partnership with Manatū Hauora and Te Whatu Ora to ensure the health system remains responsive to Māori needs. In consultation with Māori health providers, iwi, hapū and Māori communities, Te Aka Whai Ora will represent Māori health needs and aspirations in the planning, decision-making and delivery of services, so these will be incorporated throughout the health system (Department of the Prime Minister and Cabinet, 2022a). The Māori Health Authority will also commission kaupapa Māori services and monitor the performance of the health system in respect of Māori health. The government anticipates this will create more options for Māori to access kaupapa Māori services and other services which reflect mātauranga Māori (Department of the Prime Minister and Cabinet, 2022c). With these changes the government has acknowledged that in order to address inequities, the entire health system must deliver a focus on Māori health (Department of the Prime Minister and Cabinet, 2022b).

The government also anticipates that the simplified and consolidated health system will be better positioned to transform MHS, through improved access to care in the community and early intervention services (Department of the Prime Minister and Cabinet, 2022b; Health Quality and Safety Commission, 2021b). He Ara Oranga will continue to provide the blueprint for how MHS will be improved and for how the health system will respond (Mental Health and Wellbeing Commission, 2022). In line with He Ara Oranga recommendations, in the 2019 budget the government announced the national launch of the Access and Choice programme (Robertson, 2019). This will provide people with mild to moderate mental health and addiction needs with free and immediate support through various settings. The aim is to increase access to mental health support, create equitable access, increase choice, and reduce wait times (Te Pou, 2022).

Overall, recent legislative and policy changes show promise in supporting Māori health outcomes. Over several decades there has been recognition Māori may have different heath aspirations and that there are multiple issues to be addressed as to why the health system does not work to support those aspirations. Durie (1998) says that while life expectancy, death and hospitalisation rates are an indication of Māori health status, this does not capture Māori vitality or mauri. He explains that these statistics highlight differences between Māori and non-Māori and imply that Māori should aspire to these health standards; however, they in no way indicate what Māori aspirations and perspectives might be with respect to health.

Therefore, in the present study, in service of exploring the experiences of whānau, one of the research questions addressed how whānau understood and accommodated the behavioural issues they experienced with their child. Understanding how caregivers are impacted by ADHD and what they would hope to achieve for their tamariki through treatment is relevant to the treatment options whānau would deem to be acceptable. These decisions would also potentially be impacted by cultural views about health and wellbeing, and this is considered in the following section.

2.4. Māori Models of Health

As a Māori psychiatrist practicing in the 1970s and 80s, Durie noted opposition from his medical colleagues about the relevance of culture and ethnicity to health (Durie, 2011). While that sentiment still exists, there is now greater acceptance of the link between culture and health (Durie, 2017c; Kingi, 2017b). Behaviours which are considered abnormal are determined by culturally-bound parameters of normality (Kingi, 2017a). It makes sense then, that explanations and expectations of health and wellbeing will also differ between people of different cultures. Māori have been excluded from a health system which has emphasised pathology and comparative deficits and to counter this requires a health perspective which Māori can engage with (Durie, 2011).

Cultural values for many Māori include a holistic view of health, which has been at odds with the biomedical model traditionally used in health and mental health (Buchanan & Malcolm, 2010; Tipene, 2018). From Te Ao Māori, holism in respect of wellbeing promotes alignment of physical, mental, relational and spiritual health (McClintock et al., 2016). For Māori, good health is more than the absence of symptoms and disability; wellbeing is a reciprocal balance between these interrelated domains (Durie, 1985). This challenges the distinction between physical and mental health and indicates all of these dimensions are relevant to health interventions (Durie, 2017c). From this world view, depression and anxiety (for example) are less about individual disorder, than indicative of imbalance between emotions, social relationships, spirituality and the body (Durie, 2017a). A holistic model also has relevance to ADHD, as diagnosis of ADHD requires functional impairment in multiple domains (this is explained in more detail in chapter five). For example, the behaviours associated with

ADHD are known to impact on social relationships, family functioning, self-esteem, and mental health. By assessing these different aspects of wellbeing, this potentially identifies areas for targeted intervention (in collaboration with the person and their whānau).

Various conceptualisations of this holistic paradigm have been introduced in the literature; for example Te Whare Tapa Wha (Durie, 1985), Te Wheke (Pere, 1997) and the Meihana Model (Pitama et al., 2014). In differing ways, these and other frameworks based in mātauranga Māori, demonstrate Māori understand health to be multidimensional (Pitama et al., 2014). Kingi (2017b, p. 42) describes Māori philosophies of care as inclusive, emphasising holism, whānau, hapū and iwi connections. Tikanga around whanaungatanga also highlights the centrality of relationships to individual and collective wellbeing, with associated rights and obligations (King et al., 2018; Mead, 2016). Taken together, these concepts emphasise that a strong foundation for Māori health has always existed, from within Te Ao Māori (NiaNia et al., 2019). Consequently, to achieve the best possible outcomes, health practitioners must be able to work with Māori within a Māori health framework (MCNZ & Mauri Ora Associates, 2006).

A sense of wellbeing is subjective, and wellbeing is both contextual and culturally defined. Whitehead (1991) noted a move by the World Health Organisation away from measuring physical health status based on mortality towards other dimensions of health and wellbeing. There is evidence of this theoretical shift in NZ. For example, the three dimensions associated with Pae Ora signal endpoints which are associated with health and wellbeing rather than the absence of illness (Durie, 2017a). Working towards wellbeing requires a holistic understanding of a person and supports the idea of a whole-person approach to healing (Durie, 2011).

2.5. Cultural Identity and Diversity

There is no single model of Māori wellbeing, and nor could one model be universally applied by all services who work with Māori. While Māori share certain characteristics and values, there is no one definition which encompasses all of what it means to be Māori (Durie, 1995, 1998); as Durie states there are "diverse Māori realities." Distinctions exist between iwi, which have their own cultural and historical associations (Durie, 1995). Homogenous labelling does not acknowledge the differences in Māori identity within Māori culture (Heaton, 2015).

For many Māori, a strong cultural identity is important for wellbeing (Durie, 2001; Pere, 1997). Some Māori experiencing mental illness have a much deeper connection with Te Ao Māori and their needs are insufficiently catered for within existing MHS if they require an intervention firmly grounded in mātauranga Māori (Bennett, 2017). Similarly, some Māori have limited access to their culture, and it would be unreasonable to introduce a therapeutic approach for these clients which was based on Māori values such as wairua and whakapapa (Bennett, 2017). Especially, if this were to be delivered by a non-Māori practitioner. Through colonisation, it was misrepresented to Māori that progress and development meant turning away from mātauranga Māori and tikanga Māori in favour of 'proper knowledge' from the western world (Mead, 2016). As Mead explains: "Knowledge enables a person to participate in one's own culture, to move within it in confidence, to meet other people who are following the same path and to enjoy being a Māori. It is a fundamental right of every person of Māori descent to enjoy his or her birth right, and to feel good about it" (Mead, 2016, p. 25).

Aside from cultural identity, there have been changes in how Māori ethnicity has been defined over time (Kingi, 2017a). Durie (1998) explains how the statistical definitions of Māori used by the government have progressed, beginning with a biological determination which estimated race through the degree of Māori blood. This restricted Māori identity based on an ideal of how much Māori blood was needed to be authentic and was based on an underlying idea that membership of certain ethnicities by blood was preferred (Durie, 1998). This was replaced by cultural identification which identified a person as Māori based on whether they were descended from a Māori. Today, Māori ethnicity is determined by self-identification as Māori (Durie, 1998).

There are many different expressions of what it means to be Māori (Pomare, 2015). All these diverse realities equally represent what it means to be Māori in NZ. It should not be a matter for the government to determine who is Māori, which is decided by whakapapa and by a person's decision to identify with their whakapapa. Mead describes whakapapa as defining a person's identity within a tribal structure, and says this gives the individual the right to say, 'I am Māori' (Mead, 2016, p. 47); whakapapa is belonging. Therefore, in keeping with this position, the aim of the current research was to explore the experiences of participants who self-identified as Māori.

2.6. Chapter Summary

This chapter discussed the significance of Te Tiriti o Waitangi in contemporary NZ society. In multiple ways colonisation has contributed to the health status of Māori and health inequities represent failures of the government to uphold the principles and promises of Te Tiriti. Te Tiriti also represents a pathway whereby Māori philosophies have increasingly been recognised in across-government legislation and policy. Recommendations from the Waitangi Tribunal's Health Services and Outcomes Kaupapa Inquiry were included in the government's Health and Disability System Review in 2020. This has directly contributed to recent health reforms (June 2022) and acknowledgement from the government that the entire health system must deliver a focus on Māori health. The establishment of Te Aka Whai Ora also indicated a commitment to Māori leadership in facilitating a health system which better reflects Māori (holistic) understandings of health and aspirations for wellbeing. In the current study, when seeking treatment for ADHD, the aspirations whānau have for their child's wellbeing are relevant to what whānau will anticipate as appropriate treatment. Overall, this chapter informs discussion of the link between culture and health and why this is a foundational aspect of how health should be practiced in NZ. Chapter three discusses the implications this has for health practitioners working with Māori in clinical practice.

Chapter Three: Implications for Clinical Practice

Chapter three considers the implications of ongoing health inequities for clinical practice in health and mental health in NZ. This begins with the professional mandates for cultural competence and ethical practice which apply to regulated health professions. Cultural competence is further explained, and the Hui Process model is described as an example of how to enact cultural safety with Māori. The importance of the therapeutic alliance for health outcomes is discussed, and how this might be achieved through practice which draws on tikanga Māori and aligns with Māori beliefs. Case formulation is mentioned as an alternative to the traditional practice of diagnosis. This incorporates evidence-based theory with a person's lived experience and thereby contributes to a meaningful and responsive treatment plan. The Meihana Model (as a framework for how this might work in practice with Māori clients) is discussed. Having considered some of the implications for clinical practice, this chapter concludes with a discussion of the need to blend cultural and clinical knowledge to establish more comprehensive understandings of health and wellbeing. This chapter relates to the current study as one of the research objectives is to identify possible barriers and facilitators for the assessment and treatment of ADHD; this includes a question about whether whānau thought the available support for ADHD was culturally appropriate and how this influenced their experience.

3.1. Clinical Practice and Professional Mandates

Difficulties experienced by populations defined as minority by an aspect of their identity (such as their ethnicity or culture), often stem from discrimination and stigma at both individual and systemic levels (Cunningham et al., 2018). The He Ara Oranga report agreed that mainstream services and especially hospital services, could be culturally unsafe environments for Māori, Pacific peoples and other minority groups (Paterson et al., 2018). Submissions which contributed to He Ara Oranga expressed concern about the lack of cultural competence among mental health workers and there were calls for more staff who could work entirely within a kaupapa Māori or Pacific framework. Many of the submissions from Māori and non-Māori wanted support so that families and whānau could be actively involved in the care and treatment of their whānau member. Cunningham et al. (2018) identified culturally-embedded models of care and a culturally safe and diverse workforce as ways to address these concerns.

Health professionals (including medical doctors, psychologists, nurses, social workers, occupational therapists, physiotherapists etc.) gain skills through their respective training and through clinical experience (Lawrence, 2017). Various scopes of practice have their own programmes to teach skills and develop competence, including in Indigenous knowledge and cultural competence. Since the 1990s there have been increasing numbers of clinically qualified Māori (Kingi, 2017b). As it has become more widely accepted health and culture are linked, this has influenced new treatment and care protocols across services and within educational training programmes (Durie, 2017c). For example, medical schools have incorporated cultural training into their curriculum (Kingi, 2017b). While this forms an important part of training curricula, how these learnings are applied in practice is difficult to monitor, as this often happens in an organic, intuitive manner (Lawrence, 2017). As Lawrence explains, the application of cultural skills to health depends on the willingness of individual practitioners to apply these approaches and the ability of wider systems to endorse the relationship between culture and health.

The pattern whereby Māori are overrepresented across major disease categories and in mental disorder, in conjunction with crown obligations to Māori through Te Tiriti o Waitangi, acts as imperative for cultural competency to be integral in health policy and practice (Elder, 2017b). Healthcare practitioners in NZ are legally and ethically obliged to have regard for the principles of the Treaty, and to demonstrate cultural competence when working with Māori clients and whānau (Macfarlane et al., 2011). The Health Practitioners' Competence Assurance Act 2003 (HPCAA) enacts the statutory obligations of the government in this respect. The HPCAA regulates the practice of health professionals, to ensure ongoing competence and thereby protect the health and safety of the Public. Under the Act, different registration authorities set standards of clinical competence, cultural competence, ethical conduct, prescribe qualifications for scopes of practice, and review and maintain the competence of health practitioners. According to the HPCAA, this incorporates competencies that enable effective and respectful interaction with Māori; although these standards indicate a minimum requirement (Elder, 2017b). The challenge is how to provide culturally appropriate care which fosters positive health outcomes (Dunn, 2002).

3.1.1. Cultural Competence

Despite different health disciplines including cultural competence in both training and best practice guidelines (e.g., MCNZ, 2019a, 2019b; New Zealand Psychologists' Board (NZPB), 2018; Royal Australian and New Zealand College of Psychiatrists, 2000), research suggests a lack of culturally appropriate MHS continues to contribute to reduced engagement with services (Bush et al., 2019; McClintock et al., 2016). This issue is exacerbated by a lack of Māori representation in the healthcare workforce. Māori make up approximately 16.5% of the population of NZ (Statistics New Zealand, 2020). In contrast, based on available data from 2009/2010, 6.3% of registered nurses, 4.5% of psychologists, 7.5% of midwives and 4.3% of physiotherapists identified as Māori (Manatū Hauora, 2011).

The paucity of Māori clinicians has been a longstanding concern. In 2002, Levy prepared a report for the NZPB identifying barriers and incentives for Māori participation in the psychology profession. One of the barriers was that Māori psychologists were often marginalised into specific roles, which excluded and discouraged them from other areas of psychology. For example, by default Māori psychologists were often required to work with Māori clients and simultaneously supervise non-Māori psychologists working with Māori, or they were expected to deliver the cultural component of psychology training programmes (Levy, 2002). While this practice recognises that these roles require knowledge from within the culture, with a lack of critical mass this puts pressure on existing Māori psychologists. As Levy explains, there is a tendency for issues of relevance to Māori (in training and practice) to be assigned to a “cultural category,” and in doing so cultural competence is seen as an add-on to the core components of psychology training. From the perspective of NZ’s bicultural foundations, clinical and cultural competence are inseparable; to be a competent practitioner in NZ, these aspects of training and practice must go hand in hand.

From a biomedical perspective, healthcare providers may clearly understand someone's symptoms as indicative of disease or illness, while the person's experience of health and illness is much more complex (Fisher-Borne et al., 2015). Fisher-Borne et al. suggest seeking to understand the role of culture in the person's experience is the realm of cultural competence, and this is much more than 'knowing' about group differences. Dunn (2002) explains cultural competence firstly in terms of what it is not. Cultural competence is not something which can be taught outright, it is not a technical or problem-solving skill, and it is not a specific communication technique. Cultural competence is an ongoing process and there is not a point at which a clinician becomes fully competent in someone else's culture or cultures (Fisher-Borne et al., 2015). Dunn (2002, p. 107) says that cultural competence, "…requires a fundamental change in the way people think about, understand and interact with the world around them." Elder (2017b) insists cultural competence must begin with "self-reflective critique of the culture of practice" rather than assumed competency in another's culture. Other elements of cultural competence are being informed about core cultural issues, understanding issues related to health and wellbeing for the cultural groups with whom one works, developing trusting respectful relationships, and negotiating for mutually acceptable and understandable interventions of care (Dunn, 2002). The aim is that collectively these factors will create a culturally safe environment which supports the client to explain what the illness or mental health concern means to them.

While training options exist to help clinicians feel more capable when working with Māori clients, how cultural competence is best implemented in clinical practice is not something which can be readily prescribed (Lacey et al., 2011). Lacey et al. (2011) propose the Hui Process as a framework which draws on traditional Māori knowledge and describe how this can be aligned with clinical assessment. They explain the traditional hui process as incorporating principles of mihi, whakawhanaungatanga, kaupapa, and poroporoaki; that is the initial greeting phase, making connections between the people involved in the hui, attending to the purpose of the encounter, and concluding the business of the encounter. The advantage of this framework is that clinical interaction with Māori is guided by tikanga (discussed in more detail in the following section) from te Ao Māori and based on these underlying values there is an understanding that the relationship has been established should future encounters be required. The Hui Process guides health practitioners in how to incorporate cultural competency into clinical practice (Pitama et al., 2014) and is part of the Indigenous Health Framework and Hauora Māori training for medical students at Otago university and the University of Auckland, respectively.

3.1.2. Therapeutic Alliance

The use of cultural protocol or tikanga, is one way to enhance the therapeutic alliance with some Māori clients and has been found to be particularly beneficial when planning for Māori responsive services (Elder et al., 2009; Elder, 2017b). Tikanga Māori are protocols which are underpinned by a common set of fundamental core values (King et al., 2018). There are multiple ways to consider tikanga Māori, though Mead (2016) says an obvious understanding is that tikanga provides a means of social control, indicating the correct or appropriate way of behaving and acting in everyday life. Another way is to consider tikanga Māori as a component part of mātauranga Māori which puts this knowledge into practice (Mead, 2016).

Pomare (2015) describes engagement with Māori as fundamental to effective psychological assessment, as establishing the therapeutic alliance parallels the relationship of whānau and significance of collectivism to Māori identity and Māori models of health. More than simply ‘building rapport’ (Lacey et al., 2011) whakawhanaungatanga is a process of establishing relationships with others which uses social and cultural tikanga associated with whānau (Bishop, 1996). For example, Bennett et al. (2016) advocate self-disclosure by the clinician about their own background when working with Māori clients, as this typically occurs as an aspect of whakawhanaungatanga. The reciprocal sharing of information on behalf of client and clinician can be challenging for some clinicians. However, this lays the foundations for clinical work to proceed as whakawhanaungatanga identifies the nature of the relationship between the parties (Bennett, 2017; Elder, 2017a, 2017b).

The therapeutic relationship has been consistently identified as crucial to the success of a given intervention (Bennett, 2017). Drury and Munro (2008) define the therapeutic alliance as a collaborative relationship which builds on the strengths of the client, discussing what is working well while being mindful of the issues of concern. Drury and Munro say that a contributing factor to successful outcomes are the resources a client possesses or has available to them through social support. However, while the clinician is in prime position to influence the therapeutic alliance between themselves and their client, this relationship can sometimes be superseded in preference of standardising assessment and treatment. The failure to engage is often considered a client factor, rather than being attributed to practitioner skill (Drury & Munro, 2008).

In clinical practice therefore, the importance of engagement between the client (and potentially the client's whānau) and the clinician cannot be overstated. Eiraldi et al. (2006) suggest for ethnic minority families, the availability of culturally sensitive staff and practitioners of similar cultural backgrounds greatly increases client engagement and treatment seeking behaviour. In a study which engaged Latino children and their families in intervention research for neurodevelopmental disorders, Ratto et al., (2017) highlighted they were most successful in engaging families when the research staff took the time to build trust and relationships and showed genuine interest in families' lives. From their experiences, Ratto et al. surmised that parents from ethnic minority families wanted to form relationships with the researchers before they would trust their expertise in treating their children.

3.1.3. Case Formulation

Traditionally, clinical practice has focused on diagnosis as essential to guiding treatment selection and predicting outcomes (Macneil et al., 2012). However, diagnosis in isolation has its limitations, particularly in relation to mental health. As Tarrier and Calam (2002) explain, in forming a diagnosis the clinician selects symptoms from a list in which some items are present and some are not; this means people could share the same diagnosis and potentially few, if any of the same symptoms. Diagnosis also provides no indication as to causality and only incomplete information about an individual's experience of their issues (Macneil et al., 2012).

Case formulation based on individualised assessment was developed in response to the limitations of treatment driven by diagnosis (Macneil et al., 2012). Kuyken et al. (2009) define formulation as the amalgamation of an individual's experience with relevant evidence-based clinical theory and research, thereby linking assessment with treatment. As a client-focused approach, this moves beyond diagnosis and situates a person and the difficulties they are experiencing in the context of their lived experience. Tarrier and Calam (2002) say the advantage of case formulation is a flexible and idiosyncratic understanding of a person's difficulties irrespective of diagnostic category. Having a shared understanding of a person's difficulties provides a rationale and a shared agenda for what support is needed (Macneil et al., 2012). The formulation is useful to identify maintaining factors, target treatment to the client's needs and to be informed about what would be most helpful for the person. Māori psychiatrist Dr Mark Lawrence (2017) says that formulation forms the basis of any aetiological models. Therefore, understanding what this person's concerns are through formulation, informs diagnosis and treatment; this is always relevant.

The traditional focus in health has been on the individual, and more about seeking to identify pathology than identifying strengths which includes cultural strengths (Elder, 2017b). Elder says the risk with this for some Māori is the individual and their whānau feel defined by what they lack or what is challenging. Whereas whānau systems have the potential to play an integral part in recovery. As the basic building block of the social system, Mead (2016) says Te Ao Māori is full of social groups who describe themselves as whānau. Mead explains the use of the term 'whānau' contains within it the defining characteristic which distinguishes that whānau group from some other group, and often this is through shared whakapapa. A case formulation can incorporate and utilise a person's strengths and this can contribute to reduced symptomology and increased resilience (Macneil et al., 2012). As family and social histories are key components of medical and psychological assessment, assessments with Māori clients need to incorporate an understanding of the Māori concept of whānau (Elder, 2017b).

The Meihana Model is a clinical assessment framework which incorporates cultural knowledge and clinical practice to guide assessment and intervention with Māori clients and whānau (Pitama et al., 2007). Models such as this are necessary as assessment interviews involve comprehensive questions which originate from a specific cultural context (Pitama et al., 2007). The Meihana model builds on the interrelated dimensions of Te Whare Tapa Wha (Durie, 1985). As shown in Figure 1, the Meihana Model uses the analogy of a waka hourua (double-hulled canoe) in which one of the hulls represents the client and the other is their whānau. This indicates whānau as having a role in assessment, intervention and ongoing involvement of the client (Pitama et al., 2014). The hulls are connected by aku (cross beams), and each of these represents a dimension which the practitioner needs to develop an understanding of; both strengths and weaknesses and how these are related to the client’s health. The aku include tinana (physical health), hinengaro (psychological and emotional wellbeing), iwi katoa (support services and systems), wairua (spirituality) and taiao (physical environment). As well, the waka hourua is depicted as being buffeted and carried along the journey towards wellbeing by ngā hau e wha (the four winds) and ngā roma moana (ocean currents). These represent contemporary and historical factors which may be influencing the health experience of whānau such as colonisation, marginalisation, racism and Māori beliefs and values (Pitama et al., 2014). In conjunction with the Hui Process (described above), the Meihana model comprises the Indigenous Health Framework which is part of the curriculum for medical students at Otago University (Pitama et al., 2014). Together this framework provides clinicians with an indication of how to conduct the assessment interview and describes how to extend the standard history taking process to develop a case formulation when working with Māori.

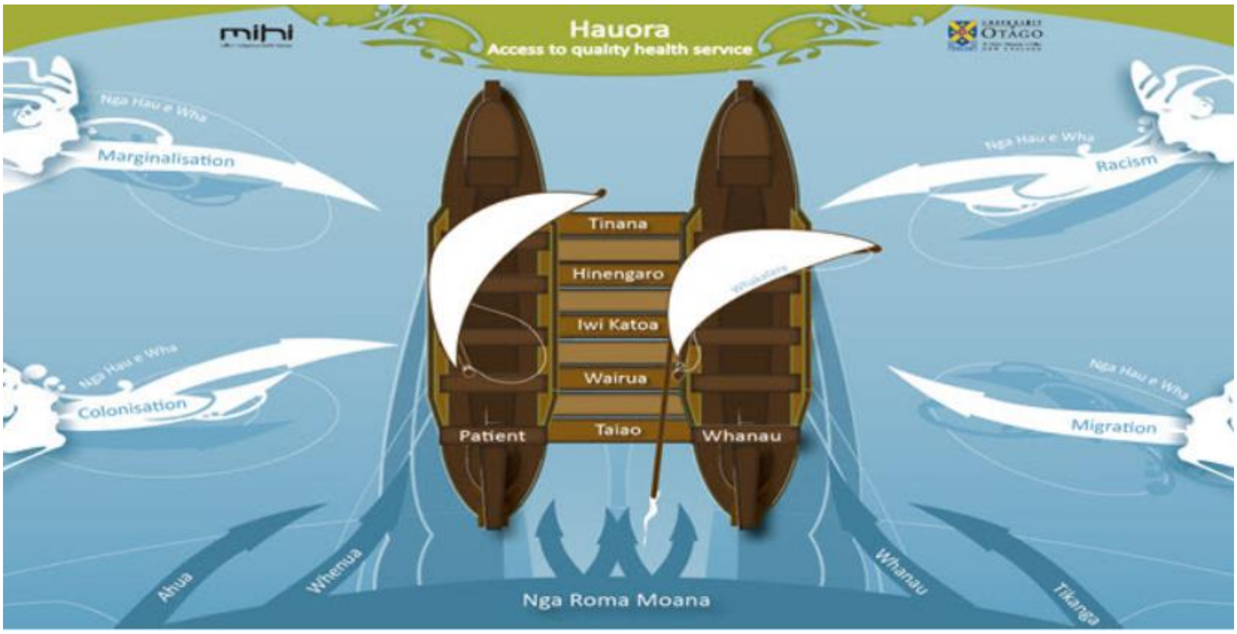

Figure 1. ***Diagram of the Meihana Model****. (From "Improving Māori Health through Clinical Assessment: Waikare o te Waka o Meihana," by S. Pitama, T. Huria and C. Lacey, 2014, The New Zealand Medical Journal, 127(1393), p.108)*

3.2. Cultural-Clinical Interface

While psychiatric and cultural phenomena can occur independently of each other, often they both appear in presenting symptoms and sequelae (Lawrence, 2017). Therefore both need to be considered in formulating an appropriate treatment plan (Lawrence, 2017). A model which reflects true integration of clinical treatment with a Māori world view assumes neither intervention has dominance and both approaches can complement each other based on the person's needs (Tapsell, 2017). Tapsell says this requires a clear model of care, competent leadership and practitioners who are competent in both cultural and clinical domains. An ongoing challenge for MHS and the wider healthcare system is building a strong cultural-clinical interface (Durie, 2011; Kingi, 2017b). The advantage is the methods and values of each system can be applied to establish more comprehensive understandings of health and wellbeing (Durie, 2004).

From a Māori worldview there is mistrust of a system which cannot account for spiritual phenomena (Durie 2004). From a scientific viewpoint, knowledge is supported by empirical evidence and if it is not able to be replicated, validity is questionable (Durie, 2004). For some types of questions science does provide the best answer; however the other key feature of scientific knowledge is that knowledge is held tentatively and is open to disconfirmation (Macfarlane et al., 2011). As Durie explains there is nothing gained by using the tools of one of these knowledge systems to scrutinise the other. Instead gains are made at the interface of these systems when the insights and methods of one are used to enhance the other (Durie, 2004). For example, Niania et al. (2019) discuss their practice where a Māori healer (Wiremu Niania) and a psychiatrist (Allister Bush) have worked in partnership for over a decade. Niania et al. describe the Māori concepts which underpin their work together and give examples of how spiritual concepts can be applied in clinical settings. In doing so they want this knowledge to assist psychiatrists to collaborate with Māori healers and kaumatua. Their goal is to seek the best outcomes for the people they support, and in doing so they agree it is necessary to address mental health issues with whānau Māori from both cultural and clinical perspectives.

The overall health system’s response to Māori health outcomes is not an issue for Māori clinicians or for whānau Māori and individuals to remedy on their own. These are systemic issues which require systems-level approaches. Working at the cultural-clinical interface requires consideration of at least two perspectives; scientific and Indigenous knowledge (Durie, 2017c). From this there is the possibility to create new knowledge which improves health outcomes and thereby the potential for NZ society to benefit from mātauranga Māori.

3.3. Chapter Summary

The aim of the current research is to explore the experiences of whānau Māori who have accessed services for ADHD in NZ to understand the impact these experiences had on service use. The objective in doing so is to gain insight into why Māori may under access MHS relative to anticipated need. As was discussed in this chapter, it has been suggested a lack of culturally appropriate MHS could be a contributing factor. He Ara Oranga heard from service users that often mainstream services were not culturally safe environments and there was a perceived lack of cultural competence among mental health workers. This chapter discussed how culturally embedded models of care and a culturally competent workforce might address those concerns.

Research points to the importance of drawing together clinical and cultural knowledge to improve health outcomes for Māori. Mandates for cultural competence are an ongoing aspect of professional development for many health professions. However, how this is applied in practice depends on the individual practitioner. It can be difficult for clinicians to know how to enact cultural competence and consequently, models such as the Hui Process and Meihana Model have been introduced in medical schools and other training programmes to support this. In this way, tikanga Māori informs clinical practice that better aligns with Māori values and beliefs. One of the questions this study will explore is whether the support available to whānau for ADHD was culturally relevant and if this influenced how whānau engaged with treatment.

From a biomedical perspective a diagnosis is descriptive of a specific set of symptoms. The diagnosis does not reveal the person's experience of their symptoms. Case formulation was discussed and is an important concept in the current study. In chapter four, ADHD is discussed in detail as a neurodevelopmental disorder which is diagnosed and subsequently treated as a biomedical condition. However, it is typically the functional impairment from symptoms which leads to assessment and support being sought. Context is always relevant to a person's presenting issues and culture is a significant aspect of context. Case formulation as compared to diagnosis better incorporates lived experience, to thereby inform a responsive treatment plan.

Chapter Four: Attention-Deficit Hyperactivity Disorder

This chapter introduces ADHD. This provides context for the experiences of whānau in the current study, and describes the symptoms which may be present, related functional impairment, and how ADHD is optimally assessed, diagnosed, and treated. The diagnostic criteria and associated features of ADHD are discussed. The prevalence of ADHD and reasons for variation in prevalence estimates are explained. This includes a focus on the prevalence of ADHD in NZ and how available data are tentative at best. The multiple etiological factors which have been suggested, high comorbidity with other psychiatric conditions and ongoing implications throughout the lifespan are also discussed, as precursor to the debate about ADHD as a controversial diagnosis. Finally, this chapter discusses the assessment and evidence-based treatment practices for ADHD.

4.1. Diagnostic Criteria and Associated Features

ADHD is a neurodevelopmental disorder characterised by behavioural symptoms in the domains of inattention and/or hyperactivity/impulsivity (American Psychiatric Association (APA), 2013b). Based on criteria in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)[2] (APA, 2013b), these behaviours (see Table 1) are inconsistent with developmental level, disrupt social relationships, and impact academic/occupational functioning. For diagnosis, the behavioural symptoms are required to be present prior to age 12, have a persistent course, and occur in 2 or more settings (such as at home and school). As such, ADHD is a syndrome as there are no necessary or sufficient behavioural deficits and only some symptoms (six out of nine in either one or both domains) are required to be present for diagnosis (Swanson et al., 2007). Resultantly, ADHD can be classified as combined, predominately inattentive, or predominately hyperactive/impulsive presentation depending on the manifestation of core symptoms for different individuals (APA, 2013b).

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[2] The DSM-5 was the current version of the DSM at the time of writing. The DSM-5 Text Revision (DSM-5-TR) was subsequently released by the APA in 2022, although the diagnostic criteria for ADHD remained the same.

Table 1

List of Possible Symptoms of ADHD in DSM-5 in Domains of Inattention and Hyperactivity/Impulsivity

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Symptoms of Inattention

1. Fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities
2. Difficulty sustaining attention or remaining focused in tasks or play activities
3. Does not seem to listen when spoken to directly
4. Does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace
5. Difficulty organizing tasks and activities
6. Avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort
7. Loses things necessary for tasks or activities
8. Easily distracted by extraneous stimuli
9. Forgetful in daily activities

Symptoms of Hyperactivity/Impulsivity

1. Fidgets with or taps hands or feet or squirms in seat
2. Leaves seat in situations when remaining seated is expected
3. Runs about or climbs in situations where it is inappropriate
4. Unable to play or engage in leisure activities quietly
5. “On the go,” acting as if “driven by a motor”
6. Talks excessively
7. Blurts out an answer before a question has been completed
8. Difficulty waiting his or her turn
9. Interrupts or intrudes on others

Note. Adapted from Diagnostic and Statistical Manual of Mental Disorders (5th ed., p 59) by American Psychiatric Association, 2013, American Psychiatric Publishing. Copyright 2013 by American Psychiatric Association. At least six symptoms are required from either one or both domains and must have persisted for at least six months. DSM-5: Diagnostic and Statistical Manual, fifth edition.

A combination of behavioural symptoms and functional impairment is required for diagnosis. The behaviours associated with ADHD can impact on family functioning, disrupt parent-child relationships, and increase parental stress; these issues can, in turn, result in psychosocial consequences such as negative parenting practices, and poor peer relationships, which then influence the severity, continuity and outcomes for ADHD (Johnston & Mash, 2001; Pham, 2015). In interactions with peers, hyperactive and impulsive behaviours, poor emotion regulation and aggression can contribute to peer rejection (Hoza, 2007). Academic functioning and achievement may be impaired, as children with ADHD are identified as being off-task more often, disruptive to peers and during teacher instruction, and as being less productive and accurate when completing academic tasks (DuPaul, 2007). Therefore, assessment and treatment would ideally address functional impairment alongside behavioural symptoms (Sasser et al., 2017). The impaired functioning is often the primary reason for referral (Sasser et al., 2017), and if a whānau or family system can accommodate their young person's difficulties, having their child diagnosed with ADHD may not have any perceived benefit. Thus, one of the research questions in the current study reviewed how whānau Māori understood and accommodated their child's ADHD-related behaviours prior to diagnosis.

4.1.1. Prevalence

There is significant variability in ADHD prevalence estimates reported by individual studies. This is partially due to changes in diagnostic criteria and different methods used to assess for ADHD in different studies (Polanczyk et al., 2014; Willcutt, 2012). However, the worldwide-pooled prevalence of ADHD has been estimated to be between 5.9-7.1% in children and adolescents, with similar prevalence estimates of 5% in adults (Willcutt, 2012). The DSM-5 (APA, 2013b) also concludes that ADHD occurs in most cultures in about 5% of children. ADHD therefore is one of the highest mental health disorders affecting children and adolescents; as there is significant associated lifetime burden, ADHD represents a major health priority (Polanczyk et al., 2015).

There is a lack of robust data about ADHD prevalence in NZ. Prevalence figures in NZ have not consistently appeared in either health or mental health statistics and in the past have been grouped with 'other' behavioural difficulties or childhood disorders. According to NZ Health Survey 2020/21 data, 2.6% of children aged 2-14 years (or an estimated 22,000 children) have ADHD (Manatū Hauora, 2021c). However, these figures are based on parent report which does not clarify if a formal diagnosis has been made. Manatū Hauora state this estimate likely underestimates prevalence in NZ, and many families may be unaware their child has ADHD. Estimates of ADHD prevalence are also unable to be made from pharmacological dispensing data as methylphenidate, the medication typically prescribed for ADHD, is first-line treatment for conditions other than ADHD. Furthermore, not every person diagnosed with ADHD will use medication and dispensing data also misses scripts which are issued by a doctor, and not filled. The available data (and lack of) indicates more reliable information is needed about the prevalence of ADHD in NZ to enable a cross-sectional description of the presence of ADHD amongst NZ children (Tipene, 2018).

There is considerable research which says ADHD is diagnosed more frequently in males, and conjecture if this is because the disorder is more prevalent in males or underdiagnosed in females (Rucklidge, 2008). The available NZ Health Survey data indicates ADHD is potentially more prevalent amongst boys than girls in NZ (Manatū Hauora, 2021c). A meta-analysis by Willcutt (2012) confirmed males were more likely than females to meet criteria for ADHD of any subtype, and were most likely to have ADHD with combined presentation. Based on meeting symptom criteria (i.e., not full diagnostic criteria) females were more likely than males to have symptoms of inattentive type ADHD.

In terms of ethnicity, Willcutt (2012) acknowledged there were few studies outside the United States (US) which looked at difference in prevalence of ADHD as a function of race or ethnicity. In their review of research within the US, they said studies which had found differences in prevalence based on ethnicity were not statistically significant once socioeconomic status (SES) was accounted for, highlighting a need for further research. The NZ Health Survey data also suggests there is no statistically significant difference in prevalence of ADHD between Māori and non-Māori children (Manatū Hauora, 2021c).

4.1.2. Etiology

As discussed, DSM-5 categorised ADHD as a neurodevelopmental disorder. Neurodevelopmental disorders are conditions which are present from birth and the cause is thought to have occurred during gestation or birth (Van Herwegen et al., 2015). Van Herwegen and colleagues define neurodevelopmental disorders as “disorders that are of a genetic or multifactorial origin that result in one or more specific cognitive deficits. These deficits are present early in life and extend into adult life without showing relapse or remission…" (Van Herwegen et al., 2015, p. 4). Although ADHD may have an expected lifelong course and be characterised by hyperactive and impulsive and/or inattentive symptoms, the domain-grouped symptom criteria for ADHD reflect variation in how symptoms present. This heterogeneity is also reflected in the number of etiological explanations which have been proposed (Kieling et al., 2008).

ADHD is one of the most researched psychiatric conditions of childhood and multiple etiological factors have been proposed, each with varying degrees of support (Swanson et al., 2007). This includes the contribution of genetics (Stevenson, 1992), environmental factors (Kahn et al., 2003), neuropsychological deficits (Sonuga-Barke et al., 2008; Willcutt et al., 2005), and neurobiological factors (Swanson et al., 2007). Overall, there is no single consistent feature present for all children with ADHD.

There has been substantial evidence of a genetic contribution to ADHD, and as a result ADHD has come to be understood as mostly due to genetics (Mick & Faraone, 2008; Stevenson, 1992). However, there are also no biological markers which definitively confirm the presence of ADHD (Goodman, 2007). Research has further identified environmental factors which are linked with increased rates of ADHD and it has been suggested ADHD potentially arises from the complex interplay between genetic and environmental risk factors (Kahn et al., 2003; Mick et al., 2002; Swanson et al., 2007).

A major theory is that ADHD involves deficits or delays in executive functions (EF) especially inhibition and working memory. As a group, research has found children with ADHD have poorer performance on tests of EF (Robinson & Tripp, 2013; Sonuga-Barke et al., 2008). The problem is the same neuropsychological deficits are not found in all studies or for all people with ADHD, and EF deficits are not unique to ADHD. Although EF deficits don't explain all cases of ADHD and are not necessary for diagnosis, EFs are relevant to overall functioning (Robinson & Tripp, 2013; Sonuga-Barke et al., 2008). For example, children who have ADHD (with or without EF deficits) have similar levels of

ADHD symptoms, though those with EF deficits have worse academic outcomes (Biederman et al., 2004). For the purpose of treatment planning, clinicians should be aware there are often different interacting causes of ADHD-related behaviours (te Meerman et al., 2017). While it is beyond the scope of this thesis, establishing a neuropsychological profile for a child with ADHD would add value as interventions could be tailored to the child's individual needs (Sonuga-Barke et al., 2008).

4.1.3. Comorbidities

The clinical heterogeneity of ADHD is complicated by high rates of comorbidity with other psychiatric concerns (Jarrett & Ollendick, 2008). About 60% of children and adolescents with ADHD are thought to have one or more comorbid conditions which includes other neurodevelopmental disorders, learning disorders, and both externalising and internalising disorders (Gnanavel et al., 2019). Oppositional defiant disorder (ODD) and conduct disorder (CD) are frequently comorbid with ADHD, particularly amongst boys, with varied estimates between 30-50% (Gnanavel et al., 2019; Jarrett & Ollendick, 2008). Approximately 25% of children with ADHD meet criteria for an anxiety disorder (Jarrett & Ollendick, 2008). Previously, criteria in the DSM precluded ADHD and Autism Spectrum Disorder (ASD) as dual diagnoses but this is no longer the case in DSM-5. Among children with ASD, one study found that the rate of comorbidity with ADHD was 42% (Mayes et al., 2012). Other commonly comorbid disorders are mood disorders and substance use issues (Anastopoulos et al., 2011; Biederman, 2003).

A large-scale study by Jensen and Steinhausen (2015) aimed to identify the full range of disorders comorbid with ADHD. Their sample included a total of 14,825 children aged between 4 and 17 years, who were diagnosed with ADHD in Danish psychiatric hospitals between 1995 and 2010. Unlike other studies which deliberately screen for comorbid conditions using standardised assessment methods, ADHD and other comorbid conditions were identified during normal clinical practice. Other studies of comorbidity also usually exclude children with intellectual disability (ID), ASD or psychosis whereas Jensen and Steinhausen's study considered all clinically relevant disorders coexisting with ADHD. 52% of the in-patient sample had at least one comorbid disorder, and 26.2% had two or more comorbid disorders. The most prevalent comorbid disorder was CD (16.5%), followed by developmental disorders of language, learning and motor skills (15.4%), ASD (12.4%) and ID (7.9%). There was also a pattern identified for different age groups. Anxiety disorders, CD, and tics manifested in late childhood or early adolescence. Substance use disorders (SUD), psychotic disorders, and affective disorders only occurred in late adolescence. Given the range of comorbid disorders which they identified, the researchers suggested long-term outcome studies to determine if comorbidity at first time diagnosis might be a risk marker of later developmental trajectories; thus, rendering comorbidity an important aspect of assessment.

Pham (2015) agrees it is likely in practice that comorbid conditions mask ADHD symptoms or are overlooked when ADHD is assessed. Either of these situations has the potential to impact on the treatment options provided to young people and their whānau, and ultimately contribute to poorer outcomes (Williamson et al., 2014). Armstrong and colleagues (2015) undertook a study which looked at functional outcomes for children (aged 5-13 years) with ADHD by comorbidity status. Compared to children with ADHD alone, children with ADHD and other comorbidities had more difficulties with their peers, greater difficulty with daily functioning and poorer rated quality of life for both the child and their family. Comorbidity thus adds complexity to both diagnostic and treatment considerations.

High rates of psychiatric comorbidity also occur for adults with ADHD. A study by Surman et al. (2010) investigated whether adults with ADHD recruited for clinical trials could be considered representative of other adults with ADHD, as exclusion criteria for clinical trials often specifies no comorbidities. They compared a community sample of adults with ADHD with a clinical trial sample on measures of psychopathology and psychosocial functioning. Due to significant comorbidity in the community ADHD sample, 61% would have been excluded from the clinical trial. In the community sample, comorbidities (as defined by formal diagnostic measures) included: bipolar disorder (19%), major depressive disorder (31%), anxiety disorder (35%), alcohol dependence (28%), substance dependence (22%), and antisocial personality disorder (12%).

4.2. Ongoing Implications throughout the lifespan

ADHD was previously conceptualised as a behavioural disorder and it was thought children grew out of their symptoms during adolescence (Goodman, 2007). Although ADHD is now classified as a neurodevelopmental disorder (APA, 2013), ADHD also occurs (and can be first diagnosed) amongst adults, although there is mixed evidence if this is a continuation from childhood or a specific syndrome (Moffitt et al., 2015). Research suggests there may be an age-related decline in (overt) symptoms of hyperactivity while symptoms of inattention and impulsiveness persist (Faraone et al., 2006).

ADHD has therefore increasingly been recognised as continuing in adolescence and adulthood (Cadman et al., 2012; Faraone & Antshel, 2008; Goodman, 2007; Waite & Ramsay, 2010). A meta-analysis of three large-scale longitudinal population-based studies (two based in NZ) considered the diagnostic transitions from childhood to adolescence to early adulthood (Copeland et al., 2013). There was strong support for a stable developmental course of ADHD, with ADHD as a child predicting both ADHD and ODD as an adolescent, and ADHD as an adult. It is fairly common that on review of their own functional impairment and ongoing difficulties, parents will recognise symptoms in themselves once their children have been diagnosed with ADHD (Goodman, 2007).

Children with ADHD are at increased risk for lifelong impairment in multiple domains of life (Armstrong et al., 2015) and (as mentioned) outcomes are exacerbated in the presence of comorbid conditions (Jarrett & Ollendick, 2008). Adverse outcomes include: academic underachievement over and above comorbid learning disorder (Barbaresi et al., 2007); increased risk for social and emotional adjustment difficulties such as poor self-esteem (Williamson et al., 2014); difficulty with self-regulation of emotion, with greater negative affect and elevated levels of emotional lability and irritability (Anastopoulos et al., 2011). ADHD has also been associated with several forms of risk-taking behaviour such as risky driving, substance use and unprotected sex (Pollak et al., 2019). A review of health outcomes linked to ADHD found associations between ADHD and elevated morbidity and mortality, elevated risk of accidental and self-inflicted injury in childhood and adulthood, SUDs particularly in the presence of comorbid CD, and increased rates of smoking (Nigg, 2013). There was also an increased risk of suicide among people with ADHD, when comorbid with mood, conduct or substance use disorders (Nigg, 2013). As functional impairment forms part of the diagnostic criteria for ADHD, an individualised treatment plan based on a thorough case formulation would ideally attempt to mediate these outcomes.

4.3. Guidelines

NZ Guidelines for the Assessment and Treatment of ADHD were published in 2001 (Ministry of Health, 2001). Recently (July 2022) the published guidelines were archived, and the MOH have noted they no longer provide treatment or clinical guidelines for ADHD. NZ clinicians are advised to follow best practice guidelines from professional bodies such as the Royal Australian and NZ College of Psychiatrists (RANZCAP) and the British National Institute for Health and Care Excellence (NICE). The RANZCAP guidelines for ADHD in childhood and adolescence have currently (September 2022) been withdrawn from the RANZCAP website, pending review. Likewise, RANZCAP refer NZ clinicians to NICE guidelines and to treatment recommendations from the British Association for Psychopharmacology (BAP). The Australian ADHD Professionals Association have also released comprehensive guidelines in July 2022 (Australian ADHD Guideline Development Group (AAGDG), 2022). Reference will still be made to MOH guidelines in the current research, as these guidelines were current when all participants underwent assessment with their child or young person and when the majority were interviewed for this research. The MOH 2001 guidelines also made specific reference to working with Māori children and whānau, and this advice will understandably be absent from guidelines developed in other countries.

The Assessment and Treatment sections which follow discuss recommended practice based on an amalgamation of current evidence-based guidelines and supporting recommendations from ADHD literature. Guidelines for ADHD exist to support clinical decision making, to improve recognition and diagnosis of ADHD, and to improve the quality of care (NICE, 2019). There is significant agreement between clinical guidelines with regards to the need for multiple assessment methods and sources of information, and for a treatment plan which incorporates evidence-based treatment options and accounts for client (and caregiver) preference and choice. While guidelines exist to support clinicians, these are not mandatory and clinicians are responsible to act in the best interest of their client, in consultation with the client and with their family (NICE, 2019).

4.3.1. Assessment

As mentioned, there is no single, definitive test to confirm ADHD and no medical, psychological, or neuropsychological test which is necessary to establish the diagnosis (Feldman & Reiff, 2014). Instead, diagnostic criteria focus on behavioural symptoms (Wolraich et al., 2019). Children who have disruptive or hyperactive behaviours are more likely to be referred for clinical assessment (Feldman & Reiff, 2014). As these behaviours may also be characteristic of children and young people during typical development, diagnosis requires these symptoms be both persistent and excessive for expected developmental level (Wolraich et al., 2019).

Ultimately, diagnosis of ADHD is a clinical decision which relies on a comprehensive clinical assessment drawing together information from multiple sources (NICE, 2019). For children and adolescents, this includes a clinical interview with caregivers to gain a detailed developmental, psychosocial, psychiatric and medical history (AAGDG, 2022; NICE, 2019; Wolraich et al., 2019). To confirm symptoms occur in more than one setting, reports are obtained from multiple informants (AAGDG, 2022). DSM-based ADHD rating scales can be useful to obtain information from caregivers and teachers, though in isolation these scales are insufficient for diagnosis (Wolraich et al., 2019). As there is a potential for bias in informant ratings, the guidelines from BAP say rating scales should be part of a comprehensive assessment (Bolea-Alamañac et al., 2014). If doubt exists during assessment about the presence of symptoms across settings, NICE guidelines also suggest observation of the child may be necessary.

Diagnosis also requires functional impairment resulting from behavioural symptoms (American Psychiatric Association, 2013a). As mentioned, assessment should therefore involve a full clinical assessment which assesses for impairment in different domains (Wolraich et al., 2019). This is necessary to determine the degree to which functional impairment is due to ADHD as opposed to another condition, or to a psychosocial factor such as dysfunctional family interactions (Sasser et al., 2017). Explaining contributing factors to the behaviours of a child or adolescent and identifying functional impairment provide targets for treatment. In determining the clinical significance of impairment from symptoms, NICE guidelines also suggest clinicians take into account the young person's view of their symptoms wherever possible (NICE,2019). Australian guidelines recommend assessment should highlight the person's strengths, and factors which might minimise the impact of symptoms (AAGDG, 2022).

Comorbid conditions potentially impact both diagnosis and treatment (Faraone & Antshel, 2008). As a standard of clinical care, clinical assessment needs to include evaluation for the presence of other disorders (Bolea-Alamañac et al., 2014). This should exclude other health and mental health conditions with similar symptoms and involve careful evaluation of potential co-occurring conditions (AAGDG, 2022; Wolraich et al., 2019). There is consensus across the guidelines that the assessor needed to be adequately trained or have ADHD-specific supervision with an experienced clinician, and this included having experience in the diagnosis of comorbid conditions and differential diagnosis (AAGDG, 2022). For children and adolescents, Australian guidelines also recommend clinicians enquire about family functioning and caregiver mental health, to enable provision of support for caregivers at the time of diagnosis.

As there is a lack of consistent neuropsychological profile, while some neuropsychological tests can be useful in the assessment of EF in ADHD these tests should not be used in isolation to diagnose ADHD (Sonuga-Barke et al., 2008). Neuropsychological testing has not been found to improve diagnostic accuracy although assessment of EFs may clarify strengths and weaknesses and assist with tailoring interventions at school (Bolea-Alamañac et al., 2014; Wolraich et al., 2019). BAP guidelines suggest that neuropsychological testing should be considered where impairment at home or school/work is greater than would be expected from the symptoms of ADHD alone, stating this may also support the case for additional support.

As well as recommendations for assessment, guidelines from NICE and AAGDG also make suggestions for best practice once a diagnosis is confirmed (AAGDG, 2022; NICE, 2019). NICE recommend services which support people with ADHD should have available a comprehensive directory of information and services. After diagnosis, clinicians are recommended to provide information to the person and/or their caregivers about what ADHD is, what causes ADHD, potential consequences and information about evidence-based treatments, "in a way that provides hope and motivation." (AAGDG, 2022). The guidelines also suggest people receiving a diagnosis of ADHD should be informed about support groups and voluntary organisations, reputable websites, support which may be available for education/employment, and eligibility for disability support. For children and adolescents, NICE guidelines also advocate for the clinician to contact the school to communicate the diagnosis and how to best support the child with their symptoms.

4.3.2. Treatment

Medication

Although ADHD is defined by a set of symptoms which occur to varying degrees for different people, ADHD is often taken to be a discrete biomedical entity (Batstra et al., 2014). As a result, ADHD is often treated as a medical condition and managed with medication. However, the medications used for ADHD do not resolve the disorder. Rather the medication supports children temporarily with some of the core symptoms, which never truly remit (New Zealand Formulary for Children, 2022). The primary benefit of pharmacotherapy is that individual functioning is improved at the "point of performance" in academic, occupational or interpersonal functioning (Waite & Ramsay, 2010). Medication may also reduce symptoms so that potentially the child can better engage in non-pharmacological interventions (AAGDG, 2022). Pharmacological treatments primarily reduce ADHD symptoms and as a secondary benefit this may contribute to improvements in functioning and wellbeing; non-pharmacological treatments primarily target improved functioning and wellbeing and these skills and interventions may temper the impact of ADHD symptoms (AAGDG, 2022).

In the Australian guidelines, the AAGDG (2022) take an ecological approach to treatment and focus on everyday functioning and quality of life. With some variation based on the age of the child and balancing desirable and undesirable effects, the AAGDG recommends concurrent medication and non-medication treatment. This is unless medication is indicated first due to the severity of symptoms, or if only one treatment option is needed or available. The AAGDG acknowledge only one treatment mode may be accessible to families, based on cost, location, and service availability. A similar situation regarding access to treatment is seen in NZ. They suggest whatever options are offered (and available) these should be accompanied with relevant information, to facilitate the choice of young people and their families regarding treatment.

In NZ psychostimulant medications, specifically methylphenidate or dexamfetamine are the initial pharmacological treatment options for children and young people aged 6-18 years (New Zealand Formulary for Children, 2022). If there is a poor response to stimulant medications, problematic side effects, or risk of the misuse of stimulants, the third-line medication for children is atomoxetine (a selective noradrenergic reuptake inhibitor) (New Zealand Formulary for Children, 2022). The NZ Formulary notes that ADHD medications should not be the first-line treatment offered to preschool aged children, citing evidence of lower efficacy, and increased adverse side effects for this age group. As stimulant medications are classified as controlled drugs in NZ, these medications are subject to prescribing restrictions and can only be prescribed by a paediatrician or psychiatrist following the diagnosis of ADHD (Medsafe, 2022). A GP or registered nurse practitioner may then continue to prescribe these medications acting on written advice from the medical practitioner mentioned above (Medsafe, 2022).

While psychostimulants have substantial evidence for their efficacy in reducing ADHD symptoms they are not always effective, and adverse side effects such as insomnia, headache, abdominal pain and appetite reduction may be intolerable for some individuals and their families (Capp et al., 2005; Chan et al., 2016). There are also long-standing concerns that the use of psychostimulants will contribute to substance use and SUD in later life, although there is limited evidence to support this. In a review of longitudinal data, Biederman (2003) found that youths with ADHD treated with medication were less likely to develop SUD than unmedicated youths with ADHD; they concluded that being medicated was in fact protective against SUD. Subsequent studies have not confirmed a protective effect from psychostimulants. However, a more recent meta-analysis by Humphreys et al. (2013) found no evidence treatment of ADHD with stimulant medication protected or increased the risk of going on to develop SUD.

Given these concerns about psychostimulant use, guideline recommendations vary according to the age of the person. For children aged four to six, the AAP recommend behaviour management training for parents and/or behavioural classroom interventions as the primary treatments (Wolraich et al., 2019). Likewise, NICE guidelines specify the first-line treatment for under-fives should be ADHD-focused group parent training for caregivers, along with environmental modifications. NICE recommend against medication for under-fives unless this decision is supported with a second opinion from a specialist with expertise in managing ADHD for preschool children. This may happen where behavioural interventions have been ineffective and moderate-to-severe impairment persists, in which case methylphenidate might be considered (Wolraich et al., 2019). The BAP guidelines suggest medication should be offered to all children with severe symptoms (Bolea-Alamañac, 2014). In all cases, the risk of prescribing medication to a young child, should be considered against the harm of delaying treatment (Wolraich et al., 2019).

For older children and adolescents, the AAP make a distinction in their recommendations between children aged 6 to 12 and 12 to 18-years-old (Wolraich et al., 2019). For 6 to 12-year-olds the AAP recommend medication alongside parent training in behaviour management and/or behavioural classroom interventions. With the adolescent's assent the first-line treatment recommended for 12 to 18-year-olds is medication. AAGDG and NICE guidelines both focus on establishing a comprehensive, holistic treatment plan (AAGDG, 2022; NICE, 2019). The NICE suggest medication be offered for children aged five and over if ADHD symptoms continue after environmental modifications.

The Australian guidelines recommend treatment with psychostimulant medication alongside non-pharmacological interventions for young people aged 5 to 17 (AAGDG, 2022).

Overall, the various guidelines mostly agree how ADHD medication should be managed for children and young people. Initially when ADHD is diagnosed, treatment options should be discussed with the young person and their family, with an explanation of possible benefits and side effects for each (AAGDG, 2022). If medication is agreed upon as treatment, (particularly with psychostimulants) this requires careful titration and monitoring for side effects as standard clinical best practice (Bolea-Alamañac et al., 2014; Ministry of Health, 2001; NICE, 2019). Follow-up by the assessing clinician regarding medication should continue until the dosage is optimised and stable (AAGDG, 2022). The NZ Formulary for Children (2022) recommend the continued need for medication be evaluated annually. The NZ Formulary also recommend prior to prescribing and at least six-monthly, the young person's height, weight and blood pressure should be taken, to monitor for adverse effects from medication. There should also be monitoring for tics, sleep disturbance, worsening symptoms, changes in mood or increased anxiety (AAGDG, 2022).

To summarise, there is substantial evidence psychostimulants are effective; even amid concerns about the possible long-term effects of medication, especially if taken over long periods of time (Capp et al., 2005). To account for these concerns, guidelines are generally conservative offering age-based recommendations to support clinical decision-making about the appropriateness of medication. There is also an emphasis that treatment should denote the preferences of young people and their families wherever possible. As is discussed in the current research this requires an understanding of whānau preferences regarding treatment and adequate information being available to support the child and whānau to decide. As ADHD involves both core symptoms and related functional impairment, standard clinical care indicates medication ideally forms part of a comprehensive treatment approach (Bolea-Alamañac et al., 2014; NICE, 2019). While medications are effective, this does not necessarily mean medication is sufficient (Waite & Ramsay, 2010).

Non-pharmacological interventions

Non-pharmacological interventions can also be effective in the treatment of ADHD and compared with medication the associated risks are comparatively low (Bolea-Alamañac et al., 2014; NICE, 2019). Psychosocial interventions are especially useful for very young children, and (where required due to severity) can be beneficial in conjunction with medication to improve efficacy or reduce required dosage (Caye et al., 2019). This includes group and/or individual psychological or behavioural interventions, cognitive training, and social skills training. Non-pharmacological interventions target functional and behavioural change, psychological distress, and comorbid mental health concerns (AAGDG, 2022). Therefore, these approaches form part of a holistic treatment plan which aims to address the young person's psychological, behavioural, and educational needs (NICE, 2019). An advantage of non-pharmacological interventions are that they improve functional impairment through the development of skills and strategies, and so the positive effects tend to persist (Wolraich et al., 2019).

A systematic review by Evans et al. (2018) looked at the effectiveness of psychosocial treatments for youth with ADHD. In their review they distinguished different psychosocial treatments. For example, behaviour management approaches were those interventions which alter behavioural contingencies in specific settings to increase the rate, frequency and intensity of desired behaviours and reduce undesirable behaviours. This included interventions such as parent training and classroom-based interventions. Training interventions were those approaches where new, or replacement behaviours were deliberately practiced until they became routine and part of daily habit. Training interventions included cognitive training, organisational training, and environmental modifications. Overall, Evans and colleagues concluded there was a well-established evidence base for the effectiveness of behaviour management strategies for young children with ADHD, and less so for adolescents. They also found evidence for the efficacy of training interventions varied between studies. The more closely the practiced behaviours resembled everyday activities the greater the improvement in functioning and in studies where a benefit was demonstrated, this improvement continued at follow-up to a greater extent than for other well-established treatments. This means there is potentially an advantage to interventions where young people gain real-life skills which support them in their specific areas of functional impairment.

As a behavioural management approach, parent training may appeal to families as an alternative to medication, particularly for younger children (Bolea-Alamañac, 2014). For children under five, parent training in behaviour management is the first-line treatment recommended by the NICE, AAGDG and AAP. Along with medication, parent training may also be offered to parents of children over five, with programmes becoming more intensive where there are also symptoms of comorbid ODD and CD (AAGDG, 2022; NICE, 2019). Parent training is not about improving deficient parenting; the aim is to develop specific parenting skills to support children with challenging behaviours (AAGDG, 2022). This is a family systems approach where the treatment is focused towards the whānau system in which the child lives. This targets the wider effects of ADHD symptoms for the child which may include the impact this has on the family AAGDG, 2022).

This impact can be substantial and bidirectional. Children with attentional or hyperactive difficulties often experience coercive family interactions, with parents experiencing more negative interactions with their child and increased parental stress (Bor et al., 2002). While most parenting programmes were not developed specifically for parents of children with ADHD, there is evidence the Incredible Years parent programme is effective for children with comorbid ADHD and oppositional/conduct problems (Bolea-Alamañac et al., 2014). There is also evidence for the effectiveness of the Triple-P Positive Parenting Programme (Triple-P) on measures of parent-reported child behaviour, improved parenting skills and satisfaction, higher levels of parenting competence and positive relationship adjustment (Bor et al., 2002). Through parent training, parents learn about developmental stages, appropriate behavioural expectations, behaviours to strengthen the parent-child relationship and skills to manage problematic behaviours (Wolraich et al., 2019).

Young people with ADHD often experience academic, social and behavioural difficulties at school (DuPaul, 2007). Therefore, school or classroom-based interventions aim to enhance school functioning by improving skills or behaviours or making accommodations to learning around impairment (Wolraich et al., 2019). The AAP state that for all young people aged 6- to 18-years, educational interventions including individual education plans (IEP) are a recommended part of any treatment plan. This may include behavioural strategies, modifications to the learning environment, and home-school communication initiatives (e.g., daily report card) (DuPaul, 2007). The AAP also specify that psychosocial treatments ideally coordinate efforts at school and home to enhance improvements for young people.

In general, initial discussions regarding treatment should elicit the preferences and concerns of individuals and their families and encourage discussion from young people and adolescents (NICE, 2019). Other cognitive/behavioural interventions can be offered specific to the client's needs (AAGDG, 2022) and might include support with social skills, adjustment, self-regulation and organisation (Sasser et al., 2017). Behavioural interventions do not require a specific diagnosis to be beneficial and these could still be considered when symptoms are sub-threshold for diagnosis or there is substantial functional impairment in a specific domain (Wolraich et al., 2019).

The Multimodal Treatment Study of Children with ADHD (MTA Study) (MTA Cooperative Group, 1999) is the largest study of ADHD treatments to date (Wolraich et al., 2019). The initial 14-month randomised clinical trial compared treatment outcomes for children with ADHD (combined presentation) following optimal medication management, comprehensive behavioural intervention, combined medication and behavioural intervention, or routine community care. All four treatment groups showed reductions in symptoms over the trial period. Combined treatment and medication management were found to have greater efficacy in reducing ADHD symptoms than either behavioural intervention or community care. For core ADHD symptoms, the combined treatment did not achieve significantly greater benefits than medication management alone, although outcomes for the combined treatment group were achieved with significantly lower doses of medication. It was also noted that behavioural intervention treatment was still effective, with more than three quarters of children who received this treatment achieving significant gains without medication.

In follow-up studies at three and eight years (i.e. two and six years after treatment ended) all four treatment groups continued to be improved from baseline (P. S. Jensen et al., 2007; Molina et al., 2009). However, the differences between groups in degree of improvement, no longer remained. Researchers hypothesised this could have been due to age-related decline in ADHD symptoms or because some of the participants stopped or started medication (P. S. Jensen et al., 2007). Overall, the improvements in ADHD symptoms for all treatment groups in the MTA Study supports the notion that interventions can be targeted to the needs and preferences of children and their whānau.

In summary, ideally treatment will focus on more than symptom reduction which is only one measure of treatment efficacy; intervention should also reduce functional impairment and improve the quality of life for people with ADHD and their families (Goodman, 2007). Decisions about treatment for ADHD depend on acceptability to the family and should account for client and caregiver preference (Bolea-Alamañac et al., 2014; Wolraich et al., 2019). As a standard of clinical care, child and family-based psychosocial interventions should be available to all children with ADHD, should be tailored to need, and ideally not depend on availability of services (Bolea-Alamañac, 2014). One of the research questions in this thesis is around the treatment which was available and what whānau would have liked to have been included or changed in respect of treatment. This information is necessary as if available interventions do not work for different whānau, this is a barrier which may see children miss out on treatment.

4.4. A Controversial Diagnosis

As ADHD is a heterogenous disorder in terms of both symptom profile and etiology this has raised questions about the validity of ADHD as a diagnosis. Differences in the presentation of core symptoms, changes to diagnostic criteria and process over time, and increased numbers of children being diagnosed and subsequently treated with medication, all contribute to concerns that ADHD is over-diagnosed (Langager, 2014; Singh, 2011). A comprehensive systematic review and meta-analysis by Polanczyk and colleagues (2014) considered prevalence estimates from the previous three decades as a function of time. Controlling for various study methods, they said the true prevalence of ADHD had not increased from 1985 to 2012. They found no evidence to suggest an increase in the prevalence of children who met criteria for ADHD when standardised diagnostic procedures were used, and instead suggested increased rates reflected increased awareness and access to treatment.

In the DSM-5 the age at which symptoms were first present was increased from prior to age 7 to prior to age 12 (Thomas et al., 2013). This added to concerns about over-diagnosis as it was seen as a loosening of diagnostic requirements (Levy, 2014). According to the APA (2013a) this change in DSM-5 was to indicate there were no clinical differences in severity, outcome or treatment response between children identified by seven years versus later. In fact, the definition of ADHD has expanded with subsequent editions of the DSM, based on concern ADHD might actually be *under-diagnosed* for some young people and adults (Thomas et al., 2013).

Erlandsson et al. (2016) discuss how a biomedical model of ADHD and the associated language implies ADHD is readily defined. A diagnosis of ADHD is descriptive and based on subjective judgement of observed or self-reported behaviours and this makes the diagnosis vulnerable to over-diagnosis (Thomas et al., 2013). With inattention and hyperactivity-impulsivity occurring to different extents for different individuals in general, there is no definitive cut-off to establish what should and should not be considered disordered (Taylor, 2017). It is contended that, a circular argument is used to validate ADHD as a diagnosis whereby a set of behavioural symptoms are explained as a disorder, and then those same behaviours are explained as being caused by the disorder (Erlandsson et al., 2016). Thus, ADHD is both the cause and the effect of these undesirable symptoms.

One of the main topics of debate is that a strictly biomedical understanding of ADHD medicalises childhood behaviour that deviates from the norm. Increased diagnosis of ADHD and other neurodevelopmental disorders is deemed to represent a shift from psychosocial, contextual background factors to neurological causal explanations (Langager, 2014). Diagnostic criteria does not take into account other factors which are known to impact childhood development such as the influence of social disadvantage, traumatic experiences, educational systems, attachment, culture and context (Erlandsson et al., 2016). According to Langager this has led to increased numbers of children with emotional and behavioural difficulties also being diagnosed with ADHD. They explain that identifying children who need additional support, treatment or special education help has not changed; how these children are described has changed. Instead of describing characteristics of the young person or their context, the young person is given a psychiatric label. This situation reflects a tendency to view human suffering as a psychiatric diagnosis and Erlandsson and colleagues question what the advantage is of excluding context.

Potential over-diagnosis leads to concerns about over-medication (Partridge et al., 2012). There is an idea ADHD is used as a catch-all diagnosis (Singh, 2011) and in the absence of clear evidence of ADHD there should be caution that behavioural problems are not unjustly medicalised (te Meerman et al., 2017). In the US, based on parent-report 69% of children between 4 and 17 years with a current ADHD diagnosis were taking medication (representing 3.5 million children) (Visser et al., 2014). This figure was a 28% increase in medicated ADHD for school-aged children between 2007 and 2011. Likewise, in Australia, between 2002 and 2009, dispensing of psychostimulants (most often for treatment of ADHD) increased by 87% (Hollingworth et al., 2011). While psychostimulants are effective for the core symptoms of ADHD, there is a lack of research which confirms either the long-term benefits or long-term safety of ADHD medication (Charach et al., 2014; Molina et al., 2009). The ongoing use of medication and the associated side effects are cause for concern for some children and their families (Charach et al., 2014).

In response to the controversy, Batstra et al. (2014) advocate for a stepped care, stepped diagnosis approach to ADHD to reduce overdiagnosis, and mitigate possible under-treatment. As Batstra et al. stress, ADHD is not a prerequisite for treatment when a young person and their family are experiencing difficulties. Their suggestion is that child behaviour problems are initially managed with behaviour modification techniques and other psychosocial interventions. If there is limited or no benefit from these efforts, then the child would be referred for psychiatric assessment and medication treatment. It is potentially true that ADHD is undiagnosed for some children and young people and misdiagnosed for others; these are not mutually exclusive possibilities, and both have associated problems and indicate the need for thorough assessment and appropriate treatment.

4.5. Chapter Summary

In conclusion, ADHD is classified as a neurodevelopmental disorder. This suggests a known neurological factor contributes to the condition which therefore requires medical treatment. Psychostimulant medications are important and effective treatments to help manage ADHD symptoms. However, these medications only have a temporary effect and do not resolve the symptoms permanently. Overall, diagnosis for ADHD is a clinical judgement and therefore should involve a comprehensive clinical assessment based on developmental and psychosocial history, with caregivers and teachers as the main informants. For diagnosis to be made, assessment should indicate a pervasive pattern of symptoms which impact on daily functioning. Several treatment options are recommended for ADHD and treatment decisions should (wherever possible) include the young person and their family's values, preferences, circumstances and needs. Of relevance to the current study, how caregivers perceive and understand the symptoms of ADHD affects the treatment they would expect for their child. How cultural values and beliefs might influence this perception, is the topic of chapter five.

ADHD is not well-researched in NZ and the following chapter provides an understanding of how ADHD is represented among youth in NZ. The discrepancy in how ADHD is diagnosed and treated across cultures is introduced through this discussion.

Chapter Five: ADHD in NZ

This chapter begins with a discussion of the importance of whānau as a component of wellbeing. Caring for tamariki and rangatahi Māori protects whānau and whakapapa, as mokopuna are recognised as the tūpuna of the future; this perspective of whānau potentially influences how whānau Māori interpret the experience of their child being assessed for ADHD. As there is a dearth of research which relates to ADHD and Māori, a more general discussion of cultural factors related to ADHD is presented in this chapter. The definition of culture in the current research is explained. Aside from cultural factors, there are aspects of current practice which make access to services challenging and these are discussed; an objective of this research is to identify factors which affect service access. As the NZ Guidelines for the Assessment and Treatment of ADHD are now defunct, there are no current practice parameters for clinicians supporting Māori families with ADHD. Consequently, the chapter concludes with a discussion of the aims of this research – to contribute to knowledge about how Māori cultural beliefs and values might be incorporated in culturally sensitive clinical practice.

5.1. Tamariki and Rangatahi with ADHD

As was introduced in chapter two, social relationships, including whānau, hapū and iwi connections are an important aspect of wellbeing for many Māori (Pitama et al., 2014). Although the word whānau is used interchangeably (in general and in the current research) to describe the extended family system in which tamariki and rangatahi are raised, whānau also has a much broader and significant meaning than the descriptor 'family.' Walker (2013) describes whānau as a multifaceted, multidimensional concept which is trans-generational and most importantly, the lived expression of whakapapa. In this way whānau embodies whakapapa, as "connections between generations, people and place over time" (2013, p. 215).

Within Te Ao Māori, pēpi, tamariki, and rangatahi Māori (these different age groups can be collectively referred to as mokopuna) have a status within whānau as a reflection of and continuation of whakapapa lines (Cameron et al., 2013; King et al., 2018). This concept is captured in the following whakataukī (Cameron et al., 2013, p. 4):

He Tupuna, he mokopuna.

Mā wai i whakakī i ngā whāwhārua o ngā mātua Tūpuna?

Mā a tātou mokopuna!

He mokopuna, he Tupuna

The meaning (and translation) of this whakataukī is that it is the mokopuna who will take the place of the tupuna and so where there is a mokopuna, there is a tupuna; the overall assertion in this whakataukī is that within the whakapapa links of whānau, 'we are all mokopuna and we are all tupuna.'

From this perspective although Māori culture is 'collectivist,' rather than meaning the collective is valued over the individual, Walker (2013) explains this refers to the collective whānau framework from which individuals may gain their strength. Moreover, the family system can also be the basis of dysfunction and require support. Caring for tamariki and rangatahi represents protecting whānau and whakapapa (Smith, 2010) and this contributes to wellbeing. Importantly, whānau involvement is essential in assessment for ADHD and with treatment for tamariki. Therefore, beyond facilitating assessment and treatment, whānau *are* the functional unit of healing (Elder, 2017a). To provide the best support for Māori children with ADHD and for their whānau requires an understanding of the beliefs, preferences, values, and cultural needs of whānau and this is best represented by whānau who have experience of ADHD. This represents the aim of this thesis, to explore those experiences with whānau Māori.

5.2. Culture and ADHD

It is useful at this point, to define how the term culture is understood and used in the current research. Culture can be defined as "the shared set of (implicit and explicit) values, ideas, concepts and rules of behaviour that allow a social group to function and perpetuate itself" (Hudelson, 2004, p. 345). As Hudelson explains, in this way culture is socially constructed by members of a particular social group and this shared knowledge and understanding allows cultural group members to effectively communicate and collaborate. While culture and ethnicity are often treated as synonymous, ethnicity refers specifically to identification with a group of people from the same race who often share a common culture (Elliott & Urquiza, 2006; Waite & Ramsay, 2010). Culture can be affected by simultaneous membership in various groups which all potentially influence an individual's attitudes, values, beliefs and behaviours (Elliott & Urquiza, 2006). Based on this understanding, culture has a role in not only structuring the whānau environment in which a child functions, but also in how parents and family from a particular cultural background might understand ADHD (Waite & Ramsay, 2010).

Numerous studies have demonstrated discrepancies in the rates of ADHD diagnosis and treatment between cultural groups. In the US, the incidence of ADHD symptomology is thought to be similar for African American and Hispanic children as compared to rates for Caucasian American children (Alvarado & Modesto-Lowe, 2017; Bailey & Owens, 2005). However, research indicates children from these minority groups are less likely to be diagnosed with ADHD and therefore less likely to have treatment than non-minority children (Lawton et al., 2014, 2016; Morgan et al., 2013, 2014). In a study by Bauermeister and colleagues (2003) caregivers of Puerto Rican children (aged 4-17 years) were given structured interviews which screened for ADHD and other psychiatric conditions, and were asked what treatments their children were receiving. Around 7% of the children were identified by parental report as meeting criteria for ADHD, and of this group 7% had received stimulant treatment within the previous 12 months. In addition, only 40% of those identified with ADHD were receiving psychosocial support of some kind. Given the efficacy of these treatments for ADHD, Bauermeister et al. interpreted this as indicating Puerto Rican children were undertreated for ADHD. They concluded further research was required to identify psychocultural factors which influence treatment-seeking for ethnic minority families. Identifying factors which may influence whānau Māori in a similar way, is an objective of the current research.

According to Eiraldi et al. (2006), disparities in service use for ethnic minority groups result from a combination of service access barriers and individual, cultural, and societal factors. They proposed the ADHD Help-Seeking Behaviour Model as a framework to understand factors that predict service use. Variables specific to ADHD were integrated within the framework which includes four stages in the help-seeking process: problem recognition, decision to seek help, service selection, and service use. In this model, culture and context are seen to pervade the entire help-seeking process and the model suggests different minority groups use different help-seeking pathways primarily due to cultural and contextual factors. As an example, Eiraldi and colleagues explain that culture influences *problem recognition* through parental expectations about children's behaviour or the *decision to seek help* through parental attitudes towards treatment. The authors state that by using the model to systematically assess factors related to service use, more effective intervention initiatives can be developed to improve identification and treatment for ADHD among underserved children.

In general, there are barriers to service access which disproportionately affect minority populations. Financial constraints, stigmatisation and language have been identified as barriers to ADHD care for minority group children in the US (Alvarado & Modesto-Lowe, 2017; Morgan et al., 2013). Concern from caregivers about stigmatisation, i.e. how their child will be perceived and whether their parenting practices will be critiqued, is likely to influence the caregivers' decision to seek help for ADHD-type symptoms (Eiraldi et al., 2006). This concern is possibly situated in a more general distrust of the health care system, based on prior experiences of discrimination (Eiraldi et al., 2006). Whether these factors are relevant for ADHD support services in NZ and if this affects service accessibility for whānau Māori has not previously been studied and is one of the research questions this study set out to address.

As diagnosis relies on both a clinical decision and information from caregivers and teachers there are elements of assessment which are subjective judgements. Caregivers and teachers are directly involved in assessment, so how they rate the child's behaviours directly impacts diagnosis (Bennett, 2021). In this way, different cultural expectations of children's behaviour, tolerance and views on normal and deviant child behaviour affect assessment (Batstra et al., 2014). As caregivers typically facilitate help-seeking for their children (Eiraldi et al., 2006), in the first instance, caregivers have to perceive their young person’s behaviour as problematic, to seek support (Alvarado & Modesto-Lowe, 2017). While ADHD-type behaviours may be challenging for families, what caregivers attribute those behaviours to, may differ.

If a caregiver concludes or agrees their child’s behaviours are symptoms of ADHD, they then make a decision about whether to initiate treatment (Eiraldi et al., 2006). At this stage parental beliefs about the etiology of ADHD influence the decision about how to manage these concerns (Alvarado & Modesto-Lowe, 2017; Lawton et al., 2014). Insisting on a biomedical perspective and treatment of ADHD as a medical condition may preclude some caregivers’ views about these behaviours. If a caregiver does not consider that their child’s inattentive or hyperactive/impulsive behaviours have a neurobiological or psychological origin, they will not necessarily seek medical or psychological support (Lawton et al., 2014).

Especially for younger children, caregiver and whānau involvement with treatment is crucial regardless of whether interventions are based on medication or behavioural therapy (Erlandsson et al., 2016). Attitudes towards the use of psychotropic medications such as psychostimulants, reflect broader cultural beliefs about how a condition like ADHD should be treated (Partridge et al., 2012). These beliefs influence a person’s willingness to use medications, to adhere to using them and to support their use by others (Partridge et al., 2012). A study by Bussing et al. (2007) looked at cultural variations in parental beliefs and knowledge about ADHD, and found that African American parents were less likely than their Caucasian American counterparts to endorse ADHD as being treatable with medication.

Personal and cultural values likewise influence the outcomes different families seek (Fiks et al., 2013). Fiks et al. identified treatment initiation and selection were associated with preference and goals for treatment; when the caregivers’ goal was academic achievement, this was associated with medication initiation, and when the goal was behavioural compliance, this was associated with behaviour therapy. Fiks et al. recommended shared decision-making and formal measurement of preferences and goals might therefore support treatment adherence. Therefore, this requires a general understanding of what whānau Māori aspire to on behalf of their children, when they seek support for ADHD.

Finally, as the process of assessment for ADHD is based on observed behaviour, there is always potential for bias to occur. The possibility of bias is shown to be greater when children of one cultural group are assessed by observers from a different cultural group (Reid et al., 2001). Unconscious bias can occur where the assessor has preconceived expectations of children of diverse cultures. This can look like bias in assuming deviant behaviour where there is none (Bailey & Owens, 2005). Concerns about bias in ADHD assessment are heightened as there is no definitive test to confirm ADHD.

5.3. ADHD in New Zealand

While there is a developing research base in NZ about various aspects of ADHD, there is a limited amount which specifically focuses on ADHD among Māori; the research which does is mentioned here in brief. In 2000, Kingi reviewed ADHD diagnostic and treatment practices in NZ, including cultural issues surrounding diagnosis with Māori and Pacific Island children. Kingi found there was wide variation in practice parameters in NZ and recommended establishing guidelines for assessing and treating ADHD (these were subsequently developed in 2001).

Aside from Kingi's (2000) master's thesis, only the current researcher's honours project has specifically examined cultural factors for Māori in relation to ADHD. This project was a small, qualitative study in which paediatricians and a child psychiatrist who routinely diagnosed and treated ADHD in NZ were interviewed (Tipene, 2018). Anecdotally, these clinicians thought Māori were overrepresented amongst children with ADHD. In their clinical practice they noted differences based on the culture of the client, which affected how a child and their family accepted and adapted to the behaviours associated with ADHD. Clinicians also thought whānau Māori might be less willing to accept medication as a treatment for ADHD, preferring to pursue other treatment avenues first. Having gained an idea of clinicians' perspectives, this research highlighted the gap in the literature exploring what ADHD meant for whānau Māori and how whānau might negotiate this in support of their tamariki and rangatahi.

Using pharmaceutical dispensing data, D’Souza et al (2020) determined there had been an overall increase in the rate of medication dispensing for ADHD in NZ (between 2007/08 to 2016/17). D’Souza and colleagues noted while the NZ Health Survey (Manatū Hauora, 2021) indicated similar rates of ADHD diagnosis between Māori (2.4%) and European/Other (2.7%), based on dispensing data the dispensing rate was lower for Māori than for ‘European’ or ‘Other.’ They acknowledged this was potentially because Māori cultural beliefs about appropriate models of treatment may not involve medication. D’Souza et al. also recommended further research was needed to determine if the observed difference was due to barriers for Māori in accessing medication.

Another study by Cargo et al. (2022) used medication dispensing data to investigate if there was a difference in medication dispensing between Māori and non-Māori pre-school aged children. They looked at the data for children between 4-5 years of age who were screened through the national B4 School Check (B4SC) programme (a pre-school health screening check) between 2011 and 2018 and identified as showing ADHD-type concerns. Although 2.8% of tamariki Māori as compared to 1.6% of non-Māori children were screened as potentially having ADHD, of these children, tamariki Māori had a lower likelihood of ADHD medication dispensing (10.8% as compared with 14.9% of non-Māori). This difference in treatment by medication was statistically significant for tamariki Māori living in the most highly deprived neighbourhoods or outside of major urban areas. The researchers observed that medication is not the first-line treatment for ADHD for this age group and without other data being available about treatment, they could not comment if these figures represented appropriate treatment by medication or if medication was compensated with other treatments. However, the difference in medication being dispensed led them to suggest possible inequities in accessing ADHD treatment for these tamariki. Cargo and colleagues noted the lack of research looking at access to ADHD treatment for tamariki Māori and recommended research was needed which identified specific barriers to accessing medication treatment.

5.3.1. Access to ADHD Assessment and Treatment in NZ

Overall, diagnosis of ADHD for children and young people in NZ, aligns with the practice parameters and guidelines for ADHD, described in chapter four. Broadly, diagnosis is based on clinical assessment and confirmed with psychiatric interview either by a paediatrician, child and adolescent psychiatrist, or psychologist. Aside from cultural factors which might influence how whānau experience and engage with services for ADHD, there are other barriers to assessment and treatment in NZ. These barriers may also contribute to the help-seeking patterns of whānau.

In NZ assessment for ADHD is often initiated by a referral from the child’s GP to the service concerned. As discussed in chapter one, these services operate through publicly funded hospitals in NZ and as such, the services are free (Gauld, 2020). However, each service is largely able to determine their own referral criteria and due to high demand, criteria can be restrictive (so that there needs to be considerable distress and/or impairment to meet criteria) and there are considerable waitlists for public services (Paterson et al., 2018). If young people do not meet the threshold criteria for assessment through a public-funded service, the alternative is whānau can seek assessment with a clinician in private practice, which the whānau would fund themselves. This is an expensive process and excludes this option for many families.

As mentioned, stimulant medications are the first-line pharmacological treatment for ADHD in NZ and only paediatricians or psychiatrists may prescribe or authorise the prescription of these medications. As psychostimulants are controlled drugs, there are restrictions on how these medications are administered (New Zealand Formulary for Children, 2022). Initially, a special authority number application is made to the MOH by the assessing clinician, and the authority number is required before the controlled drug can be prescribed for an individual. This authority then needs to be renewed every 24 months either by application from a paediatrician or psychiatrist, or by another medical practitioner who has consulted with the paediatrician or psychiatrist and they have recommended ongoing pharmacological treatment (Pharmac, 2022). Therefore, to ensure medication is continuous, whānau require access to see the specialist at least every two years which can be difficult to manage when services are overwhelmed. Although the GP can issue regular scripts, if any changes are required the GP must request this from the psychiatrist or paediatrician. In Te Huringa, it was noted there were issues with the connection and communication between specialist and primary care services, such as when medication is prescribed by a specialist and managed by a GP (Mental Health and Wellbeing Commission, 2022).

Once the special authority number has been obtained and the medication has been optimally titrated, typically the individual's GP assumes responsibility for ongoing prescribing. As a controlled drug, methylphenidate is only prescribed in sufficient quantity for a one-month period (Misuse of Drugs Regulations 1977). The result is, whānau are required to regularly request a repeat prescription from their GP. While these restrictions are intended to make it harder for these drugs to be misused and/or diverted, this also makes it difficult for whānau with legitimate need to access these medications. Although the prescription medication itself is subsidised and free for children 13 years and under (Manatū Hauora, 2021b), general practices charge a fee for every repeat prescription even when there is no direct GP consultation. This ongoing cost can be difficult for low-income families to manage and may compromise their ability to access the medication their child has been prescribed.

There is no clear, consistent pathway from assessment to treatment in NZ. Other than pharmacological treatment, which is universally available upon diagnosis, available non-pharmacological interventions vary greatly by region. Due to the severity of symptoms, functional impairment, or comorbid mental health concerns, if a child is assessed through CAMHS they may receive behavioural therapy or other psychosocial support as a part of a wraparound service; how this is managed is determined by the CAMHS service based on need. For other children, behavioural or parent support may be through NGOs and other community-based services. Since February 2022, the Triple P Online parenting programme has been fully funded by the MOH so that the Triple P programmes are available free and online for all New Zealanders (Whāraurau, 2022). For other supplementary supports which may be beneficial there may be a cost involved which is again restrictive for some families.

Some of the concerns raised in He Ara Oranga about MHS being difficult to access and navigate (Paterson et al., 2018), also apply for services which support young people with ADHD. To even begin the referral process whānau need to know to speak with their GP about their child's behaviour, which may seem an odd proposition for whānau who do not see this as a health concern. As different services can set their own referral criteria to manage demand for services, there can be inadequate information about who is assessed and who isn't able to be assessed. All of which is based on the assumption whānau know when and how to access these services when they need them (Lawrence, 2017).

5.4. Guidelines

NZ Guidelines for the Assessment and Treatment of ADHD were published in 2001 (Ministry of Health, 2001) and before being archived in 2022 had not been revisited to reflect current practice and available treatment responses. The guidelines stated that assessment with Māori tamariki and rangatahi should incorporate whānau and cultural aspects and that culturally appropriate staff should be available to address those aspects. Clinicians were also advised to consider how services were delivered and by whom and the guidelines suggested home visits, marae-based clinics, kaupapa Māori services, and having Māori staff available might improve access to services for whānau Māori; none of which is consistently available through all (or most) publicly funded service providers. Overall, the NZ guidelines endorsed an assessment appropriate to the cultural needs of Māori clients, though there was minimal guidance on what this meant and how this could be enacted in practice. While ADHD guidelines developed overseas are comprehensive and evidence-based, these are not specific to the NZ context and therefore do not include a cultural focus which is specifically Māori.

The recently released Australian guidelines for ADHD have similarly acknowledged a framework is necessary to guide clinicians in working alongside Aboriginal and Torres Strait Islander peoples[3] (AAGDG,2022). The Australian guidelines say that when working with Aboriginal and Torres

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[3] The phrase Aboriginal and Torres Strait Islander peoples refers to the Traditional Custodians of the Land as the Indigenous peoples of Australia, as described in Dudgeon and Bray (2018).

Strait Islander peoples, clinicians should conduct a culturally appropriate screening assessment of ADHD, maintaining a strengths-based focus. They describe that this assessment should include a "cultural and social assessment of the meaning and significance of symptoms" (AAGDG, 2022, p. 30). Clinicians are also advised to employ the assistance of a cultural interpreter or Aboriginal and Torres Strait Islander health worker if needed. The guidelines caution clinicians that ADHD symptom questionnaires and other screening and assessment tools have not been psychometrically validated for use with Aboriginal and Torres Strait Islander peoples and should be used with discretion. To maximise treatment effectiveness, it is recommended interventions should have input from parents, families, community, and Elders as appropriate and their preferences regarding treatment options should be prioritised. Non-pharmacological interventions should be appropriately tailored for the local cultural context, and it is noted medication options may be more acceptable if offered as part of a broad package of treatment.

As the current research will be asking clients whether their cultural needs were addressed during their experiences with ADHD services (and what those cultural needs might be), this creates an opportunity for this information to inform a similar framework for clinicians working with whānau Māori. Consumer perspectives would thereby be the foundation of this framework. The aim is to facilitate whānau access to services for ADHD which are culturally sensitive, relevant and which meet their needs, according to what whānau determine their needs are.

5.5. Culturally Sensitive Clinical Practice

The intent in the current research is not to provide a prescribed list of steps for working with whānau Māori. As Singh (2011) describes, behavioural interpretation and expectations are culturally relative, and diagnostic and treatment practices for ADHD index certain social values. This emphasises the need for clinical practices which attend to the young person's environment in a reflexive way, accounting for culture and context (Singh, 2011). Singh's suggestion is a sociological model which looks at the interaction between the child and their environment as the basis for diagnosis, as opposed to locating disorder in either the child or their environment. In a similar approach, Pham (2015) considered the application of the biopsychosocial-cultural model to ADHD assessment. While originally developed to assess physical health in a holistic way (Engel, 1977), the biopsychosocial-cultural model uses systemic and multifaceted assessment taking into account biological, psychological and social-cultural factors (Pham, 2015). Pham suggested this might reduce bias in assessment and the framework could also be used to consider barriers to treatment acceptability when working with minority families. There are obvious parallels between these models and Māori (and other holistic, Indigenous based) health frameworks such as Te Whare Tapa Wha and the Meihana Model. These other models have been specifically applied to clinical practices for ADHD, which indicates there is capacity within clinical practice to better incorporate mātauranga Māori.

Overall, what these approaches describe is a way of working holistically with youth clients and their families during assessment. This way of thinking about assessment aligns with case formulation. As was discussed in chapter three, case formulation considers a person's difficulties in the context of their lived experience and draws this information together with relevant clinical knowledge (Kuyken et al., 2009; Macneil et al., 2012). Through assessment and case formulation then, the clinician and the whānau collaborate on creating an understanding of what the behaviours associated with ADHD mean for this whānau and thereby together, establish culturally sensitive interventions. Without an understanding of how whānau would like to support their tamariki, and what outcomes they would hope for, clinicians will remain uncertain if the treatment plan is relevant; the aim of this research is to contribute to developing that understanding.

5.6. Chapter Summary

To summarise this chapter, from a Māori cultural perspective whānau is significant for individual and collective wellbeing. Mokopuna are central within the whānau structure, as they are recognised as tūpuna in the whakapapa line. In supporting tamariki and rangatahi, for many whānau this represents protecting whānau wellbeing. Help-seeking and treatment decisions are influenced by access to support services, expectations of child behaviour, beliefs about etiology and caregiver goals for treatment outcomes. These factors are influenced by a family's cultural views and ideals.

Guidelines point to cultural sensitivity without really detailing or expanding on what that means in practice. Understanding how whānau Māori experience and understand assessment and treatment for ADHD is the basis for the current research. This knowledge is needed to ensure culturally appropriate services and to facilitate choice for whānau Māori about how to support their young people. This and preceding chapters have introduced what the current research aims to address, and the objectives and research questions are summarised in chapter six.

Chapter Six: Current Research

This chapter summarises the rationale for the current research. This begins with an overview of general health service utilisation by Māori. How this relates to the focus on how whānau Māori experience ADHD is then explained. Finally, the objectives and research questions that this research is intended to address are discussed.

6.1. Rationale

Health outcomes for Māori are inequitable and yet in relation to need, Māori people are said to under-access available services (Baxter et al., 2006; Cunningham et al., 2018; McClintock et al., 2016). Improving access to health care has been suggested as the basis for addressing health disparities (Ellison-Loschmann & Pearce, 2006). Researchers have previously looked at health and mental health services in general and considered a variety of service access barriers and facilitators for Māori (for example, Hatcher et al., 2016; Hetrick et al., 2017; McClintock et al., 2016). Although factors have been identified, as a result there are yet to be discernible changes in either health outcomes or service use by Māori. Therefore, the current research considers what could be gained from exploring service use by whānau Māori for a specific concern to see whether this specific information provides insight into how to support service access for Māori. The research aim is to explore the experiences of whānau Māori who are supporting a young person with ADHD, to understand how these experiences impact service use.

The rationale for exploring ADHD within this research is based in part on Māori views about the holistic nature of health. As discussed in the previous chapters, ADHD has a typically persistent profile and diagnostically requires functional impairment in multiple domains. It is treated as a medical condition with medication (suggesting a biological etiology) and with behavioural management strategies. ADHD is highly comorbid, which includes comorbidity with mental health concerns. The behaviours associated with ADHD can impact on family functioning and result in family stress (Bor et al., 2002), and assessment and treatment decisions also rely on whānau support. Therefore, ADHD evidently impacts various domains of wellbeing, and this aligns with Māori beliefs about health, incorporating whānau (relational), wairua (spiritual), tinana (physical), and hinengaro (mental) (Durie, 1985).

Although there is a substantial body of knowledge relating to ADHD, there is an identifiable gap in the literature with respect to culture and ethnicity, especially Māori culture. The research which exists is largely from the US and pertains to differences in prevalence as a function of ethnicity or speculates on culturally based explanations for under-diagnosis and under-treatment in Hispanic and African American populations (Bauermeister et al., 2003). There are less than a handful of studies which look at ADHD for tamariki and rangatahi Māori. Therefore, the current research represents an opportunity to contribute to international research on the topic of culture as it relates to ADHD, and to contribute a Māori perspective.

Every clinician working in child and adolescent health or mental health will have involvement with ADHD at some point (Capp et al., 2005). As ADHD affects multiple life domains and can be associated with lifelong impairment (Armstrong et al., 2015), it is important whānau have access to the support they need for their mokopuna. The intent is this research will have clinical value, as whānau perspectives will inform recommendations for clinicians working alongside Māori children and their whānau. The desired outcome is to contribute to services which meet the needs of whānau Māori in meaningful ways, as whānau support their tamariki who are diagnosed and treated for ADHD.

6.2. Research Questions and Objectives

Broadly speaking, the current research explored if services and support for ADHD in NZ were accessible and useful for tamariki and rangatahi Māori and their whānau. There were three main research objectives. The first objective was to gain an understanding of the experiences of whānau Māori who have a child who has been assessed and treated for ADHD. The second objective was to describe how these whānau understood the ADHD-related behaviours prior to diagnosis. Finally, the third objective was to identify barriers and facilitators for assessment and treatment for ADHD, for whānau Māori.

As a result, the present study was qualitative in design. This involved semi-structured interviews with whānau of young people who had been assessed and/or treated for ADHD. The research questions to be answered were:

- How did whānau Māori understand and accommodate their child's ADHD-related behaviours prior to diagnosis?
- What factors were facilitators or barriers for whānau Māori in accessing services for the assessment and treatment of ADHD?
- Was the support which was available culturally appropriate and relevant; did this influence engagement with services?
- What would whānau Māori like to see changed or included in the overall process of treatment for ADHD?

In answering these research questions, the hope is the information gained might contribute to suggestions for culturally responsive service development. The premise is that services for Māori need to shift toward authentic, tikanga-informed engagement with Māori clients. This would move current service delivery beyond the superficial, where there is a façade of cultural sensitivity over what arguably continues to be a flawed system. In seeking a Māori consumer perspective, this study will provide insight into cultural considerations which should be factored into assessment and interventions for ADHD in NZ and how services might respond to those needs.

6.3. Chapter Summary

To summarise thus far, statistics show health disparities exist for Māori, where services are said to be available and underutilised by Māori health consumers. Research has also demonstrated that in general, health care and mental health services are not meeting the needs of Māori. Given the underutilisation of services, the current research explored reasons why this happens, and whether this situation can be understood more completely if looked at in relation to ADHD. Specifically, this research considered: based on the experiences of whānau Māori, are services which address ADHD available, accessible, and useful for Māori clients and their whānau, and are they culturally relevant? The following chapter details the methodology and methods used to explore the perspectives of whānau participants.

Chapter Seven: Methodology

This chapter provides an overview of the underlying theoretical position of the current research and the rationale for this approach. This begins more generally by locating the current research in the context of Māori-centred research and describing the He Awa Whiria framework (Gillon & Macfarlane, 2017) for drawing together cultural and clinical knowledge. This current research was guided by Māori tikanga, and these tikanga are described in this chapter. The specific methods used in recruitment, interviews with whānau participants and in analysis are outlined. Reflexivity on behalf of the researcher was a necessary aspect of the research process and this is discussed, as the interpretation and analysis of interview data were inextricably influenced by the researcher's own values, beliefs, and experiences. Finally ethical considerations made during the research process are overviewed.

7.1. Māori-Centred Research

As discussed in the preceding chapters, Māori have rights as tangata whenua to expect good health on their own terms; in addition, there are equity- and needs-based reasons why this is a priority for the NZ healthcare system (Berghan et al., 2017; King et al., 2018; MCNZ, 2019a). It is therefore vital Māori are involved in all aspects of health research. As well as contributing to improving Māori health and wellbeing, Māori health research should at a minimum maintain, and ideally enhance, mana Māori (Health Research Council of New Zealand (HRC), 2010).

Kaupapa Māori research is one way of conducting research with Māori participants which is fundamentally based on Māori tikanga and principles. The roots of Kaupapa Māori theory are in the "transformative practice and structural analysis" of critical theory (Smith, 2012, p. 11). While Māori language, knowledge and culture are central to Kaupapa Māori research, there is both a cultural and a political element (Smith, 2012). Smith explains Kaupapa Māori research involves the politics of social change, and this requires both action that is focused on Māori self-development, and analysis of the structures informing the action. Kaupapa Māori research is not only a cultural framework; it has political roots and intention (Smith, 2012). This defining characteristic of Kaupapa Māori research is important, as a distinct methodology with an underlying paradigm and a specific purpose.

Therefore, calling the current research Kaupapa Māori research would be a misnomer. The present research is similarly born from a situation where there is inequity in the health system and acknowledges there are multiple systemic factors and structures which have contributed. However, the focus is not on exposing, confronting and challenging the forces which have created those disparities (Eketone, 2008). Numerous researchers from different fields such as health, mental health, education, sociology, and politics have, and continue to contribute Kaupapa Māori research with those outcomes in mind. The current research is an alternative way of conducting research with Māori participants which still maintains the ideal of effecting positive change, taking a Māori-centred approach while drawing on Western research methods.

As with all research, how Māori health research is conducted is in part a methodological consideration determined by research aims, expected outcomes, tikanga and ethical conduct, and the maximisation of benefits for those involved (HRC, 2010). The HRC describe a range of approaches to Māori health research from Kaupapa Māori research, Māori-centred research, to research where Māori are involved as participants. The current research would most accurately be described as Māori-centred research. Māori have been involved with the research design and data analysis, as participants, and as members of the research team. The methods described within this chapter are guided by Māori tikanga and principles. This aligns with Durie's (2004) explanation of 'research at the interface' as being research which incorporates Indigenous beliefs into research protocols. This involved identifying opportunities throughout the research design to combine both knowledge systems to ultimately expand knowledge and understanding (Durie, 2004).

7.1.1. Blending Cultural and Clinical Perspectives

As Kingi (2017b) discusses, there is increasing interest in culturally inspired solutions to health service delivery for Māori. A suggested way forward is to blend cultural and clinical knowledge (Durie, 2011; Macfarlane et al., 2011). The current research incorporates Māori tikanga and values with qualitative research methods and reflects on the challenges and the benefits of doing so. As Macfarlane and Macfarlane (2019) explain, this respects Māori ways of 'knowing' and 'being,' and incorporating cultural knowledge with clinical perspectives is done in a quest for better outcomes for Māori.

The current study was strongly guided by He Awa Whiria ('Braided Rivers approach') outlined by Gillon and Macfarlane (2017), as a framework for blending cultural and clinical perspectives. In this approach, it is recognised while Western knowledge and theory may be fundamentally sound, they are culturally bound (Macfarlane & Macfarlane, 2019). MacFarlane (2004) says when a dominant culture determines all children are the same, they are treated the same, so cultural identity, values and practices are then marginalised or ignored. This is potentially the situation when tamariki and rangatahi Māori experience cross-cultural clinical assessment within the NZ health care system; particularly for a condition like ADHD which is treated as if there is a known neurobiological cause. He Awa Whiria illustrates drawing together knowledge from Indigenous and Western knowledge bases, while maintaining a Māori-centred focus and affirming Māori culture (Macfarlane & Macfarlane, 2019). In this way, the research methods mirror the research objective; to draw together cultural and clinical knowledge to inform clinical practice, while affirming Māori cultural identity and values.

7.1.2. Ngā Tikanga

To ensure a Māori-centred approach was maintained from the outset, tikanga were adopted to guide how the research was conducted. While the methodology describes the research parameters and how the data are gathered and analysed, Māori tikanga were necessary to support decision-making about the research protocol and the way in which the researcher engaged and collaborated with whānau participants about their experiences. The following tikanga were adapted from the He Ara Oranga review panel (Paterson et al., 2018) and from Professor Linda Tuhiwai Smith's (1999) guidelines on engaging respectfully and ethically with Māori in research:

- Whanaungatanga: relationships and interpersonal connections were established with whānau through Māori processes of engagement, such as karakia and whakawhanaungatanga
- Aroha ki te tangata: empathy and genuine respect were demonstrated for all people involved, tamariki, rangatahi and adults alike
- Kanohi kitea: all the interviews were in person/face to face. Being visible to participants meant the researcher took responsibility for delivering on promises about the research objectives
- Titiro, whakarongo, kōrero: as Smith (1999) explains, researchers need to remain humble and observe, listen, and develop understanding, before they begin to talk
- Mahi tahi: a reminder to collaborate and cooperate to achieve research outcomes which are of benefit to Māori
- Tūmanako pai: this research took a strengths-based approach and where possible highlighted what had worked well in the experiences whānau had and what might be done differently to better meet the needs of whānau Māori.

7.2. Theoretical Framework

As the current research was exploratory and sought to understand the experience of whānau Māori, a qualitative design was deemed appropriate. Braun and Clarke (2019, p. 591) characterise qualitative research as “about meaning and meaning making [which is] always context-bound, positioned and situated.” Qualitative research can be based on several methodologies, theoretical positions, and epistemological assumptions. This research was underpinned by a social constructionist epistemology where knowledge is not seen as singular and fixed, but as contextually and interactionally constructed (Chamberlain, 2015). From this viewpoint, the narratives people construct about their experience are not assumed to be an accurate reflection of an objective, observable reality; rather, they are a product of human interaction (McAllum et al., 2019). Therefore, in qualitative research, knowledge and understanding are co-constructed in the interactive process between the narrator(s) and the interviewer (Glynn et al., 2011; Lainson et al., 2019).

As the current research conceptualises culture as a social construct, Māori cultural values are understood to influence whānau perceptions, interactions, and experiences as they navigate ADHD with their tamariki and rangatahi. How an individual constructs meaning and represents their experience is based on their cultural and social perspectives; thus, social constructionism views knowledge as both socially-constructed and value-laden (Moon & Blackman, 2014). For many marginalised populations, the narratives available to them have been limiting and defined by others (Rappaport, 1995). For example, a Māori worldview and mātauranga Māori have been marginalised through the 'colonial construction' of the world, and Māori knowledge systems have been dominated by knowledge which has been deemed socially acceptable or useful (Eketone, 2008). Therefore, this research purposefully explores whānau perspectives and experiences of ADHD, as the co-construction and representation of whānau experiences creates an alternative to the dominant narrative which exists about ADHD among Māori children.

7.3. Ethical Considerations

Ethical approval for the current research was granted by the Southern B Massey University Human Ethics Committee, application reference SOB 20/59. All relevant documents, including consent forms, participant information sheets and the interview guide can be found in the appendices.

The experiences of whānau Māori were the focus of this research, and the intent was the discussion which resulted would be of relevance and benefit for Māori. To ensure the research would have benefit, cultural consultation was sought right from the initial planning stages. Decisions included: how to conduct the research with Māori participants in a way which was culturally appropriate, the research being guided by both ethical guidelines and tikanga, and that whānau Māori should determine how and by whom their whānau was represented during interviews. In addition, cultural supervision was important throughout the research process, particularly how to go about recruitment, introducing the research to potential participants and how to approach meeting with whānau. Cultural supervision was also sought to ensure cultural considerations were incorporated throughout the research, while also keeping ADHD in mind as the research topic. As part of the researcher's clinical training, the researcher held an internship placement with a Māori NGO and had regular supervision from a Māori clinical psychologist. This supported the researcher's understanding of how tikanga Māori and mātauranga Māori could be applied in a clinical and research setting. These were ethical considerations which reflected the researcher's beliefs about the value of blending cultural and clinical viewpoints; as well as how to negotiate the tensions in doing this well, from both perspectives.

7.4. Method

The method described here was developed in consultation with an experienced Māori researcher and educator. In addition, the researcher attended several hui and researcher wananga (seminars) with other Māori academics and researchers over the period of this thesis. These wananga were intended for Māori researchers to discuss their research and proposed methods with one another and to further refine their ideas through mutual collaboration. This consultation helped to identify suitable research methods and recruitment strategies when working alongside whānau Māori (as per HRC guidelines). As has been established in preceding chapters, there is a dearth of NZ research regarding ADHD and even less from a Māori perspective. To address this research gap, narrative style interviews were undertaken with whānau supporting a young person who had been assessed for ADHD.

7.4.1. Participants

As has been discussed in chapters one and two, Māori have long been calling for active participation in the design and delivery of health care services. Aligning with Te Tiriti principles of partnership and participation, the present study takes the position Māori clients and whānau have a key role in deciding what is required for health and mental health services to be culturally relevant and safe (this reflects the research tikanga of 'mahi tahi'). As the research aim was to gain an understanding of whānau experience, Māori needed to be involved as participants. Throughout this study the terms whānau, whānau participants, and participants have been used synonymously to describe those who contributed their experiences, whether an individual or other whānau members were involved in the interview.

Whānau and caregivers who identified as a whānau Māori and who supported a young person (up to the age of 18 years) who had an assessment for behavioural difficulties consistent with ADHD were eligible to participate in the study. The assessment was required to have been made by a psychologist, paediatrician, or child psychiatrist in at least the previous 24 months (either an initial or follow-up assessment). Maintaining a Māori-centred focus and following the tikanga of whanaungatanga - and to account for the broader definition of whānau within Māori culture - caregiver and whānau roles were not limited to blood relatives. While diagnosis of ADHD following assessment was not a pre-requisite for participation, in this study, all the children who had been assessed had been diagnosed with ADHD.

Ten caregivers participated in the interviews, representing eight whānau. Some demographic information was collected from participants and was optional for whānau to provide. Due to the small number of participants, to ensure anonymity (and in line with the principle of 'aroha ki te tangata') this demographic information is presented in brief. Whānau represented several different iwi and hapū and only some chose to share their iwi affiliations. All interviewed caregivers were female. Between the eight whānau, there were 13 children who had been diagnosed with ADHD. The age of the children when first diagnosed was between 4 and 13 years. There was a representation of different experiences of assessment for ADHD across the interviews. Of the 13 children diagnosed with ADHD, 6 were diagnosed by a psychiatrist, 6 by a paediatrician, and 1 by a clinical psychologist. One of whānau elected to privately fund the assessment themselves because of the potential wait time for CAMHS. Of the other assessments, six were through CAMHS, four through a Children's Health Clinic, and two were through specialist Māori mental health services for children and adolescents.

7.4.2. Recruitment

Recruitment of whānau participants was based on purposive sampling. Participants were recruited through an advertisement (Appendix A) shared by email to NGOs and other community organisations who were identified as working primarily with whānau Māori, or with youth. This advertisement was also shared via a Facebook parent support group for ADHD and on the Facebook page for ADHD NZ, which is a national organisation supporting families with ADHD. Potential participants submitted their contact information and preferred contact method to the researcher by following a hyperlink or QR code which were made available in the research advertisement.

To initiate whakawhanaungatanga, the researcher contacted respondents directly and firstly introduced themselves and then the research in more detail. This was an opportunity to initially speak with whānau and answer any questions they might have. After introductions (and if participants chose to continue), they were provided with an information sheet (Appendix B) which further outlined the purpose of the study and what was involved in participation. At this point, it was also confirmed participants met inclusion criteria. If whānau agreed to participate, the co-ordinating investigator arranged a location and date to meet 'kanohi kitea' for the interview.

There were 51 respondents who expressed interest in the study. Respondents were contacted in the order in which their interest was received to determine their eligibility. 35 initial respondents were contacted, and 13 replied, from whom the 8 whānau participants were identified, 3 did not meet criteria and 2 did not reply. In determining an appropriate sample size, research suggests that data saturation is typically met within the first 12 interviews and is sometimes starting to be met within 6 interviews (Guest et al., 2006). Therefore, prior to data collection, eight interviews were agreed as an appropriate sample size estimation that was feasible and reasonable for the exploratory scope and aims of the study.

To confirm data saturation had been achieved, the method described by Guest et al. (2020) was employed. This method assesses for saturation with inductive thematic analyses. Using the number of themes identified in the initial four interviews as a base, data saturation was determined by assessing the relative amount of incoming new information with subsequent interviews. After the four base interviews the number of additional themes generated following subsequent pairs of interviews were counted (i.e., after interviews 5 and 6, 6 and 7, and 7 and 8) and divided by the base number of themes. The relative amount of incoming new information is referred to by Guest et al. (2020) as the new information threshold and a threshold of $\leq$5% was selected to indicate adequate data saturation. In the current study, using a base size of 4, the $\leq$5% threshold was reached at 6^{+2} interviews. This means that data saturation was reached at interview 6, with the following 2 interviews generating less new information than the set threshold of 5%.

There were 13 tamariki whose experiences were represented within those 8 interviews. Once interviews had been confirmed and conducted, the researcher then contacted the remaining 16 respondents to thank them for their interest and offered to share the results of the study with them.

7.4.3. Interviews

Participants were recruited and interviewed over 6 months from April 2022. In commitment to the principle of whanaungatanga, it was deemed necessary to conduct interviews 'kanohi kitea' as a way of setting up reciprocal, equitable relationships with participants (Gillon et al., 2019). Whānau were able to decide where the interview should take place and in all instances, the interviews were held in participants' homes. The location was an important aspect of the interview process for both ease of access for whānau, and because whānau could relax in their own environment where they had control over the interview. This was intended to mitigate the perceived power imbalance which is typically present in the clinical environment and during assessment interviews (principle of 'mahi tahi').

Every interview commenced with a process of whakawhanaungatanga. This included an offer of karakia and the sharing of whakapapa by the interviewer and participants. Some of the whānau carried out karakia themselves, and either shared their pepeha or introduced their whānau and where they were from. Other whānau preferred the researcher perform the karakia, or that the interview proceed without karakia. Following this, the researcher again introduced the research purpose, sharing what had motivated the researcher to carry out the study from a personal perspective (principle of 'mahi tahi'). This was to familiarise the participant with the researcher and their background, and to put the participants at ease. An additional copy of the information sheet was offered to whānau and discussed, and any remaining questions were answered. Whānau were encouraged to ask questions during the interview and it was explained they could decline to answer any question. Confidentiality was discussed, including how the interview transcript would be used, and how the whānau and their young person's anonymity would be protected (aligning with 'aroha ki te tangata'). A consent form, (which included consent to audio record the interview) was completed, prior to every interview (Appendix C).

A narrative style of interview was used. Participants were told that the research was based on the whānau's story and so the interview would be semi-structured to enable participants to freely to develop their narrative. The basic topics the interview would include were discussed and whānau were encouraged to speak about whatever they felt was important about their experience. In the manner described by Riessman (2008) and in keeping with qualitative interview methods, to ensure the basic topics were addressed the researcher followed a semi-structured interview guide (Appendix D). Using this guide, a conversational style was encouraged and facilitated with open questions as necessary. This was in keeping with the tikanga of 'titiro, whakarongo, kōrero.' The interviews took between 70 and 90 minutes and with permission, were all digitally recorded.

At the conclusion of each interview, to mihi participants for sharing their time and experience the researcher verbally summarised what the researcher had gained from their account of their experiences. This was to affirm and acknowledge the whānau's experience, confirm the researcher had understood that experience and collaborate toward a shared understanding, if that hadn't occurred. It was reiterated how this information would contribute to the research aims. This was akin to the poroporoaki process (as described in chapter three) to symbolise the conclusion of the interview and to define the parameters of the research relationship that had been established should further encounters be required (Pitama et al., 2017). In some instances, whānau wanted to access community support for themselves or their young person for related concerns, and where available the researcher emailed information for local support agencies following the interview. All whānau were offered the opportunity to receive a summary of the data collected on completion of the research. Whānau were also offered a koha (a $50 grocery or petrol voucher) to acknowledge their willingness, and time taken, to participate in the study.

Interviews were transcribed verbatim by the researcher. As whānau participants represented a specific population, any information which might potentially identify participants was removed from transcripts and pseudonyms were used. Names of places, schools, community group services, clinicians, support staff, service names and hospitals were also changed. In one instance, when the draft transcript was returned to the whānau for review, they requested details about their employment and interactions with their employer be removed from their transcript as they felt they could potentially be identified from this information.

The interview transcripts were returned to participants to review for completeness and accuracy. Participants were advised after reading the transcript they could still withdraw their consent to participate up until they had signed the transcript release form (see Appendix E). Whānau were asked if there was anything they thought should be added or removed from the transcript or that required clarification. If whānau approved the transcript, they returned the signed release form to the researcher, consenting for the transcript to be used. Due to a disability, one participant was unable to sign their consent for their transcript to be released. The contents of the transcript were discussed via Zoom call during which the participant asked for some additional information to be included and gave verbal consent for the transcript to be used.

7.5. Thematic Analysis

The objective of analysis was twofold: to understand the experiences of whānau Māori who have had a child who has been assessed for ADHD and how this influenced service engagement; and to consider how these experiences might relate to Māori engagement with the health care system in general. Within a broad social constructionist perspective this research used thematic analysis (TA), specifically codebook TA, in the manner described by Braun and Clark (2019).

TA represents several approaches for identifying, analysing and interpreting themes across a dataset (Braun et al., 2015). As a method rather than a distinct methodology, TA is flexible in respect of underlying theoretical and paradigmatic assumptions (Braun & Clarke, 2013). With a focus on data content, TA looks for meaning in the ways people make sense of and understand their experiences (Braun & Clarke, 2013). As is the case in this research, TA is useful when the subject area is under-researched, or participants' views are largely unknown (Braun & Clarke, 2006). The lack of research about ADHD amongst Māori indicated an inductive TA approach was appropriate, whereby identified themes were derived from the interview data, as opposed to being pre-empted by existing theory.

Braun and Clark (2019) differentiate three approaches to TA: coding reliability TA; codebook approaches to TA, and reflexive TA. Coding reliability highlights the significance of reliability when coding data, seeking consensus between multiple coders (Byrne, 2022). In coding reliability and codebook approaches to TA, themes are often predetermined before coding (Byrne, 2022), or themes are typically 'domain summaries' or summaries of responses to questions about a particular topic (Braun & Clarke, 2019). In contrast, reflexive TA emphasises the interpretive nature of coding data, prioritising the qualitative philosophy of TA (Byrne, 2022). As Byrne explains, reflexive TA is a purely qualitative approach which forgoes positivistic ideas about how to accurately interpret data. Codebook TA sits between coding reliability and reflexive TA approaches. As with coding reliability, codebook TA follows the more structured approach to coding whereby a coding frame is used to guide data coding (Braun & Clarke, 2019). However, (as with reflexive TA) in place of positivistic notions about reliability, the analysis itself is understood to be subjective and the researcher is acknowledged to have an active role in the production of knowledge (Braun & Clarke, 2006, 2019); this aligns with social constructionism and with the objectives of the current research. With this approach to TA, researchers are encouraged to involve reflexivity, subjectivity, and creativity as they involve themselves in the data (Braun & Clarke, 2019).

7.5.1. Analysis

Analysis followed Braun and Clarke's six phases for TA and began with familiarisation with the interview data (Braun et al., 2015; Braun & Clarke, 2006, 2013). Firstly, the primary researcher conducted all the interviews. Following each interview, the researcher initially listened to the audio recording and recorded notes about points of interest, before preparing the transcript. Every transcript was reviewed by the researcher and whānau and where necessary the researcher asked questions to clarify meaning and to confirm the participant’s experience had been adequately captured.

In the process of searching for patterns of meaning across interviews, the unique aspects of each whānau’s experience were potentially overshadowed. As this research is concerned with context and lived experience, it was important to respect the whānau’s narrative and experience. Therefore, a synopsis of each whānau narrative was constructed, and these are included as an appendix (Appendix F). As well as deepening the researcher’s engagement with the narratives, the synopses were to acknowledge what was unique to each whānau and significant to them in their account of their experience.

The next phase was to code the transcripts and begin to organise the data into meaningful data groups or codes (Braun & Clarke, 2006). With the research questions in mind, the researcher generated semantic and latent codes which identified important features of the data. One or more codes were assigned to sections of each transcript using NVivo software (QSR International Pty Ltd, 2022). As new codes were identified, the researcher then went back and reviewed each coded transcript and considered additional codes. The NVivo software was useful in this respect as it allowed the researcher to readily review codes and examine related data extracts for each code.

Using NVivo, the next phase was to systematically collate codes into potential themes. While a code captures an idea, themes are patterns of shared meaning which have a ‘central organising concept’ (Braun & Clarke, 2019). This phase was about developing broader patterns of meaning from identified codes and focusing on producing themes which addressed the research questions. This involved reviewing the collated data extracts relating to each potential theme to determine where there was overlap (Braun & Clarke, 2006). In collaboration with a clinical psychologist supervisor, the themes were reviewed, refined, or eliminated, particularly where themes did not capture something in relation to the overall objectives. According to Braun and colleagues (2015), themes should not overlap. However, to produce a coherent analysis, they should relate to each other. Therefore, a thematic map was developed to provide an overview of the relationships between themes and a clear picture of how these related to the research question.

The final two steps were to define and name the themes and then to analyse the themes and associated extracts. The nominated themes and the respective definitions were discussed in cultural supervision. Feedback was sought regarding the appropriateness of the themes, and alternative explanations and definitions were considered to ensure a Māori-centred focus was present in analysis and interpretation. The analysis of themes is discussed in the following two chapters.

7.5.2. Reflexivity

In TA, researcher subjectivity and reflexivity is considered a resource to knowledge production (Braun & Clarke, 2019). In the current research, the qualitative focus of codebook TA privileged participants' experiences and accounted for my (as the researcher) influence on the interpretation of their accounts. There were dual layers of interpretation, where meaning and experience were produced firstly in the participants' re-construction of their experience during the interview, and then again in my analysis and re-telling of that experience as the researcher. The themes which are presented reflect shared meaning co-constructed between myself and the whānau I spoke with. As qualitative research methods invite subjectivity and interpretation, it was necessary I was reflexive about my personal stance with regards to the research, and how my participation impacted on analysis and findings.

As a wahine Māori, I have my own experience of being raised within a Māori family with connection to our tūrangawaewae and marae. I am also a parent of two Māori children who have a much different upbringing to my own as we do not live near our marae and their other caregiver is Pākehā. It was important that I was aware my cultural knowledge, experience and involvement may or may not resemble that of the whānau I spoke with. My position as a researcher with Māori whakapapa invoked a cultural, social, and moral responsibility that inevitably impacted on the research process; my aim was this would enhance the research process and outcomes through my engagement with whānau. I also held a responsibility to the whānau who participated, as in accessing knowledge from whānau Māori, I was thereby a kaitiaki (guardian) of that knowledge and how it would be treated.

Inevitably, my experience as a Māori clinician training in Clinical Psychology also influenced how I engaged with whānau. Over the period of this thesis, I completed an internship in an Adult Community MHS and post-internship in Health Psychology. While the skills I had developed were useful for connecting with whānau participants and conducting the interviews, it was also important I maintain a clear role as researcher (and not a clinician). To do this, I was guided by both tikanga and ethical research guidelines.

My own values and beliefs also affected my decision to research ADHD among whānau Māori and mokopuna in the first place. I was concerned that Māori are labelled as passive and unwilling participants of a health care system which was not designed with Māori or with cultural responsiveness in mind. As a clinician, I prefer to work from a holistic, strengths-based perspective and to try to understand the person I am speaking with in the context of what is significant and meaningful in their life. In my opinion this is how clinical assessment would ideally be undertaken. The emphasis in this research is on drawing together cultural and clinical knowledge because I believe this can be difficult for clinicians in clinical practice. I had to remain reflexive of these beliefs during interpretation and analysis of data, particularly where participants' views resembled my own position and experience. It was important that in my interpretation and analysis, I analyse all possible codes and themes from the interviews (at least those which related to the research questions) especially those which may not reflect my beliefs.

7.6. Chapter Summary

This chapter outlined the Māori-centred approach and social constructionist epistemology which underpin this research, as well as the specific methods of data collection and analysis. After eliciting accounts from the eight whānau, thematic analysis was used to interpret and analyse the data and address the research questions. The following two chapters present the analysis and a discussion of these findings, respectively.

Chapter Eight: Findings

This chapter presents the findings from the analysis of the perspectives of the whānau in the current study. A brief explanation is given of each of the seven themes and subthemes identified from the thematic analysis of whānau interviews. This is followed by a discussion of the themes and subthemes, along with example extracts from the interview data to illustrate those themes.

8.1. Thematic Analysis

The objectives of the current research were to gain an understanding of the experiences of whānau Māori who had a taitamaiti assessed and treated for ADHD; to describe how whānau understood and accommodated ADHD-related behaviours; and to identify factors which influenced service access for ADHD for whānau Māori. The identified themes and subthemes are presented in Table 2.

Analysing the kōrero of whānau in this way potentially removes unique aspects of each whānau's experience. As discussed in chapter seven, a synopsis of each whānau narrative is included as an appendix (Appendix F).

Table 2

Themes and Subthemes

Themes	Subthemes
1. Whānau Experience of ADHD before diagnosis	
2. Whānau Understanding of Symptoms and Behaviours	"I knew there was **something** up with my kids" The More Whānau Knew About ADHD, the More This Seemed to Fit
3. The Experience of Assessment	"We need to know what we're working with" Barriers to Assessment Factors Which Facilitated Assessment

4. Whether to Medicate Was a Big Decision for Whānau	"It was definitely not something I **wanted**" The options were "medication or no medication" Whānau Were Willing to Try Anything That May Help
5. The Experience of Treatment	"They don't actually explain that process to you" Barriers to Treatment and Support Factors Which Facilitated Treatment and Support
6. The Benefits of and Concerns about Diagnosis	"It's not healing anything" "Oh, that explains a lot!" Medication has been beneficial
7. "That could have made the whole process a lot easier"	"That could have made the whole process a lot easier" "You have to find different ways to parent a child with ADHD" "There is not a lot of support out there for parents"

Theme 1: Whānau Experience of ADHD before diagnosis

This theme captured whānau describing their experiences before their taitamaiti was assessed for ADHD and what they now recognise to have been symptoms of ADHD. This included the behaviours which different whānau experienced with their tamariki in the period before they knew what these behaviours represented, as well as the impact of the behavioural issues on the whānau.

Many participants described non-specific behaviours which happened from a young age, though to begin with these issues were not always problematic for the whānau. The behaviour indicated to caregivers there was something happening for their child which was out of the ordinary, even if they weren't sure what this was:

> *We sort of started to notice he was a bit different, well his behaviour was, mainly when he was at daycare (Taranga about Maui)*

Several of the behaviours which whānau described as happening were recognisable (in hindsight) as ADHD-related behaviour. Whānau talked about disorganised behaviours, hyperactivity, and issues with focus and concentration:

> *They had to get a new gate at daycare because it just wasn't a particularly sturdy gate and he would be able to climb over it … he would rock on it quite hard. … He'd hit his head or he had an accident form at least once a week. Once a week he'd run off, or he'd flung off the swing and come off, or something had happened. There was always something, at* ***least*** *weekly where it was from his body just going too fast. (Amohia and Āwhina about Īhāia)*

> *…it probably was that hyperactivity…and also … inattentive. And like* ***complete*** *mess. … You'd* ***literally*** *turn around and that whole area would just be like* ***diabolical****. And then like, if I didn't check the room for a day under the bed would just be like a* ***ridiculous*** *amount of um, shambles. (Emere about Hina and Pua)*

There were some instances where their taitamaiti's impulsive behaviour became unsafe and this was concerning for whānau, who had to take extra parenting steps to keep their taitamaiti safe:

> *When he was younger, he was actually quite unsafe … because he was* ***gone****. He was a child that needed to be on a leash at times … We were lucky that we lived quite rurally, so we didn't need like the leash around cars. But around like a … car parking lot, it used to literally stress me out. He used to sit on my hip the whole time and I would carry him over that carpark until he was about seven. (Taranga about Maui)*

For whānau who had no early concerns, challenging behaviour came up as their tamariki grew older and had more expectations placed on them about how to behave. Their tamariki struggled to conform in environments outside of the home, where allowances were not made for their behaviour.

The transition to school was a particularly difficult period for tamariki and their whānau. How their young person was behaving in school was a common theme which whānau spoke about:

> *…like just the interrupting people and disrupting people and just always on the go, doesn't sit still. Those kind of things. Like, I don't know how many times I've heard them at parent-teacher interviews and I'm just like... [shrugs and shakes head]. (Kiri about Kura and Hamua)*

> *He was doing things like not participating. Would* ***absolutely*** *ghost his teacher. … couldn't sit still. Lots of constant kind of negative stuff. (Miriama about Luke)*

For a few of the whānau, due to behavioural concerns their taitamaiti was not able to be at school for the whole school day. In some instances, this caused issues with the parent's employer which had financial implications for the whānau:

> *He was only going half days and I was needing to take half days off. … You know, initially I just thought it would be a transition, but it became longer and needing to happen more often. (Amohia and Āwhina about Īhāia)*

For their tamariki, this affected their learning, peer relationships and school attendance. Especially when the child was excluded from normal classroom activities or excluded by, or from peers:

> *Maybe six months into school … there was a whole lot of behaviour issues. I had to have a meeting with his teachers … And he would have to often sit outside. He got sat outside because he wasn't behaving. (Kahukura about Matiaha)*

> *Every day he was having to sit on the bench during lunch time. He wasn't allowed to touch anyone. In the classroom they isolated him so that he had to sit at the back in a corner, away from all the other children on the mat. (Katrina about Nikora)*

Some of the whānau discussed how their taitamaiti was gradually excluded from school due to their behaviour. For one whānau this started with suspensions and progressed to completing more and more of their schoolwork at home, until the child was no longer attending school in-person:

> *He got in trouble like, all the time. I don't know how many suspensions. … We got … part way through the third term and he had to go to school* ***part-time*** *… Monday, Wednesday, Friday, and he could only go till lunch time. So, I'd have to pick him up and bring him home to do the rest of his schoolwork. And then we got to term four, and then they pretty much just said that he needs to do all his schoolwork from home. (Kiri about Kura and Hamua)*

> *A few weeks went by, and the school kept ringing to say you need to come and pick Nikora up because he's just punched a boy in the face … or he's just pulled a girl's hair. … He's tried to catch children and trip them up and this...to me was quite serious because I felt like Nikora is now acting out, he's hurting other children. And then a couple of the parents complained to the school, saying that, "I don't want my child near him." (Katrina about Nikora)*

Whānau talked about accommodations they made to support their tamariki, as these same allowances were not made outside of the family. In one situation, the caregivers were mātua whāngai to their biological niece and nephew and had tamariki of their own. When their niece's and nephew's behaviour was significantly different to their own tamariki, they realised they needed to reassess what was important for their tamariki whāngai to flourish. Many of the whānau said they focused on behavioural strategies and having good routines in place:

> *And that was a big jump for us. Because we'd always sort of thought with our kids, we'd used a ruler that was about happiness, values, are you living in line with your values, and … are we providing an environment that's going to allow you to thrive. And I think with Hina, we*

> *really realised look, let's just drop that and just focus on happiness. (Emere about Hina and Pua).*

> *I'm quite routine with him. Just so that he … knows what to expect. … it's mainly just in the morning before school and before bed ... There was a time where mornings were really hectic for me. I'd* ***always*** *go to work late … mornings would be really stressful… (Kahukura about Matiaha)*

Of the eight whānau, nearly all the parents had separated and were not living together. Therefore, tamariki might move between homes or were raised solely by one parent. As explained by this participant, the behaviours were more challenging as there was limited support at home and no opportunity to have a break with only one parent present:

> *Very stressful, very hard. ... 'Cause I don't have anyone, like it's just me and him, 24/7. … You know if I'm really stressed out or … if he's in one of his moods, I can't leave. I will try go to my room to get some peace and quiet and he'll just follow me ... I could not escape my own house. So, I struggled a lot. ... Those were probably the hardest times. (Kahukura about Matiaha).*

As difficult behaviour became more apparent or more frequent, the repercussions also became more serious and whānau identified they needed support. Caregivers were often concerned about the social implications for their tamariki from their behaviour and that they would be misunderstood and judged by other people. In the following extract, the caregiver described repercussions from within their whānau which worried them, and motivated them to get support for their taitamaiti:

> *And then my sisters are having birthday parties saying, "oh, you can bring Bren," which is the little one, "but is it okay if you don't bring Nikora?" And I thought gosh if my own family are*

> *now not wanting him around their children in their homes ... this is a problem. (Katrina about Nikora).*

There was a common thread where caregivers spoke about losing confidence and doubting their ability as parents. This was especially true when a parent's concerns were dismissed by others:

> *And then sometimes you do think maybe it was my parenting and I did something wrong and he's actually not ADHD, I've just babied him. [laughs]. He's my baby boy. (Taranga about Maui)*

> *And also, just losing your confidence. … Like, when the daycare teachers [brushed it off] … I remember feeling frustrated …Yeah, but I remember thinking this is* ***not*** *normal, this should not be happening. (Amohia and Āwhina about Īhāia)*

Most whānau at some point struggled with how their taitamaiti was behaving at home and school. They were personally affected managing the behaviour and dealing with the school about any issues:

> *His behavior was* ***so erratic****. So impulsive. Like…it was [laughs]…it was a really tough time because the other two brothers are really chilled, relaxed, very like logical, focused kids. And yet I've got one kid who was just… (Katrina talking about Nikora)*

> *Yeah, so two years were quite* ***horrible*** *for me because yeah, it was just lots…Like the behaviours happening at home, happening at school, everything. Like I think it was almost every day I would go in and there was an issue. And it was just like, you know, as a parent, you're like, oh my gosh like, that's not what you want to hear. (Kahukura about Matiaha)*

This was not the situation for all the participants. For other whānau, even when there was difficult behaviour, for various reasons they did not believe this was a major issue. As one participant explained, “You get used to it, that’s what you do.” For other whānau, they had experience of an older child also with ADHD and in comparison, they were not troubled by their child’s behaviour:

> *It was just their behavior. … **I** wasn't too concerned he was behind at school … because he's gone through a lot … I’d rather hear he wants to go to school. (Taranga about Maui)*

> *Like **every** time I came to pick him up, and for a kid who was as violent as [his older brother] was and like all the issues we had with him, it was like, what? You’re ringing me over this kid? Luka is bloody brilliant, come on! … He was going to school and doing annoying as hell things. And I said to his teacher, “can’t you just get past it? He’s a kid, kids do this stuff.” (Miriama about Luka)*

Summary

To summarise, this theme captured the kōrero of whānau about their experience of ADHD before their child was assessed and diagnosed. This included the behaviours and symptoms whānau noticed and how this impacted on the tamariki and their whānau.

Some whānau observed challenging behaviours from an early age and said in hindsight, they recognised these were related to ADHD. As tamariki became older the behaviour became harder for the whānau to manage and more obvious as either impulsive, unsafe behaviour or difficulty at school. In the school environment there were not the same accommodations for the ADHD-related behaviour as whānau were able to make a home. At school, there were tamariki who were isolated or excluded from the classroom and their peers due to their behaviour. This concerned whānau because of the social implications of being excluded and not wanting their child to be misunderstood. Other tamariki were suspended from attending school for periods of time or required to do their schoolwork from home.

Most of the parents were either supporting the child on their own or between households (where parents were separated) which was an additional challenge. Many of the caregivers said they lost confidence in their parenting and especially when others didn’t share their concerns about their child's behaviour. Some caregivers said to manage, they reassessed their priorities and focused on behavioural strategies and good routines with their tamariki. There were some whānau who were not concerned about their child early on because they were accustomed to the behaviour and could deal with it, or comparatively (compared to an older sibling for example) the behaviours seemed minor and manageable.

Theme 2: Whānau Understanding of Symptoms and Behaviours

This second theme is closely related to the whānau's experience prior to diagnosis as it describes the explanations whānau had for the difficulties their child was having. Whānau had multiple ways in which they initially accounted for the difficulties of their taitamaiti, with some whānau knowing about and attributing this to ADHD. Other whānau had different understandings of the circumstances and factors which resulted in the behaviour they noticed. Therefore, there are two sub-themes also discussed here: "I Knew There Was **Something** Up With My Kids" and The More Whānau Knew About ADHD, the More This Seemed to Fit.

"I Knew There Was Something Up With My Kids"

As expressed in the following extracts it was common for whānau to say they had no prior knowledge of ADHD. As one caregiver explained, when they were tamariki themselves, ADHD was not common knowledge and not something they knew about until their taitamaiti was eventually diagnosed:

> *I don't know it was like, "what the **** is ADHD?" I knew that there was **something** up with my kids. (Tui about Ururangi and Waitā)*

> *Because back in our day … there was no medication, and they probably were the kids that were getting in trouble [laughs] at the back of the class. Yeah, and when I go back … and go through ADHD in our family, I'd probably have two cousins that would have had that full ADHD. And at the time, they were just **handfuls**, that's what they were known as… (Taranga about Maui)*

Whānau often thought their tamariki had a difficulty of some kind, although they weren't sure what the issue was. As a proactive measure, some whānau had taken steps to consider any possible issues like health and developmental concerns, or sleep issues which might explain the behaviours:

> *They were also unfit as well. So, … we were thinking is it just being unhealthy? Like do they just need to have a healthy diet and, that will…rectify the behaviour. (Emere about Hina and Pua)*

> *By that stage I think we were finding sleep* ***really*** *difficult as well. … We used to set up like visual kind of routines. Looked at natural sleep drops, full night routine. It would start from around 5p.m. at night with all lights being dimmed, music down, stimulation down, big bath routines ... no noise. (Amohia and Āwhina about Īhāia)*

Within different whānau there were also differences of opinion between caregivers about how difficult behaviours should be managed and what the origin of the behaviour was. One of the explanations was that the behaviour was related to parenting style:

> *The boys' dad at that point was like, "nah, this is just behaviour." He was like, you know, you're just too soft and we just had very different parenting styles… (Amohia and Āwhina about Īhāia)*

> *His dad was saying at the time, "there is nothing wrong with Nikora's behaviour at my house, it must be your house. Something you're doing is creating … these issues at school." The school just needs to be…more accommodating and I need a better routine at home and it's my parenting style that has caused all of this. (Katrina about Nikora)*

Some caregivers and other adults who were involved with the child were sceptical about ADHD as a valid diagnosis. They thought the challenging behaviour from their tamariki stemmed from a lack of support for the whānau and that it was the child being 'naughty:'

> *ADHD has become even more of a thing nowadays, right? But like I mean … if the right support is there, like you don't get these behaviours … from these kids. (Tui about Ururangi and Waitā)*

> *…particularly [one] teacher. She might not have come out and said it in so many words, but she was pretty sure he was in that box of naughty. Yeah, not ADHD. (Emere about Hina and Pua)*

A common rhetoric used to account for the hyperactive behaviour of ngā tamatāne (male children) was "boys will be boys." Some caregivers explained their own children's behaviours this way, and in other instances this was used by others to downplay parental concerns:

> *There were so many like … outsider perspectives being like, oh no, it's just boys. 'Boys will be boys.' (Amohia and Āwhina about Īhāia)*

> *They would go, "he's just a boy." And I was like, I've seen all my nephews raised … And yeah, I know some of the behaviour is boys absolutely. But I was like, no! [that's not what this is] (Kiri about Kura and Hamua)*

Whānau also thought the challenging behaviour could potentially be a developmental stage. They were hopeful that given time, their tamariki would grow out of it:

> *I think everyone was … hoping that some of his behaviour difficulties were just because of the … chaotic life he had led and his age, right? 'Cause lots of four-year-olds are sort of hyper … So, with Pua I was hopeful that … he would* ***grow*** *out of the behaviours. (Emere about Hina and Pua)*

> *And see [his older sister] … she grew out of her issue. … It was actually teachers that commented, "has she been assessed for ADHD?" … And I knew that she actually wasn't [ADHD] because … she wasn't off the charts busy. So, when Māui was … a little bit busy I*

> *thought oh yeah, he's just like [his sister] and he'll get to six and it will all slow down. (Taranga about Maui)*

Another explanation was that the behaviour was situational or in response to a significant change in the young person's life. There were a range of reasons whānau named as contributing factors including parents separating, grandparents moving away, loss and grief, a relative being unwell, and having to move. Whānau said they thought these factors were at least part of the reason for the difficult behaviour, if not a complete explanation. Another caregiver thought the behaviour was entirely due the difficult situation their family was in and not having many positive options:

> *My relationship was ending at this time as well. So, I was saying to them, "hey look, he's got so much going on at home* ***I*** *think it's that." (Miriama about Luka)*

> *They're sportsmen. They're amazing at sports, but we can't get our kids into sports. And so, our boys have nothing to do after school here every day. You know, they're up the courts smoking vapes and even bongs and tobacco at 10 and 11, because there's nothing to do, but then if they're in sports. But like we can't afford it. I can't drive because the trauma made [me] blind … Phones cut off, no one can ring us … we can't deal with the world. (Tui about Ururangi and Waitā)*

Unfortunately, for some whānau their tamariki had traumatic experiences where they either witnessed violence or were themselves mistreated. In one of the following extracts, the whānau said it was difficult to know how much was due to neglect and trauma. In the other extract, the other whānau felt strongly that the difficult behaviour was a significant change following a traumatic experience:

> *Um, so it was quite … hard to determine whether the behaviour was a result of neglect and the chaotic life that they had. Because both parents used P and there was domestic violence*

> *… So, we sort of wanted to provide that security and then uh (shrugs)… (Emere about Hina and Pua)*

> *We [moved] … and we were homeless … We got a whare and it took a few months. … Waitā's being real naughty one day and…I say, "what's wrong with you? Why are you being so naughty?" And his tears start rolling and he says because of what happened to me in foster care. And this was like six months later ... and his brother tells the same story. (Tui about Ururangi and Waitā)*

Lastly, some whānau talked about their cultural background as Māori (and Pasifika) families. They talked about having a strong family orientation whereby multiple people were involved in raising their tamariki. For these participants this could be both a good and a 'bad thing' at times. As expressed in the second extract, it was the lack of strong whānau support and presence which led to these issues:

> *I'm not saying that non-Māori or -Pacific Islanders aren't family orientated, but I actually believe that* ***we*** *are … It's not just the parents … it's the village that raises children. Sometimes it's a bad thing, but…you know it's not just one person that's ever involved... (Kiri about Kura and Hamua)*

> *They ain't coping in school, because mum ain't coping, because the family is not there in the way they should have been, because it ain't how it was. … I was here by myself trying to access help from the services. Because there are amazing, social workers all around us, right now. There's ten hundred services. Everyone would look at it on paper and go, "she's got all the support." You know? (Tui about Ururangi and Waitā)*

The More Whānau Knew About ADHD, the More This Seemed to Fit

It was more common for participants to not have (detailed) prior knowledge of ADHD. However, once ADHD was suggested to them (often by a teacher or health professional) or if they came across ADHD themselves while searching for an explanation, this prompted caregivers to begin their own research about ADHD. After reading about possible symptoms of ADHD, it was often at this point that whānau became sure this explained their child's situation:

> *I had **no idea** [about ADHD]. So, I just went straight into research mode and the more I read about it, the more I was thinking actually, yeah, this sounds like Nikora. This is sounding like what he's going through. (Katrina talking about Nikora)*

> *And then I did a course with work … Mental Health 101 ... And they kind of touched over … ADHD … and I was just like, "oh!" Some of the things they were saying [it was] like, "woah, that's very familiar." … It was kind of **that** which made me first … think maybe he does have that. And then when I spoke to the doctor about that, he was like, "no, no." I'm just like, "okay, you guys know!" What would I know? I only did a course. (Kiri about Kura and Hamua)*

Other whānau members had pre-existing knowledge of ADHD and some experience of working with tamariki with ADHD through their employment. Even in those instances where whānau knew about ADHD they did their own research to confirm their suspicions and then wanted an assessment to be sure:

> *All that time I was thinking … potentially he could have ADHD. I always thought his dad did. And I knew about it … a bit from work, and I was interested in it. (Amohia and Āwhina about Īhāia)*

> *Just being an early childhood teacher and I was just really interested … I always [like to do my own] research. And … I'd heard about ADHD and I was like I wonder if it's that. I actually thought it might have been Oppositional Defiance … 'cause he had a lot of those traits as well. So, I was like maybe it's one of these. (Kahukura about Matiaha)*

Summary

This theme encapsulated the different understandings whānau had of their tamariki's behaviour, and the frameworks they used to interpret the behaviour. Initially, some whānau had no prior knowledge of ADHD and only learned about this after their child's diagnosis. Some caregivers sought help with their child's overall health, other developmental concerns, and sleep problems as potential solutions. Within some whānau, parents disagreed about the cause of the behaviour and how this should be managed. Some caregivers didn't believe ADHD was a valid diagnosis. Instead, issues were often blamed on parenting style and the child was just being 'naughty.' Whānau said they were told there was nothing to be concerned about, 'boys will be boys' and that their children would probably 'grow out of it.' For some whānau, they also thought difficult behaviours could be related to major changes in the child's life, or in some instance trauma. Other whānau also discussed a lack of strong whānau support as contributing to their struggles which they associated as typically being part of their cultural upbringing.

Other whānau were prompted to do their own research when it was suggested their child may have ADHD. This gave whānau an alternative framework for understanding their child's behaviour, and subsequently, whānau often recognised that the symptoms of ADHD matched their child's presentation. The more whānau knew (as in the case of whānau who were employed to work with children) the more likely they were to conceptualise the behaviour as ADHD, leading to them wanting their child to be formally assessed.

Theme 3: The Experience of Assessment

As eventually all the whānau participants underwent an assessment for ADHD with their taitamaiti, there were several reasons which whānau discussed as prompting the assessment to take place. One reason (captured in the theme above) was because whānau had learned about ADHD and thought ADHD likely accounted for their child's difficulties. Many of the whānau were also desperate for support and open-minded about the outcome of the assessment. Whānau also discussed factors which either made the assessment process difficult or which facilitated the assessment. This theme is organised into three sub-themes: “We Need to Know What We’re Working With”, Barriers to Assessment, and Factors Which Facilitated Assessment.

“We Need to Know What We’re Working With”

While primarily motivated by the difficulties their tamariki were having, participants discussed several reasons why the whānau decided themselves that an assessment was necessary. When whānau knew about ADHD before the assessment, their approach to getting their child assessed was purposeful as they noted behaviours they knew were associated with ADHD:

> *Because then I started identifying the behaviours that I knew were consistent with ADHD. It was one of those moments where you’re like, you’re fine … you’re just young, I can explain that. And then hello… (Emere and Hina and Pua)*

> *I was like maybe it’s [ADHD]. So, I … went through the checklist and I was like oh yeah, he’s showing that with me, he’s showing that, he’s showing that at school. Well, maybe I’ll just go get it checked out (Kahukura about Matiaha)*

Alternatively, other whānau said not knowing what was going on for their child was their reason for wanting the assessment. If caregivers could find out what was happening with their child, they said they could better respond to helping them:

> *And that’s what I said to his dad, even though he gets assessed, it doesn’t mean we have to put him onto medication, or we have to do this or do that. That’s for us to decide at the time, but at least we need to know what we’re working with. (Katrina about Nikora)*

The decision to get their child assessed was often driven by whānau feeling they were at “breaking point” managing the behaviours at home and wanting external support:

> *But by that stage, I think at home we were also at breaking point as well, with the behaviour and just trying to keep him safe. (Amohia and Āwhina about Īhāia)*

> *I'm holding on by the skin of my teeth sort of thing, you know? (Mirama about Luka)*

Across participants, tamariki struggling at school was one of the most common concerns discussed. As one whānau member stated, "I wanted him to succeed at school, like all the other kids" (Miriama). Several whānau participants discussed their taitamaiti as not being able to conform and manage the expectations of mainstream education. Wanting their child to do well at school, was motivation for some whānau to follow through with the assessment:

> *He did* ***okay*** *at mainstream [school]. But there was that pressure to be* ***perfect*** *and he* ***struggled*** *with that. … As soon as he walked in the door, it was like right go and do this … go and get your maths book and do like what you need to do for maths. … he's just not one of those kids that would sit down and fill out a worksheet. That's just not how he learns. (Kahukura about Matiaha)*

In other instances, whānau said it was the school who approached them and wanted the parent to initiate the assessment. In the following extract, being told by their child's teacher was the first time the parent had ever thought their taitamaiti might have ADHD.

> *All this [behaviour] went on for weeks before the teacher actually pulled me aside and said, "your child's behaviour is just not going to be tolerated at this school. This is actually your* ***warning*** *that you will need to find a new school if you don't sort this out." And it was news to me! … So, [the teacher] said, "to be honest, I think he has ADHD and you need to get him seen by a doctor." … When she said that I thought, "wow, that's a bit* ***drastic!****" (Katrina about Nikora)*

Whānau also talked about their child's school eventually becoming insistent about the assessment being done. For some whānau this was confronting as they felt the school was not giving them an option about having their child assessed, even if the whānau were not convinced their child may have ADHD:

> *The schools, the people working for them, the social workers, everyone [wanted the assessment done]. Because like everyone's looking, going … what's wrong with these kids? We need to fix it in the Western system. There must be a problem with their mental health. There must be a medication that will fix it. (Tui about Ururangi and Waitā)*

> *And that's when I had him assessed. Because [the new school] said this would be a good idea. It was just the way [his old school] came at me, now that I'm thinking about it and looking back on that time. It was the way they came at me. I already had my back up… (Miriama about Luka)*

The other main reason whānau went ahead with the assessment, was because this was suggested by their GP, support worker. or other specialist who was already involved with the family. In the following extract, this whānau felt like they had no choice to have the assessment because of the pressure from multiple agencies who were already involved:

> *Well because you* ***have to****. Because it's Oranga Tamariki telling you to. Or it's the school telling you to. And then you've got truancy [officers] from the schools. You've got everyone ******* telling you [to get the assessment and the medication]. But also, you … just want something to help too… (Tui about Ururangi and Waitā)*

> *We were at the pediatricians one day and he must have been about … five and the pediatrician was just like, "do you think your child has ADHD?" And I looked at him and I went, "Umm? Maybe!" [laughs]. Because [my son] was like…bouncing. … He was like, "do you think we could get him assessed? (Taranga about Maui).*

Barriers to Assessment

Once whānau had determined they needed to have their child's behaviour assessed, they then had to get the assessment done and this sub-theme captures the barriers to assessment which whānau discussed. One of the first challenges was knowing how to approach their child's behavioural concerns, particularly as not all whānau were aware this may be ADHD. Some whānau were unsure how to request an assessment and who to contact. In the following extract, the caregiver explains they did not think their doctor (GP) would deal with a concern like ADHD and so they hadn’t considered going to see them:

> *I didn't really* ***know*** *what to do. Like I was just … googling. I thought … I need to go see a child psychologist. I didn’t really think about, you need to go see your doctor … 'cause I don't know … if they’re actually* ***trained*** *to understand that kind of thing? … I guess for me it was just like I need to go see like a psychologist to help me, instead of like really a doctor. (Kahukura about Matiaha)*

Another barrier to assessment was the whānau’s concerns being dismissed meaning it was difficult to get anyone to make the referral for their young person to be assessed. As in the following extract, some whānau had to insist to their GP that the referral and assessment was necessary, and not all participants were comfortable doing this:

> *Yeah. I went back, I think maybe it was the third time to the doctor and I was just like, “nah, can you just like refer him to the hospital?” Because I said, “I get that you think nothing is wrong with him and he's just a boy, but I don't think that.” (Kiri about Kura and Hamua)*

In a similar scenario, some whānau said they had difficulty with other specialists not taking ownership. For this tamariki and whānau, multiple specialists were already involved for health concerns and none of them could determine what the problem was, other than to say it wasn’t something they dealt with. Their caregiver described feeling like the whole process was a battle and they had to “fight” to get their child the support they needed which was a sentiment shared by other whānau:

> *The paediatrician saw him at that point and said both of them are completely fine, there's nothing abnormal. All they need is love, support and a stable life. … and I sort of was like, “oh*

> *okay?" … I know, they seem happy … but are we sure there's nothing going on? (Emere about Hina and Pua)*

> *Yeah, and I had to fight so hard. Like, so hard! … 'Cause that was very much what I kept getting, "oh it's not mine … there's something else wrong with her." … Yeah, it would have been … two or three years of just getting* ***knocked back …*** *And me knowing. This girl can't communicate with her peers, she's not retaining information, she's not meeting any standards … All these behaviours! So, I knew I had to keep persevering with it. (Emere about Hina and Pua)*

Once a referral was made to a secondary service for the assessment, this was another difficult period for whānau. Extensive wait times for CAMHS and other services for the initial assessment, were a significant barrier:

> *Six weeks later, I hadn't heard from anybody and we'd all done our forms and apparently they couldn't* ***find*** *our forms. … So, for two weeks they tried to find the forms and then found the forms. And then um, we finally got an appointment for* ***August*** *[five months later]. And I'm thinking, wow, this is* ***so far away****. (Katrina talking about Nikora)*

> *To me it felt like it was years, but it wasn't … I want to say maybe three or four months? Like to be fair, [Kura] was like way worse than what Hāmua was. And we got in way earlier with Hāmua and so that's why they were* ***trying*** *to get [Kura] rushed, because he's, you know, he's getting in so much trouble at school. Like it was…****ridiculous****. (Kiri about Kura and Hamua)*

Other barriers which participants discussed related to the assessment process once this was underway. As part of the assessment, often both parents would complete a questionnaire, as well as one of the child's teachers. In some situations, whānau found it difficult to ask the teacher to complete the questionnaire. Some whānau said this was difficult because they felt the teacher didn't like their child and others said the teacher did not understand their tamariki's difficulties or believe this was ADHD:

> *And I think it's an older generation thing because…she's like mid to late 50s and that other teacher was mid to late 50s, and I feel like they just don't have an understanding of children with ADHD, in the classroom. (Katrina about Nikora)*

> *And then we had to get the teacher to do it, which was…to be honest, hard. Because … I could tell she didn't like him. You know, like … the bias is there or whatever. All of that, right? You just know that's playing out (Emere about Hina and Pua).*

Another barrier which whānau discussed was that the overall assessment process was rushed and not thorough. This left some whānau wondering if the diagnosis of ADHD was accurate:

> *It was hard. Like … we felt like we were there to quickly get in and get out. Like, "oh, cool we've seen him…we'll see you next time." (Kiri about Kura and Hamua)*

> *His dad, myself, and Nikora all went to the appointment and [Nikora] was so well behaved in the waiting room. He was just sitting in the middle of us, and we were talking about things. And we go into this Doctor and sit down. and he says, "your son has ADHD." I said to him, "how do you know? Like we only just sat down. Like do you need to assess him or ask him questions?" He said, "oh, I could tell just by walking past you guys in the waiting room." I thought, my son was sitting perfectly still, chatting to us. Like…? (Katrina about Nikora)*

Negative interactions with the assessor were a barrier for some whānau too. In this extract, the parent discussed how the assessor was openly critical of their parenting and what they should be doing to support their child, and the assessor's opinion of the situation was the favoured perspective:

> *It was all my fault. It was my parenting, it was this, it was that. It was because I wasn't feeding him properly, wasn't saying the right things. You know all of that sort of stuff? And like nothing I did [was working]. And [he] was getting into so much trouble at school, he was so violent. I'm not very big, I couldn't control him physically and he was saying to me, the doctor was saying, "you just need to put your foot down." Are you* ***serious*** *mate? (Miriama about Luka)*

There were also factors relating specifically to whānau and the parents (as opposed to external factors) which were barriers to the assessment. For some whānau only one of the parents wanted to have the assessment done. Where parents disagreed about having the assessment, this was often based on a difference of opinion about the origin of the behaviours, and whakamā about their child being diagnosed and "labelled:"

> *And the first thing his dad said was, "I do not want him being labeled as anything, it will bring shame on our family. And I do not want to be told that my son is a ******." And he was* ***adamant*** *that [ADHD] is not even a thing. (Katrina about Nikora)*

> *Āwhina: I think for him it was more around like, almost not wanting to believe that his son could have something...Amohia: Yeah, the whakamā and the denial. So, that was hard, that was really hard too. See, I cried with relief [when Īhāia was diagnosed] and was almost happy. I remember him just going into shock. You know quite a different response and just being like, "oh ****!" there's actually something. (Amohia and Āwhina about Īhāia)*

As this parent explained, some whānau were concerned a diagnosis of ADHD for their child would mean they were judged as a parent and how they may have contributed to this diagnosis:

> *At first, I actually didn't even want to tell my family. Because I felt like … I didn't want them to be like "oh, Katrina's got an ADHD child. Like there must be something that … she has done to make him that way." Or that he eats too much of this and now he's got ADHD or … it's*

> *because of the parenting or the routine. Like I just felt like I would be blamed for it. (Katrina about Nikora)*

Finally, another barrier to assessment which whānau discussed was that they or their children had prior negative experiences and a general mistrust of the health system, and they were reluctant to engage while feeling like they had no other option:

> *The kids didn't talk [during the assessment]. The kids won't talk to anyone because social workers took them away. Because they got hurt [while they were in foster care]. They got hurt by the social workers. (Tui about Ururangi and Waitā)*

> *Nobody likes to be under the spotlight and, and it feels like a* ***very*** *out there place to be and you've got people [involved]…they kind of circle the wagons. (Miriama about Luka)*

Factors Which Facilitated Assessment.

It was not the case that every whānau had a negative experience of the assessment process and these whānau discussed different factors which facilitated the assessment. Some whānau said they and their young person were well supported by their school or an understanding teacher who was involved. This made a difference to how participants were prepared to meet with the specialist as they understood what the school's concerns were about their child's behaviour:

> *And then with the teachers they went through* ***all*** *their questions with me, what they were doing and what they answered, and they were really good … I think, we were well supported in our school, because we had a small school. (Taranga about Maui)*

> *I had heaps of stuff from the school at the same time. Like because he was already with the RTLB (Resource Teacher of Learning and Behaviour) at that point. So, they … were the ones that were kind of like, "hmm, [is this ADHD]?" … They were like, "what do you think…?" And I was like, "yeah, I do think that, but…" [the GP was saying no]. And so, they were the ones*

> *like, “I think [this is ADHD] too.” So, they had written up … a letter saying … what the behavior and stuff is that was happening. (Kiri about Kura and Hamua)*

In this extract, this whānau had a similar supportive relationship with their GP and this facilitated the assessment for them, as the GP readily made the referral when asked:

> *[Our] GP was aware, and right from those early years I was getting guidance from him too. … I'd say, please take notes about this. And so, he was kind of working alongside us. He also* ***saw*** *Īhāia as well and so you know, I felt I had his support. (Amohia and Āwhina about Īhāia)*

Another factor which was beneficial for whānau, was when both parents or caregivers were involved in the assessment. Going through the assessment together enabled caregivers to agree about the symptoms they were seeing and their experience of those symptoms:

> *My husband and I had to do a questionnaire. … And we did that separately and then we looked [at each other’s responses] and it was really similar. So, that was quite nice, knowing that …because you want to check in on yourself. (Emere about Hina and Pua)*

> *[His dad] started seeing it at school and I think by that stage he might have had a bit more experience of parenting him on his own … [and] having them for pockets of time and experiencing it first-hand. So, he was on board. He came to the assessment. He was very much involved in that process. I think there was a bit of reluctance, but it was a relief too for him to hear. (Amohia and Āwhina about Īhāia)*

The other factors which whānau spoke about as helpful during the assessment were related to their experience with the assessor. Several of the whānau spoke about their positive experiences with the assessor because they collaborated with the whānau and listened to them. In the following extract, the caregiver had felt very protective about having their son diagnosed with ADHD even though this had been suggested to them as a likely by other people:

> *He was like, "do you think we could get him assessed? Could I send a letter to his school, and they can answer their side and we'll do our side, and we'll work together. And I was like "oh yeah. Oh, okay then." (Taranga about Maui)*

> *Like he, he listened, he* ***was*** *interested. He is very interested. I tautoko that doctor… (Tui about Ururangi and Waitā)*

Whānau also stated it made a difference to them when the assessor was personable and seemed genuinely concerned about the child and their whānau. A considerate and empathic approach facilitated the assessment, for several whānau:

> *It was just the way he* ***spoke*** *to us. Like we'd come in and he'd be like, "how are you doing Mum? Goh, it's been a tough week aye?" … those sorts of things. Like, just a lot more personable [than the previous doctor we saw]. Easy to deal with. I could understand him … and I'm not uneducated. (Miriama about Luka)*

> *He was* ***incredible****. And* ***every*** *time,* ***every*** *time we talked about a different, possible change to consider, he would draw it up on the board. He would write it out. I just felt incredibly* ***safe*** *in his knowledge and skills. I felt like he could explain it to us. He always gave us time to think about it. And that was* ***every*** *time. Because obviously this happened over and over and over again to get to where we are now. (Amohia and Āwhina about Īhāia)*

Summary

In summary, this theme developed from whānau discussion about the process of assessment. While wanting support for their child was an important reason, there were several factors which prompted whānau to seek the assessment. From their own research, some whānau thought it was highly likely their child had ADHD and they wanted to confirm this. Feeling overwhelmed and not knowing how to support their child also prompted the assessment. Many whānau wanted support for their child at school, or the school had suggested to the caregivers their child may have ADHD. As other support workers, or health professionals were sometimes already involved with whānau for other reasons, sometimes they suggested the assessment to whānau.

When it came to getting their child assessed, whānau mentioned several barriers. The first was not knowing how to access support, particularly when whānau did not know about ADHD. It didn't make sense to some whānau they would go to their GP for behavioural issues although this was the pathway for assessment. Once whānau went to the GP it wasn't always straightforward to get the referral and whānau described having to fight for the help they needed. Other barriers were service issues such as long wait times for the assessment, negative interactions with the assessor and the assessment being rushed. There were also whānau factors which were barriers to assessment. Some caregivers did not want their child to be diagnosed with ADHD due to whakamā about the label. There were whānau who said they had a general mistrust of the health system which left them reluctant to engage.

The assessment was not always a negative experience and there were factors whānau discussed which facilitated assessment. Having a supportive GP, or an understanding teacher helped whānau to understand what behaviours were of concern and the purpose of assessment. Having both caregivers involved was also beneficial as this validated the difficulties caregivers were having. Whānau also discussed positive experiences with an assessor who collaborated with them, listened, was personable and showed genuine concern and empathy.

Theme 4: Whether to Medicate Was a Big Decision For Whānau

Following on from their tamariki being diagnosed as having ADHD, whānau then needed to decide about treatment. This theme captures whānau talking about the decision of whether to give their tamariki ADHD medication, as this was a contentious issue for many whānau; this is represented by three sub-themes. On one hand, whānau did not want to medicate their tamariki and their concerns are presented here. On the other hand, as this was the only treatment option offered to them, eventually most families did give their child medication. In addition, some whānau said they were willing to try anything which might support their taitamaiti.

"It was definitely not something I wanted"

There were specific reasons whānau gave for why they were concerned about giving their child ADHD medication and these are represented in this sub-theme. Some whānau talked about feeling strongly that medication was not the right option for their whānau and was not aligned with how they would choose to support their child, preferring a more holistic approach:

> *[The medication] is not right at all. But it's like how the **** do we fit in the world without it? Like, you know what I would love to see is that we find a way back to where we don't need to be medicated to be in the world. (Tui about Ururangi and Waitā)*

> *I live quite a holistic kind of lifestyle. So, for me and for him. I wanted to see if there's anything holistic that I could support him with instead of going straight to the medication. So that's kind of where my view was. So, we didn't do the medication. (Kahukura about Matiaha)*

Several whānau struggled with their child not wanting to take the medication. Most caregivers said they noticed positive differences in their child's functioning, from the medication. However, this was weighed up against the child not liking how they felt:

> *He said it makes him feel gross. It makes him feel yuck. He is unmedicated during the holidays and the weekends. But … he hates it! And that's important. If he doesn't like how he feels … you can imagine how that's gonna affect him. (Miriama about Luka)*

> *Like he could never explain what he meant, but like he just, every time we would speak, he was like, "I don't know mum, I just don't like it. Like I don't like how it makes me feel." … and so, I'm like okay. But then … he would get in trouble at school when he doesn't take it! And I'm like, "oh, gosh." (Kiri about Kura and Hamua)*

One of main issues whānau discussed which made the decision difficult, was their concern about the side effects of ADHD medication:

> *And also, when you look at Ritalin, the facts on like kids with ADHD and the outcomes for kids with ADHD, it doesn't look good. And then, I was scared that…yeah, the growth thing. … So, it's not just that he's little, it affects him…like, he can get so skinny that he gets too cold to swim. And little things like that. (Taranga about Maui)*

> *Ururangi when he first went on it, he just lost so much weight. He was a zombie. … And this was going back, I mean he's 11 now and he was 7 at the time. … But he was like a zombie, zombified. We were all going like, "what the ****, man?" (Tui about Ururangi and Waitā)*

The options were "medication or no medication"

In all cases, regardless of whether whānau had concerns about medication, this was the suggested treatment. When whānau asked for an alternative, for most whānau, no other interventions (specifically for ADHD) were available through the service in which their child was assessed. The choice was between "medication or no medication" (Taranga):

> *[The psychiatrist] asked me why I was so opposed to medication. But gave me pretty much **no** other option. (Miriama about Luka)*

> *And [the psychologist] was just like he needs to be on **medication** … And it was pretty much **only that**, and that was it, kind of thing. So, she referred me onto a [psychiatrist] who did … the medication. So, I went and had a chat to her about it. And then they're like, if you do the medication, we can carry on. But … **that was it**. And so, if you don't basically choose to get medication, then we're not going to help you anymore and that's pretty much what happened. (Kahukura about Matiaha)*

Especially where the whānau had been uncertain what their child was struggling with beforehand, it was confronting to be told their child had ADHD and then to be offered medication. As one participant explained they had wanted to learn more about whatever the concerns might be, and then make decisions about how to support their child:

He says, "no, I've got your assessment forms here. And so basically, what I'm going to do is…don't panic, your child will be fine! He can live a normal life. I'm just going to do a script now for Ritalin or Rubifen and you can collect it today and start him on it tomorrow and he may feel a bit sick and have headaches for the first few days, but he should be fine after that, and you should notice some good results. And you can come back and see me in a month, and we can see how it's all going." … We left in total shock and…there was no alternative. It was, here's your script. (Katrina about Nikora)

There was a consensus among whānau that ideally medication would be a last resort after exhausting other avenues, and only if necessary:

I think for me that was going to be like the last resort if I really, really needed him to be on it. Um, I don't know. I guess I kind of did my research and I was just a bit kind of on the fence about it and I wanted to try and see if other methods would work. (Kahukura about Matiaha)

And then of course we went back to the pediatrician, and he said, "oh yeah, we think he's got ADHD, … would you be interested in trialing meds on him?" And I went, "I'm not too keen on that." Because you hear all these things about Ritalin and … at first I said, "oh, I'll think about it." (Taranga about Maui)

At least two of the whānau made the decision not to medicate their tamariki in the end:

And if it was like if it got really, really, bad then I would consider putting him on to medication. So, I haven't needed to do it ***so*** *far. (Kahukura about Matiaha)*

[With] Waitā, I haven't even been giving him the medication a lot to be honest, because I don't think he needs it. (Tui about Ururangi and Waitā)

Whānau Were Willing to Try Anything That May Help.

Another factor in the decision-making around ADHD medication was that some whānau wanted to try anything which might be useful. As the following extract states, often whānau felt they had exhausted options at home and had already decided to see if medication would be beneficial:

> *Yeah, you know, and three years' worth of what I considered behavioural therapy type stuff. By the time we got there, I was like he needs the medication. (Amohia and Āwhina about Īhāia)*

> *And I'm the type of person that isn't against medications if it improves. … I sort of knew … that I'd put him on medication, but I wanted to make sure I was happy with it. Because in my mind if he got to 18 and hated me because I had him on medication then I would have to live with it, or vice versa, you know? Or else he knew he should have been on medication back then and struggled the whole way through school, that would be my … issue. (Taranga about Maui)*

Summary

As all the tamariki in the current research were diagnosed with ADHD, every participant talked about treatment and the decision they made about ADHD medication for their child. Overall, there were whānau who did not want to use medication however, this was often the only intervention offered. Medication was not an option whānau would normally choose for their tamariki, preferring a more holistic approach and typically using medication as a last resort. Tamariki also told their whānau they didn't want to take medication which made the decision more difficult when whānau had noticed an improvement in functioning. Some whānau also said it was confronting to be told their child had ADHD and then to be offered mediation straight away. They wanted information about ADHD and options about how best to support their child. While some whānau ultimately chose not to give their children medication, others said they were willing to try anything if it helped.

Theme 5: The Experience of Treatment

In addition to making the decision about using medication, accessing treatment and support was a challenging experience for participants and there were factors that either facilitated or acted as barriers to this. These factors are captured here as sub-themes. There were specific issues which caregivers dealt with once their child started taking ADHD medication, and these were barriers for some whānau to accessing medication and are thus, presented as a sub-theme.

"They don't actually explain that process to you."

This sub-theme outlines the difficulties whānau talked about regarding accessing medication once their tamariki had begun to take the medication. As medication was the only option in many cases, these issues were potential barriers for whānau to continue with treatment.

One problem which participants said they encountered was that they were not given enough information about the medication. They said they were not told how to access the medication, that it would require titration and ongoing monitoring, or what potential side effects might be:

> *[We were told] nothing. And I said to him, "where do we even get this from?" He said, "well you get it from the pharmacy, but because it's a controlled drug you only get … a 30-day supply. So, we'll do another appointment for 30 days' time and then we can arrange the next months' worth, if you feel like it's having any sort of impact." But they still didn't say like in six months' time we'll reassess, or if you have any problems give us a callback, or these are the* ***potential*** *side effects. They didn't talk about any of that. (Katrina about Nikora)*

> *I knew … about the dosages just because of [his older brother]. So, I knew … we will go back in a month and…then you'll change the dose, or … make sure it's okay. But … they don't actually explain that process to you. (Kiri about Kura and Hamua)*

Multiple whānau discussed challenges with getting the right medication for their child. Whānau said they had issues like the medication being ineffective, the effect not lasting the entire school day, or it took months of changing medications and dosage to find a good balance. In the second extract here, the caregiver said that although they had issues with the medication and were concerned it was triggering other (safety) issues, they had to fight to get the service to review the medication after only having had one appointment with them:

> *It was like three weeks [every time] before we could get anything changed. And by that point we had to … get a repeat … But I didn't want to take him off, because I was like I know it's not lasting, but something is better than nothing. So, … then I'm getting a repeat … for nothing because we're still…not on the right medication. (Kiri about Kura and Hamua)*

> *That's when I started screaming at the doctor saying, "we need a new referral. We need a new assessment." At that time, I felt like he didn't even have ADHD. I felt like there was some sort of mental disorder…going on. And I said, "that medication is not right for him, I just know it." … it was a real mess … So, the GP said, "all I can do is try another referral." And we got a letter saying, we received your referral, but we're sorry we're not able to see you. (Katrina about Nikora)*

Accessing the medication on a regular basis was also problematic for most of the whānau. The process to request the repeat prescription from the GP every month was time-consuming and not always straight forward. Some general practices required that an appointment or phone appointment be made for the child every month, and this was difficult for caregivers to manage:

> *Because the GP had this stupid thing where I had to go and take* ***all the kids*** *in. … I had to take 4 kids into the waiting room and get the medication once a month. (Emere about Hina and Pua)*

> *You have to remember before you run out, because at our GP you actually have to make a phone appointment for the script … And often I'll ring up, and he'll only have like a week's worth left and they'll say sorry we have no phone appointments for two weeks … But I think too, like even though it doesn't physically cost us, like with the medication and the*

> *appointments. There* ***is*** *a cost to all this. Because* ***every*** *month I'm having to do cell phone calls, I'm having to drive to the pharmacy. Like there is a cost associated with having your child on medication like that. (Katrina about Nikora)*

Barriers to Treatment and Support.

Many of the other barriers to treatment which whānau identified were service-related issues over which whānau had no influence. One of the main barriers was having consistent access to the service. As discussed, there were often long wait times for both the initial assessment and ongoing appointments; however, following diagnosis this complicated the process of titrating the ADHD medication with the psychiatrist or paediatrician. This had serious repercussions for whānau in some cases:

> *They said they would book an appointment start of January so we can [try] something new … Then he's got time before he starts high school. And January came, no appointment. So, I rung them…and nothing. Then two weeks before school started, I rang again. …And then the first week back at school he lasted five days and got booted out of [school]. (Kiri about Kura and Hamua)*

Several whānau had issues whereby they had to contact the service, even though they had been assured of follow-up. More than one whānau had the impression this was because they were forgotten. Multiple whānau said after only an initial prescription, the service told them to contact their GP for further scripts even though the GP could not adjust the medication. This was a barrier as tamariki were sometimes without medication awaiting a script, or whānau had concerns about the medication which they wanted to discuss before getting another script:

> *A month rolled by and I'm thinking no one has made an appointment. So, I rung the hospital…The meds had run out. … I rung so many times and they said, "because of COVID, we're not actually doing appointments." And I said, "well, this is the follow-up appointment."*

> *And she said, "I'll have to see what the doctor wants to do…" And I said, "well, my son has actually got like one day left of his medication." (Katrina about Nikora)*

> *I then went back to the GP and was screaming and yelling at him. Because I said like, "this is not good enough. It's like we've gone MIA, in their system. Like they've done an initial script and that's it. See you later." (Katrina about Nikora)*

Related to this concern, whānau commented that while their GP was more accessible than the specialist, the GP was limited in the support they could offer whānau. They could only repeat the prescription they already had and could not make changes without the specialist's written instruction. This was an issue when there was poor communication between the secondary service and the GP:

> *I kept ringing the doctor and he said all he can really do is the prescription. He can't recommend or change anything. … I felt the GP was very restricted as to what he could and couldn't say or do. I felt he did everything he could … I couldn't fault him in that aspect. (Katrina about Nikora)*

> *They're not communicating because we ring … the [general practice] and then they'll be like … we haven't been told to give him [that]. And they … [give us] his last prescription … not reading his hospital notes that actually, they've changed it. Then … they're like, "well no, we have to … go back to the hospital." (Kiri about Kura and Hamua)*

Another barrier which whānau discussed was that following diagnosis, for many of the whānau no ongoing support was offered. This was either not available through the service, only available in the community and whānau had to access this themselves, or they did not meet criteria for additional support:

> *[The psychologist] … gave me the diagnosis and then it … just stopped … and I didn't really know what to do ... I was like okay I'll just send him to school. There wasn't any support ... It*

> *was like right, he's got [ADHD], give him some medication and that's it. (Kahukura about Matiaha)*

> *Like we were never even offered respite…and looking back I think that would have probably been very helpful. (Emere about Hina and Pua)*

In situations where whānau were offered other support, for some whānau this was not suitable for their needs, or not a viable option. In the following extract, when the family thought the support offered was inappropriate, this made them doubt they could trust the service to act in their best interests:

> *They thought they [could] refer him to the STOP programme. No* ***way!*** *What the* ***hell?*** *That's for extremely violent offenders … they would have eaten my kid! …Once they started doing that sort of thing … I was like … No! I don't trust you anymore and we're gonna do this on my own. (Miriama about Luka)*

> *They offered me respite care, that I had to find myself. Which I couldn't because none of my family members wanted to take him. (Miriama about Luka)*

Some whānau also described feeling worried about asking for help and support although they were struggling. They talked about feeling judged, feeling uneasy about having so many people knowing their business, and being concerned that Oranga Tamariki (the child welfare/protection service in NZ) might become involved. This was also a barrier to whānau getting the support they needed:

> *I was ***** ***scared*** *of Oranga Tamariki because I thought they'd remove [my older son]. They would think all these things about* ***me*** *… because of his behavior at school. I'd already had a notification made ... I was trying to get into Social Work at that time too. And it just stopped me [asking for help]. (Miriama about Luka)*

> *You do get, degraded … at the doctors, with stuff like [asking them to sign forms to get financial support]. When it's stuff you're actually entitled to. … I was just like if we weren't entitled to it, we wouldn't have been offered it right at the beginning. … It makes you feel about this big [indicates something small]. (Taranga about Maui)*

Factors Which Facilitated Treatment and Support.

While there were service issues which were barriers to treatment, whānau also discussed service-related factors which facilitated treatment and support. This included having a positive experience working alongside the specialist where the specialist was responsive and took the time to explain; this helped caregivers to implement solutions:

> *A lot of [issues] get brushed to the side. But with Dr A, if you came to him with something he would get on it right then and there. He wouldn't be like 'oh we'll, just keep an eye on this.' He would find a solution or a temporary solution and put it in place straightaway ... Like he was very, very proactive. (Amohia and Āwhina about Īhāia)*

> *I liked how [the clinician] spoke to Pua about three things and we still talk about that. That's the device time, sleep, and kai. He needs to eat, he needs to sleep. … Because … that's helped me be able to enforce those things (Emere about Hina and Pua)*

While it depended on the service whānau were referred to (which depends on locale-specific availability), some whānau had a support worker or nurse who met with them in the period after diagnosis. This was to monitor medication, to offer support with ongoing issues, and to be the liaison between the whānau and the service. A supportive, empathic support worker made all the difference to these whānau:

> *Amohia: We also had Mereana, who was … the nurse, but like our whānau support. So, she would … [do] weekly, catch-ups … and she'd come see us at home … And she was just very reassuring, she would be like, "mum I know this is really hard." … Āwhina: She really made*

> *that effort to like know him, rather than just as a patient, as a person. (Amohia and Āwhina about Īhāia)*

Whānau also said it was helpful that the medication was monitored and reviewed by the service once it was prescribed. This facilitated treatment by medication as whānau felt more confident about side effects being managed. Some whānau also said they felt more confident about their decision because the initial dosage was conservative:

> *So, the medication was reviewed … and monitored quite closely. The school and I communicated really well, and Dr A. … I remember that we had* ***very*** *regular, scheduled appointments and I knew how to contact Dr A or the service. (Amohia and Āwhina about Īhāia)*

> *[The nurse] would ring … and she would … make sure that especially in that first little while that we weren't having too many side effects. (Miriama about Luka)*

As mentioned, several caregivers were familiar with ADHD or worked with tamariki through their own employment. Other parents also had prior knowledge of ADHD because of experience with an older child who had ADHD. This was an advantage and facilitated these whānau being able to access other supports in the community or elsewhere:

> *I knew what to do having done it with Hina. … If I be completely honest, I was very … firm with them. ... I spoke a lot about risk in the first phone call. I didn't want it to take two years to get him assessed and access medication, and in that two years he would be firmly labeled the naughty boy. … After all that learning from Hina it was like okay, I need to talk about why he's at risk. (Emere about Hina and Pua).*

> *I had that background training as a social worker. So, I know where to go and who to talk to. I know there is help … out there, I've just gotta find it. …* ***Imagine*** *not having that. I think*

> *that's frightening. That there would be other families that don't know. … Too scared to get help. (Miriama about Luka)*

Summary

To summarise, this theme presents whānau accounts of the treatment and support they received for their tamariki. A common topic which whānau discussed were barriers to treatment which were specifically about accessing medication. These were related to not having enough information about medication and how the medication was issued and struggling to get the medication and dosage right for their child. Additionally, having to regularly request the medication from the GP every month was also hard for whānau to manage at times.

As with the assessment process, there were factors whānau discussed as barriers to treatment. Many of the barriers related to the service including access following diagnosis, and lack of follow-up from the service. There was also inconsistency about titrating the medication. Often whānau went back to their GP who could not make changes to the medication. Often there was no ongoing support from the service and where support was offered this was not always viable or appropriate for whānau. As whānau were worried about needing to ask for help, this was also a possible barrier to getting support.

Facilitating factors included whānau having a positive experience of the specialist who was involved. This happened when the specialist was proactive and offered practical solutions to issues. Another facilitating factor was when a support worker or nurse met with whānau after the diagnosis. When medication was regularly reviewed, whānau said they felt more confident about their decision as possible side effects were monitored. Whānau also used their prior knowledge to access support from community services.

Theme 6: The Benefits of and Concerns about Diagnosis

On reflection, whānau had different opinions about whether the diagnosis of ADHD had been beneficial, and this is captured in this theme. If there was no perceived benefit for tamariki and/or whānau from the diagnosis, this would be an obvious barrier for assessment and treatment and is discussed as a sub-theme. Most whānau said they found at least some benefit as they gained an understanding of their tamariki and could access ADHD medication; these benefits are both presented as sub-themes.

"It's not healing anything."

For some whānau, they were concerned about other people's opinions about their child was diagnosed with ADHD. Some whānau said they anticipated they would be judged by other people and unfairly "labelled":

> *With Pua, we were really careful [who we told]. …there's lots of people in the whānau who we have not told. There's lots of people in the community who don't know he's ADHD. Only because … we don't want people's …views about whether it's true or not. (Emere about Hina and Pua)*

> *I **really** don't like my child to be labelled. So, I never tell people he has ADHD, because it's got nothing to do with them. But sometimes it does pop out, mainly when they mention something about ADHD in a negative way. I usually say, "yes, I have an ADHD child." (Taranga about Maui)*

Some whānau said they were also worried about how their child would feel about being diagnosed with ADHD. Caregivers did not want their child to feel they were different. In the following extract, the caregiver told their child about the diagnosis a couple of years after they had been diagnosed, once the caregiver felt the child was mature enough to understand that ADHD just meant his brain worked differently from other people:

> *We're pretty open about it now, but it took me a long time to [tell him] because I didn't want him to feel … outcast or whatever. … He took it quite well actually. I think because he's a bit*

> *older now. I think if I told him at six, he wouldn't really understand. (Kahukura about Matiaha)*

There were also strong opinions from others about the whānau’s decision to use ADHD medication with their child. In one case, a caregiver described comments from a teacher around “parents just drugging kids to help them behave” which concerned them as their child took some of their medication at school. Other whānau described similar comments against ADHD medication:

> *[To help make my decision] I remember asking a few people questions [about ADHD medication] and they were like … anti-medications, anti that, and “they tried to say that my grandson was ADHD and they're wrong!” And gosh, it’s like… (Taranga about Maui)*

> *There were quite a few people …within the community and within …our wider whānau that were really anti…Even to the point where one [whānau member] was…looking after them and refused to give them the medications. So, I said, “well, okay, you can’t look after them anymore.” ... [Their concern was] you're drugging kids and kids should just be free. (Emere about Hina and Pua)*

Finally, there were some whānau who felt that diagnosing their child with ADHD achieved no real benefit for their child or the whānau. As this parent explains, the diagnosis and the subsequent medication did nothing to heal whatever the underlying issue was:

> *You come [here] at seven in the morning when ain't no one had their meds and this place is ******* chaos. It's* ***not healing anything.*** *It's just making him okay enough to fit in school. Me okay enough to ******* follow what day it is (Tui about Ururangi and Waitā)*

“Oh, that explains a lot”

The main benefit of diagnosis which whānau discussed was that as they learned more about ADHD and how this affected their tamariki, they better understood the reasons for some of the challenging behaviour. Having an external explanation for challenging behaviours enhanced the parent-child relationship and improved how the caregiver approached these concerns with their taitamaiti. Whānau said they could look back at different situations with their child and see how these were due to the symptoms of ADHD:

> *Yeah, I think it was helpful … I know he's got the diagnosis now. What is it? How can I understand it more? And what more do I need to do to support him? … I'm finding out something new about [ADHD] all the time, you know? (Kahukura about Matiaha)*

> *There are a few times that I think back, like when he was two or three and …how he responded to different things going on, it really made sense. Once I was able to understand that this is something he potentially has, those situations made total sense to me. (Katrina about Nikora)*

Having a better understanding of their tamariki and their behaviour because of the diagnosis also extended to the wider whānau. In this extract the caregiver describes how their whānau responded once she told them about the diagnosis, as she had anticipated they would blame her for the situation:

> *They were more like, "oh, that explains a lot. That explains why he does this or does that." And I've noticed, they are a lot better with him now. So, if there's something that he doesn't want to do, or doesn't like, they don't push him. Whereas, before they would have pushed him and felt like why is he not joining in like all the other cousins? And why is he being difficult? Whereas now they kind of have taken a step back and tried to understand. (Katrina about Nikora).*

As many of the caregivers shared the experience that they were initially told their child's behaviour was nothing to be concerned about, eventually having their tamariki diagnosed with ADHD, validated the parents' concerns. Whānau talked about feeling relieved by the diagnosis as they had some insight that their child was not just being 'naughty:'

> *The psychiatrist … was like, "look this is this is what I'm thinking … your son does have combined ADHD." And he kind of talked through it a bit and I just remember crying and thinking, oh thank goodness! (Amohia and Āwhina about Īhāia)*

> *Now we can actually understand, and I think that has been the huge thing. Whereas before we didn't know, is he being naughty? Is he playing up? Is he being difficult? But we know that that's not the case. (Katrina about Nikora)*

> *[The diagnosis] definitely made it easier … at home. … Because honestly I was … like, "oh my god Hāmua, why can't you just listen?" I was thinking, he was … just being a naughty kid. But actually … when I heard some of that stuff, I was just like, "oh, okay! … It made me think … because he's actually not a bad kid (Kiri about Kura and Hamua))*

Medication Has Been Beneficial.

There were other participants who said the diagnosis was beneficial because this enabled them to access medication. While some caregivers still had reservations about ADHD medication, they also talked about benefits from medication, particularly the positive difference in their young person's behaviour:

> *I [gave] it to him on a Saturday before we [went] to the market … Usually, if we're going anywhere near cars ... he's right next to me and I've got his hand, so that he doesn't run. Or I used to scoop him up and I'd hold him. …And I went to the market and* ***he, walked beside me*** *the whole time. Didn't run anywhere, didn't go anywhere. I didn't have to like say to his sister, "watch your brother." … And I was just like, "oh my God, this is what it's like." (Taranga about Maui)*

> *We could notice straight away the behaviour was [better], it clearly worked. A hundred percent…both of them were noticeably better. (Emere about Hina and Pua)*

> *I asked Nikora what he thought about it, and he said, "I like doing the medication because it helps to calm me and I can think and focus whereas before I was doing bad things and I actually didn't mean to do them." He's like, "the medication helps me." (Katrina about Nikora)*

Having improved focus and being able to concentrate because of the ADHD medication was most beneficial at school. Participants said their children typically took the medication before school and the effect had worn off by the end of the day. This resulted in improved school performance for some children, and for other tamariki it was enough that they were not in trouble all the time and could stay at school:

> *A couple weeks into it and he was engaged at school ...but by the time I'd pick him up …it pretty much had worn off. …Then his reading just went [up] about five spaces in two weeks. Because he could actually sit [and learn] and the teacher was like, "oh my God!" (Taranga about Maui)*

> *I was pleasantly surprised when … his grades shot up after he started taking …the medication, and he could concentrate. … Like Pua went from, …not meeting stuff and to the teacher saying, "I* ***thought*** *he'd* ***cheated****…" on the test. (Emere about Hina and Pua)*

Medication benefitted some whānau as there were improved relationships at home and school. Impulsive behaviours were less often disrupting their child's relationships with siblings and parents.

> *[The medication has] allowed them to be able to operate, in particularly that education sphere … in a way that's expected, that's the norm. …And then at home it's allowed relationships to form. Not interrupted relationships. (Emere about Hina and Pua)*

> *Now I feel like the* ***true*** *Nikora is here. He's part of the family. He wants to like* ***help*** *cook dinner. He* ***wants*** *to be involved. He* ***wants*** *to have a laugh with his brothers. And* ***their*** *relationship is so much better now that he's not attacking them all the time. (Katrina about Nikora)*

Summary

Another common theme in whānau kōrero was whether the diagnosis had been useful. Some whānau said they were concerned diagnosis would attract judgement from others and their child would be labelled. They were worried their child would feel different and excluded because of the diagnosis. Other whānau couldn't really see a benefit to diagnosis as the medication only controlled the symptoms and didn't treat the underlying cause.

The main benefit of diagnosis according to whānau was a better understanding of their child. The diagnosis also validated caregivers' concerns as they knew this was not just their tamariki being naughty. The other positive outcome was the diagnosis allowed access to medication. Due to the medication, children could focus during school which improved their school performance, and they were not in trouble all the time. The medication also helped improve relationships at home and school.

Theme 7: Preferences About Treatment and Support

One of the research questions in this thesis, explores what whānau Māori would like to see changed or included in the overall approach to how ADHD is assessed and treated in NZ. This theme collates some of the preferences whānau discussed about the treatment and support they would have liked to have been available. This is not to suggest whānau were only relying on external support to help with their child's difficulties; every whānau spoke about different ways they had managed these challenges at home, and these are presented here as a sub-theme. Whānau also spoke about a distinct lack of support aimed at caregivers and whānau who support a child with ADHD, and this is also a sub-theme.

“That could have made the whole process a lot easier”

In terms of cultural support or access to culturally based services for Māori, only one whānau had the choice of a Māori MHS and both of their children were assessed through this service at different times. They spoke about their experience (of assessment and the treatment offered) as entirely positive due to the wraparound support they received. The caregivers also said this worked well for them as a whānau Māori because the psychiatrist who worked with them (who was non-Māori) approached this from a Te Ao Māori perspective:

> *[We were supported as a Māori family], definitely. … They [said] we could have had access to a tohunga if we wanted. They talked about mirimiri. … I loved it actually because although Dr A isn't Māori, you …felt he had an understanding of Te Ao Māori. … [The Māori CAMHS] would be my recommendation from our experience. Definitely. Just a whole lot of little things … offering karakia, having quite a comfortable, … homely-type space … When we went to appointments at [the service], we always … felt really comfortable. …Those kinds of things that you* ***may*** *not experience in mainstream, although we* ***should*** *with cultural responsiveness and awareness. (Amohia and Āwhina about Īhāia)*

Every other whānau said they were not asked about their cultural background during assessment. There was no cultural support or kaupapa Māori service available for whānau through mainstream health care. At least half of the interviewed whānau said had this been available to them they would have chosen this option. These whānau said although the outcome would have been the same, the process may have been improved for them in that this may have felt more welcoming and less confronting:

> *If the access to [support] wasn’t so scary and … was in the community in which you live in, like I think it would … feel more welcoming. If I be honest. I would feel more welcome [in a*

> *Māori-based service]. … I would feel more welcome and understood. … And less like I **had to fight**. (Emere about Hina and Pua)*

> *It could have been nice because ... it is a lot easier sometimes when the other person sitting across from you is a bit like you, you know? But … most workers are trained [about being] culturally appropriate. …They'll try hard. Even if it is tokenistic… (Miriama about Luka)*

> *I think if there was a Māori psychologist or something they would have more [of] a holistic view. Like how can we support him in our community? How could we support him through your iwi? … I think there would be a bit more of that kind of approach. (Kahukura about Matiaha)*

There was discussion from some whānau that options to support their child in the community were either mainstream non-Māori services at one end, or kaupapa Māori or Māori NGO services at the other. One caregiver said this catered for children and whānau for whom either of those positions felt comfortable. They explained that in a way because some children were disconnected from their reo and whakapapa by circumstance, this excluded them from being able to attend a kura kaupapa school although this might better meet their needs. Therefore, ideally what they thought would have been helpful for their whānau was opportunity for their tamariki to connect with a Māori service. Ultimately, to support whānau to connect with Te Ao Māori.

> *I'm largely, not a very 'good Māori.' I'm trying. I'm on the journey. But I would have liked to have maybe had some help in connecting the boys to some sort of service or a little bit more Māori-oriented way of working. You know it's why I quite liked [the local Māori NGO service]. But they didn't really have anything [to help]. (Miriama about Luka)*

> *I've been starting to really struggle with my boys. I've been able to help them when they're little. … but then they get to this age. And [traditionally] … that's when they would have been taken out to those environments [to figure out] where are you good? ... Where is your place?*

> *… They need to be in Te Ao Māori … but without the pressure of having to be in the kura kaupapa Māori schools. … We don't have the ability to do that right now, for many reasons. … They don’t have the reo at 10 and 11 because we haven't had access due to violence, family being taken away, all of that. (Tui about Ururangi and Waitā)*

Another factor which whānau said would have helped them to support their children, was if there had been collaboration between health and between other social services or the education system. This would have helped whānau to access the help they needed more efficiently. Also, parents were trying to support their child at school and had to relay information to the school from the service:

> *If the two services had overlapped more … Oranga Tamariki and Health. Like, if that first assessment that was done, took a little bit more time that could have made the whole process a lot easier. And if they understood the context in which our whānau were operating in, I think … we would have had a completely different three years. … You know, to be told there's nothing wrong when no one can understand what Hina is saying, it's like (shakes head). And clearly, I’m not saying I was right, they were wrong, but it was, I* ***was*** *right (laughs). … And if it had just happened at* ***that*** *time and they had said* ***clearly*** *somethings not quite right here, or this whānau could use some help along the way to work out, what's going on, then that would have been far easier. (Emere about Hina and Pua)*

> *[Nothing was passed onto the school]. Like it was up to me to relay what they would say and it would be like, “oh cool, so we're just trying this.” That was pretty much* ***all*** *I had to say to them, because I didn't have anything else to say. [It would have been helpful] if [the school] were given* ***something****, yep. (Kiri about Kura and Hamua)*

By and large whānau stated they wanted to have had options available for their child other than medication. Even some whānau who found medication to be helpful, wanted something else to help alongside medication. Medication temporarily addressed the symptoms of ADHD and not the associated impaired functioning which whānau said they still needed support with.

> *I mean I don't want to say no. [The medication was helpful] but what would be more helpful would be that we actually have the right access to the healing that needs to be done so we aren't covering it with these chemicals. (Tui about Ururangi and Waitā)*

> *I was asking [CAMHS] for help. I was saying to them we can't just medicate him. That's not all this is. I need some like I don't know, some behavioral therapy, cognitive whatever! There's something going on. We need some family functioning stuff. (Miriama about Luka)*

> *[I wanted the doctor to] give us … some booklets and go through them with us as to what is ADHD, what it means, and where we can get support. And then give us some phone numbers of some support groups.* ***That's*** *the ideal that I would have liked to have seen. And then … talk about the script, right at the end. Don't just like shove it in our face. And actually give us some options and ask us, you know, do you want to try this first or try that? Or do you want to just give the medication a go and then we'll do a follow-up and see how it's going. (Katrina about Nikora)*

Lastly, whānau made various comments that what they were hoping for overall, was a more holistic approach to treatment. For some whānau this better fit with their personal or cultural beliefs.

> *I think because our [Māori] people … back in the days we had our own medicine and our own holistic way of living ... Our rongoā Māori medicines and that kind of stuff. I think I look at it more with a holistic lens, … for myself personally. And … what else I can do to help him holistically? As a whole. I think it's life that I look at like that, through a different lens. (Kahukura about Matiaha)*

"You have to find different ways to parent a child with ADHD"

This sub-theme looks at the ways whānau said they managed the impact of the ADHD-related behavioural symptoms at home. What whānau did themselves to support their tamariki, gives an indication of the support which might be useful for different whānau circumstances.

As mentioned, most tamariki were only given medication and were either not eligible or not offered other support from the service, or they did not meet criteria for referral to external services. Therefore, most whānau engaged other community services on their own. They said they searched for supports in the community and self-referred or in a couple of instances were referred by the school. Some whānau tried therapy for their taitamaiti, which they funded themselves.

> *I've tried lots yeah. … I went to [a local Māori NGO] because … I heard that they had a really good youth service, and I was* ***hoping*** *that they might be able to hook [him] in…he didn't fit the criteria. Too much. See because that's a lot of the issues you have here when you're trying to find help. They're either too much or they're not enough. (Miriama about Luka)*

> *He ended up going to art therapy for about six months, which worked out really well. … [The therapist] was doing sleep training with him as well because he struggles to go to sleep at night. … It was very like hands on and … he did art, and yeah, he really enjoyed it. But I just couldn't afford it, so I had to stop it. (Kahukura about Matiaha)*

Whānau also talked about needing to reflect on their own parenting practices. Some participants said they felt the way they parented other children in the whānau did not work well with their child with ADHD. Another caregiver became aware how and what she was saying to her child was causing them to be upset. This required the parent to reflect on these situations and approach them differently in future.

> *Like my two [other} boys, I do the same parenting style. But then for Nikora, I do a different parenting style… (Katrina about Nikora)*

> *We had to learn {and change] … what happens when he gets in trouble. Because obviously he can't go to a naughty spot (back then) ... Like he can't stand there … and be still and talk to you, like that just didn't happen. … And it's just like support. There's no support for it. It just felt like they give you the pills and they expect you to be fine… (Kiri about Kura and Hamua)*

> *So, I've had to really reflect on* ***my parenting*** *with him because …* ***sometimes****, what I say can trigger him. Like even just like raising my voice … just a little bit and he thinks I'm like yelling at him or he thinks I'm angry at him, you know? So, I've had to really reflect on how I speak to him, how I answer him. … So, I've done a lot of … reflecting on trying to change my parenting to support him. Because you can't just really do normal parenting [laughs] … you have to … find different ways to parent a child with ADHD. … So, I've done a lot of work with him like for school, at home … by changing how I parent him. (Kahukura about Matiaha)*

Other whānau talked about introducing behavioural strategies at home to support their child and how the rest of the whānau functioned. Particularly, where there were other children in the household this was necessary to keep the household running smoothly.

> *Well, in order to survive for [those] three years, … we had our own sort of strategies in place. … You know, getting enough sleep, making sure to get them to bed before they're really hyper, no junk…try to eliminate junk food. Those sort of things. (Emere about Hina and Pua)*

> *I always thought the go-to initially [from any service involvement] would be behavioural-type therapy or strategies, interventions you could put in place at home to support him. So, I started a lot of those or what I thought was appropriate for him, from a young age. (Amohia and Āwhina about Īhāia)*

Another option which some whānau found beneficial were natural remedies or complementary medicines which they got from a naturopath. The whānau used these most frequently to support sleep and general brain function and said they found them to be beneficial.

> *He's taking magnesium, like for sleep. He's taking zinc, vitamin D. She made-up some herbal stuff … like magnesium and … other stuff for his brain, **all** that kind of stuff. … He takes that twice a day and I've noticed really good outcomes. … I haven't really thought that I've needed to put him on anything else, because [that is] working for us at the moment. (Kahukura about Matiaha)*

There was also considerable discussion from participants about the support they received from grandparents and wider whānau. Where participants had previously had whānau support and this was no longer available to them this was a big loss for those caregivers. Whānau were supportive by being involved with the children, contributing to discussions about how to deal with behaviours, and giving advice to the caregivers.

> *My mum, and my dad and my dad's wife are **always** in my kids' life. They go to **so much** of their stuff, … and they get along really well, which makes things **so** much easier. … They play **massive** roles in my kids' lives. Even when they're being naughty … we have family meetings … because everyone needs to be on the same page. (Kiri about Kura and Hamua)*

> *I said something to my mum because my mum knows. … and she said no that's fine because they do it on their weight. … Mum does a lot of that. Especially if I have **any** medical stuff for the kids, I tend to involve her because she's a nurse, and [medical] people tend to be better with other nurses. (Miriama about Luka)*

"There is not a lot of support out there for parents"

Every whānau who was interviewed discussed the significant need for support for caregivers and whānau of children who are diagnosed with ADHD. As one parent explained, "…you know there's so much pressure on parents to look at the parenting environment, but how can you do that if you're just surviving?" (Amohia). Some caregivers acknowledged there was a toll on them personally because it was challenging to effectively parent a child with ADHD.

> *There's not a lot of support out there for parents. I'd like help for parents. Like how can we support our children? … Even … to be able to go and talk to someone. …I think that's lacking out there. Because …where am I supposed to go for support to be able to handle this, to try and parent and deal with it. … I mean, you can go and see counsellors and stuff, but it's hard to find a counsellor …Like it's* ***really hard*** *to get support. … Because my mum and dad were like you need to go see someone as well to help you with this … It might be better for you instead of talking to us because we don't know. … how to deal with it sometimes. (Kahukura about Matiaha)*

> *My [work] interest from here on in, is supporting … parents who are supporting children with ADHD. Since … the boys have gotten older, I started talking to other people and just getting out there a bit more. I don't know any parents who have ADHD children who are still together. Your home life is* ***so*** *seriously affected. … I would really like to set up something geared towards parents. (Miriama about Luka)*

Specifically, some caregivers said they wanted to be supported with parenting their child. They felt that supporting their child was beyond their parenting skills and felt very much left on their own to figure it out.

> *Come into my home and teach me how to parent this kid because I don't know what the hell I'm doing! (Miriama about Luka)*

> *There was not really anything about what I can do as a mum to support him. Like I had* ***no idea*** *how to support him. … I've just kind of been figuring it out as I go and researching and*

> *joining groups that other parents have and like what their experiences have been. And I've just kind of been doing it on my own. (Kahukura about Matiaha)*

Although some parents had done a parenting course such as Incredible Years or Triple P which in some cases was recommended by the service, this varied between different services. For other whānau, like in the following extract, there was no support to access a parenting course.

> *I also asked are there support groups? Are there courses? Like I'd be very interested in doing like a parenting course. Or is there a course on ADHD that I could do, to learn more? … And the doctor said, "oh, I'm not really aware of anything, but I think there's a parenting course you can do, but I'm not sure who it's through or what it's called." Well, this is very helpful! (Katrina about Nikora)*

Summary

In summary, this theme captured whānau talking about their preferences for assessment and treatment. Only one whānau was seen within a Māori service (for two of their children) and they described a supportive, wraparound service and an approach which was based in tikanga Māori. Whānau said they were not asked questions about their cultural background and there were no kaupapa Māori options through the mainstream services. If a kaupapa Māori service was available, some whānau said they would have elected to be referred to this service. Some whānau said they would have welcomed support to connect with a Māori-based service in the community. There was also discussion it would have been helpful if there was collaboration between the health service and other social services involved, or the child's school. Whānau largely wanted other options instead of medication and in conjunction with medication, including access to support groups, parenting courses and overall, a more holistic approach.

Whānau also talked about the work they did on their own to support their tamariki. Some whānau gained support from community services, self-funded art therapy or used complementary medication. Parents said they reflected on their parenting practices and introduced behavioural strategies at home. Most whānau also discussed the significance of whānau support.

The final aspect to this theme, was whānau noting a lack of support for caregivers and whānau who support a child with ADHD. They discussed how challenging it was to support their child when they felt they were just managing. It was common for whānau to discuss wanting someone to help them figure out how to parent a child with ADHD.

8.2. Chapter Summary

This chapter presented the findings of the current research. Seven themes were identified using thematic analysis: whānau experience of ADHD before diagnosis, whānau understanding of symptoms and behaviours, the experience of assessment, whether to medicate was a big decision for whānau, the experience of treatment, the benefits of and concerns about diagnosis, and preferences about treatment and support. Overall, these themes illuminated the experiences of whānau Māori who have tamariki with ADHD and helped to understand how these experiences impact on service use for ADHD. The following chapter will discuss these findings in relation to the specific research questions and consider the implications of these findings in more detail.

Chapter Nine: Discussion and Concluding Comments

This chapter discusses the key findings of the current research which explored the experiences of whānau Māori supporting a child with ADHD and factors which were barriers or facilitators for assessment and treatment. This research aimed to contribute to literature on ADHD from a Māori cultural perspective and in the NZ context. Consistent with He Awa Whiria, the findings are considered in relation to literature about the provision of health and MHS in NZ, clinical practice guidelines for the assessment and treatment of ADHD and te ao Māori perspectives of wellbeing. The clinical significance of these findings is discussed with recommendations for how services and clinicians might evolve their practice to support engagement with whānau Māori. Comments for how this extends to clinical practice in general are made. The strengths and limitations of this research are discussed followed by opportunities for future research. This chapter finishes with concluding comments about this research.

9.1. Summary of Key Findings

The aim of this research was to explore the experiences of whānau Māori supporting a child with ADHD, and to understand how this related to service use for ADHD. The objectives based on this aim were: to gain an understanding of the experiences of assessment and treatment for ADHD for whānau Māori; to describe how whānau accounted for ADHD-related behaviours prior to diagnosis; and to identify barriers and facilitators for assessment and treatment for ADHD. Whānau spoke about their experience of their child's behaviours before they were diagnosed with ADHD, how their child came to be assessed and diagnosed, the treatment and support their child was given, the barriers and facilitators for assessment and treatment, and finally what whānau would have like to have happened throughout this process. TA of the interview transcripts produced seven themes.

Although ADHD is one of the most researched conditions of childhood, the author could find no literature which has previously explored Māori experiences of ADHD and whānau accounts of their needs in assessment, diagnosis, and treatment. Therefore, this research was exploratory. The findings from whānau interviews are considered here, in relation to each of the research questions. Reference is also made to the ADHD Help-Seeking Behaviour (AHSB) Model from Eiraldi et al. (2006) which was introduced in chapter five. The AHSB Model is a hypothetical framework which proposes factors that influence service use for ADHD, and accounts for how different cultural groups may be influenced by different factors on their help-seeking pathway. As this research is guided by He Awa Whiria and the concept of blending cultural and clinical perspectives, the findings are also discussed in respect of existing cultural frameworks; the Hui Process (Lacey et al., 2011), the Meihana Model (Pitama et al., 2007) and Māori models of wellbeing. The Hui Process (described in chapter three) incorporates tikanga Māori principles around mihi, whakawhanaungatanga, kaupapa and poroporoaki, to guide the process of engagement with Māori, during clinical assessment. Likewise, the Meihana Model (also described in chapter three) incorporates mātauranga Māori concepts in a framework for clinical assessment whereby assessment and intervention with Māori clients and whānau, can be culturally informed. And finally, Māori models of wellbeing represent holistic understandings of health that were important to the whānau in this study with regards to their understanding of their child’s difficulties and possible treatment solutions. Solutions that would lead to not just symptom management, but healing.

9.1.1. How did whānau Māori understand and accommodate their child’s ADHD-related behaviours prior to diagnosis?

Overall, regardless of how whānau initially understood and managed their child’s difficulties, all whānau (to some extent) struggled with their child’s behaviour at home and/or school. Whānau spoke of initially being able to make accommodations for the behaviour, but as the young person grew older, the behaviours became more difficult to manage. According to the AHSB Model the first stage of seeking help for ADHD is problem recognition (Eiraldi et al., 2006). Based on diagnostic criteria, the behavioural symptoms whānau described in their kōrero were indicative of ADHD (American Psychiatric Association, 2013b), but it was the experience of these behaviours which contributed to problem recognition and the decision to seek help. In line with previous research, the functional impairment associated with ADHD-related behaviours was often the key driver for assessment (Sasser et al., 2017).

Whānau discussed a range of experiences with their tamariki prior to diagnosis. Some tamariki demonstrated unsafe, impulsive behaviour which indicated to whānau they might need additional support. For the most part whānau noticed challenging or different behaviours from a young age that became more obvious when there were increased demands on their child (often outside of the home) that required appropriate behaviour. For example, the transition to school was mentioned as a difficult period. Once tamariki were attending school, in contrast with their peers their hyperactive behaviour was deemed disruptive, and thus several whānau wanted additional help to support their child in the classroom. Previous research has confirmed there can be significant impairment for children at school as academic achievement is affected by the child's difficulty with planning and focus (Biederman et al., 2004) and disruptive classroom behaviours (DuPaul, 2007). Where whānau had been able to accommodate the behaviours, other people (such as extended family and teachers) were less prepared (and less able) to make those same allowances. Subsequently, many of the tamariki were isolated from their classroom and peers or excluded from school altogether. How tamariki were responded to at school because of their behaviour, whether they were able to perform academically, and the related social implications were common concerns for whānau. These factors were strong motivating factors for parents to seek help.

In addition to the impact of behavioural challenges on the young person and their whānau system, there was also a toll on the caregivers. This finding is consistent with existing research which acknowledges increased caregiver stress and burden related to supporting children with ADHD-related behaviour (Bolea-Alamañac et al., 2014; Bor et al., 2002; Cadman et al., 2012). Common to most participants' kōrero, caregivers lost confidence in their parenting as they struggled with their child's challenging behaviour. This was particularly difficult when other people, including another caregiver or a health professional, did not agree there was reason to be concerned. The caregivers involved in the interviews talked about accommodating the behaviour at home with behavioural strategies, supplements, natural remedies, and by establishing routines. If there were no significant gains for children from these strategies, this was another prompt for caregivers to seek help. As discussed in chapter two, from a holistic, Māori perspective of wellbeing (as represented in Te Whare Tapa Wha, for example), whānau is a component dimension of health (Durie, 1985). The relationship of whānau to a person's wellbeing is reciprocal and inextricably interrelated with the other dimensions of wairua, tinana and hinengaro. The difficulties a whānau member is facing also affect the whānau (Durie, 2017a; Kingi, 2017b) Within the Meihana Model, whānau is illustrated as one of the two hulls of a double-hulled canoe (the other hull representing the individual), indicating the role of whānau in assessment, intervention and the client's life. Therefore, addressing whānau concerns supports individual whānau members as the whānau structure is reinforced to support itself.

As well as perceiving the behaviour as problematic, what whānau attributed the behaviour to contributed to whether they initiated support. Most participants did not have prior knowledge of ADHD and identified other factors they thought were at least contributing to their child's difficulties. Caregivers with some knowledge of ADHD thought these other factors were more pertinent and would exclude their child being diagnosed with ADHD. Other explanations for challenging behaviour included: ineffective parenting (other people told the caregiver this), social constructions and perceptions of what was typical/normative behaviour for boys, this was a developmental stage the child would grow out of, a response to big changes happening at the time, or the child was just being 'naughty.' Several whānau also explained there were adverse experiences which had affected their child and possibly caused the behaviour. An existing criticism of diagnostic criteria for ADHD is there is no accounting for other factors which impact childhood development such as traumatic experiences, social disadvantage, attachment and culture (Erlandsson et al., 2016). These other factors do not exclude a child being diagnosed with ADHD, though they could contribute to behaviour which masks or mirrors ADHD symptoms, and this is a potential barrier to the decision to seek help.

Some participants had prior knowledge and experience of ADHD (personally or through work) and recognising potential symptoms of ADHD in their own tamariki advanced the whānau's decision to have their child assessed. Other whānau had ADHD suggested to them and when they learned more about ADHD this validated the whānau's experience and prompted the assessment. Manatū Hauora (2021c) note that prevalence estimates suggest many families are likely unaware their child has ADHD, so improved psychoeducation about ADHD and its symptoms would facilitate more whānau to recognise possible symptoms and seek support.

9.1.2. What were the barriers or facilitators for whānau in respect of service access for assessment and treatment for ADHD?

Barriers for Assessment

Thinking about help-seeking as a pathway to treatment for ADHD, following problem recognition is the decision to seek help (Eiraldi et al., 2006). Once participants recognised there was a problem and wanted support, they then had to know how and when to access help. In the Meihana Model, the two hulls of the waka hourua (representing client and whānau) are connected by aku; one of which is iwi katoa. According to Pitama et al. (2014) in this model, iwi katoa represents access to services and systems which might provide support for the client and the whānau within the health system. Therefore, in terms of clinical assessment and case formulation, an integral aspect of assessment is to identify whether whānau Māori have had access to services appropriate to their needs, and what barriers and enablers to those services might be (Pitama et al., 2014). In the current research, some participants did not know how to request the assessment, especially when whānau had no knowledge of ADHD. As was discussed in chapter one, in NZ GPs are usually responsible for referring patients to specialist health and mental health services (Gauld, 2020; Lawrence, 2017). However, as one caregiver explained, they did not approach their GP as they did not think the GP could help with a behavioural issue which was not a health concern. This finding adds weight to concerns that families have to know how to navigate a fragmented health and mental health system in order to get support (Lawrence, 2017).

For whānau who did request support through their GP, in some situations the GP dismissed their concerns, and caregivers said they had to push for a referral. It wasn't always clear why this was the case. Possibly, the GP did not agree there was sufficient evidence, that the child had ADHD. There is also the possibility the referral was hard to come by because paediatric and CAMHS services are in high demand and therefore have restrictive criteria (Cunningham et al., 2018). Thus, the decision to refer is more about whether there is sufficient impairment to meet threshold for publicly funded treatment even if the child has symptoms indicative of ADHD. As mentioned, publicly funded MHS in NZ are directed towards meeting the needs of the most unwell 3% of the population, and this covers all mental health concerns (Ministry of Health, 2016). Where there is no evidence of either significant impairment or a comorbid mental health concern, a CAMHS service may decline a referral for ADHD assessment. Either way, having to insist on the referral was a barrier to assessment for some whānau.

Another key finding was that caregivers were concerned about seeking help as they thought they would be judged as responsible for any identified issues, and their parenting would be critiqued. Whānau anticipated this judgement from clinicians, their wider whānau, and other adults who knew about their child's diagnosis. This is consistent with previous research with parents of minority group children in the US, where concern about stigmatisation was identified as a barrier to ADHD care (Alvarado & Modesto-Lowe, 2017; Morgan et al., 2013). At the level of individual clinician, some participants described negative interactions with an assessor who was critical of their parenting and dictated what the caregiver should be doing to support their child. Some whānau said their concerns about assessment were based in a general mistrust of the health system. As a framework for case formulation with Māori, the Meihana model also accounts for contextual and societal factors which are known to influence health and the way in which whānau Māori engage with health services; this includes marginalisation, colonisation, and racism (Pitama et al., 2014). This has previously been identified in the literature as a barrier to help-seeking for ADHD, where ethnic minority families distrust the health care system because of prior discrimination (Eiraldi et al., 2006).

It was not uncommon for caregivers to disagree (between each other) about the underlying cause of their child's inattentive and/or hyperactive-impulsive behaviour in which case, only one caregiver wanted the assessment done. This is corroborated by prior research which found if a caregiver did not believe their child's behaviour to have a neurobiological or psychological origin, they would not necessarily seek support or diagnosis (Lawton et al., 2014). While the interviewed parent thought this may stem from a lack of understanding about ADHD, they also said the other parent felt a lot of whakamā about their child being labelled with a diagnosis.

Once the referral for assessment had been made, there were also service-related barriers which made the assessment more difficult. There were long wait times for an initial appointment when parents often felt they were at breaking point by the time the referral was made. For some tamariki, whānau said the assessment was rushed and not thorough, and this created doubt around the diagnosis. The lack of process for the assessment likely reflects the pressure services are under to meet demand with limited staff and funding (Allan, 2020; Cunningham et al., 2018; Elliot & ActionStation, 2018). Service access barriers are corroborated by findings in the Health and Disability and MH and Addictions Reviews (Health and Disability System Review, 2020; Paterson et al., 2018), where service users have previously highlighted these same concerns.

Another barrier whānau identified was that it was difficult to ask their child's teacher to contribute to the assessment. As discussed in chapter five, there are subjective elements to diagnosis, and together with a clinical assessment, information is gathered from caregivers and teachers. Therefore, how a teacher rates a child's behaviours has the potential to impact diagnosis (Bennett, 2021). There were two main issues whānau encountered asking the teacher to contribute: either the caregiver believed the teacher did not like their child and they found it hard to ask them for support, or they were aware the teacher did not think ADHD was a valid diagnosis or an accurate explanation for their child's behaviour. Although ADHD is a relatively common diagnosis, this suggests different understandings of ADHD amongst teachers, and this complicated the assessment for some whānau.

Facilitators for Assessment

As discussed, for most whānau seeing their tamariki struggling at school and wanting them to succeed, was often the reason to seek help. Other reasons whānau were prompted to request the assessment were because the child's school suggested or insisted on the assessment, or someone else (such as the GP or a support worker) recognised ADHD-related behaviours and suggested the assessment. In these circumstances, someone already involved with the family who was familiar with ADHD symptoms, guided the whānau toward assessment.

There were also relational factors which supported whānau to prepare for the assessment. This included whānau who were well supported by their child's school, or a teacher/RTLB who clearly explained what the school's concerns were for the child. Some whānau also benefitted from having a supportive GP who guided the family and helped them to gather evidence relevant to assessment. Existing literature highlights the importance for Māori of trusting, respectful relationships within health care, which support whānau to explain their situation and experience (Bennett, 2017; Dunn, 2002). As a tikanga-informed framework for how clinicians might enhance their engagement with whānau Māori, the Hui Process describes the relationship-building aspect of assessment as whakawhanaungatanga. The whānau who felt well supported in respect of the assessment, had adequate information and guidance, and said they were asked what help they needed.

Whānau also discussed positive interactions with the assessor where they felt they were listened to and understood. Participants emphasised the importance of collaboration as the situation was less confronting and they felt their whānau's best interests were at the forefront of decisions. Another positive aspect of a good assessor was that they were proactive, responsive to emerging issues, and seemed personable, genuinely concerned, and empathic. This finding again emphasises the significance of engagement with Māori as this fundamental to effective assessment and treatment (Bennett, 2017; Pomare, 2015). As has been discussed, mokopuna Māori embody whakapapa, and caring for tamariki represents caring for whānau and whakapapa (Cameron et al., 2013; C. Smith, 2010). If whānau are the "functional unit of healing" (Elder, 2017a), an important aspect of the therapeutic relationship is that the whānau feel understood and supported.

Barriers for Treatment

Once the diagnosis was made, whānau then needed to make decisions about treatment and their next steps for supporting their taitamaiti. In the AHSB Model, Eiraldi and colleagues (2006) call these, service selection factors, where parents review what options are available to them and their child, and the various factors which facilitate or impede help-seeking. As previously described, the Meihana Model accounts for contextual and societal factors which may influence how clients/whānau engage with the health system (Pitama et al., 2014); as a framework for case formulation, the Meihana Model could be useful to identify (and therefore resolve) factors which are barriers to service selection. Many of the treatment barriers which whānau discussed were related to the medication.

Firstly, for most of the whānau in the current study, medication was the only treatment which was offered or available which does not fit with a holistic model of wellbeing. For some whānau, medication did not align with how they wanted to support their tamariki. Treatment with medication fits with the understanding of ADHD as a neurodevelopmental condition (Batstra et al., 2014) - although, not necessarily with the multi-dimensional, holistic view of health exemplified by Māori frameworks such as Te Whare Tapa Wha and the Meihana Model (Durie, 1985; Pitama et al., 2014). This holistic paradigm has been depicted in the literature in various Māori frameworks where interrelated domains are seen to contribute to wellbeing (e.g., Durie, 1985; Pere, 1987; Pitama, 2014); none of which focus on physical health in isolation. This is also consistent with research that suggests there is cultural variation in beliefs and attitudes towards medication (Bussing et al., 2007; Partridge et al., 2012). The Australian guidelines for ADHD, emphasise management of ADHD symptoms in ways which improve everyday functioning and quality of life (AAGDG, 2022). With that outcome in mind, these and other guidelines recommend concurrent medication and non-medication treatment, though acknowledge this is not accessible and available for all families. Thus, participants discussed treatment with medication as a barrier to other interventions which whānau felt would be more relevant to them.

Secondly, there were issues with how medication was presented to whānau. In some instances, whānau said at the first appointment they were confronted with an unfamiliar diagnosis, a script for medication, and minimal or no information about ADHD, the medication, or possible side effects. When whānau did not have enough information, they felt they could not make an informed decision about how to support their child. The Australian guidelines (AAGDG, 2022) also suggest there should be relevant information about any treatment option to facilitate the choice of young people and their families; this would be possible of any service provider, whatever treatment options were available.

Regardless of whether whānau chose for their child to use medication, or whether they would have preferred this to be used only as a last resort, all whānau had doubts about medication and this was a potential barrier to ongoing treatment. Many caregivers were aware of strong opinions from friends, teachers and other whānau members against medication and parents "drugging" their children to behave. The controversy associated with ADHD as a 'catch-all' diagnosis is well documented in the literature and the general concern is that ADHD can potentially be (mis)used to medicalise challenging behaviour (Partridge et al., 2012; Singh, 2011; te Meerman et al., 2017). Even parents who said the medication was helpful, were concerned about side effects, mostly appetite and how their child's growth might be affected. While there is substantial evidence of the efficacy of psychostimulants in reducing core ADHD symptoms, there are also considerable side effects (Capp et al., 2005; Chan et al., 2016). The medication (while effective) does not treat ADHD, it only supports people with the symptoms temporarily; from a holistic perspective, other interventions are needed to deal with symptoms when the person is not medicated.

As recommended best practice by the AAGDG, BAP and NICE, once prescribed, medication is then titrated and children should be routinely monitored for side effects (AAGDG, 2022; Bolea-Alamañac et al., 2014; NICE, 2019). This practice was inconsistently applied for whānau in this study.

In NZ, the GP usually assumes prescribing of ADHD medication from the written instruction of the specialist (Pharmac, 2022); this should typically happen after the medication has been titrated. Several whānau said the medication was not titrated, and it was difficult to get support to get the medication right. Either the dosage was ineffective, did not last the entire school day or there were side effects. For whānau who did have follow-up with the specialist and the medication was titrated, this still involved months of changing medication type and dose and waiting to see how their child responded each time.

There were also service-related issues which were barriers to whānau accessing treatment. The service was difficult to access after diagnosis, and there were long wait times for follow up appointments. This was during the period when the medication should have been titrated and caregivers said it was frustrating if there were medication issues, they could not discuss with anyone. Again, this corroborates findings reported in He Ara Oranga (Paterson et al., 2018) where consumers raised concerns that high demand, led to excessively long wait times. At times, whānau said they were told by the service to go to their GP and while the GP was easier to access, whānau were disappointed the GP was limited in how they could help as they could only issue the same script. In addition, regulations in NZ mean stimulant medications can only be prescribed for 30 days at a time, and whānau had to routinely remember to request a script from their GP before the medication ran out. As discussed in chapter one, general practices can set their own co-payments and often charge a fee for repeat prescriptions (Gauld, 2020). Therefore, although the prescription may be subsidised, there is a regular ongoing cost for whānau in obtaining their child’s medication.

For most of the whānau ongoing support after diagnosis was either not available to the whānau through the service, or the whānau did not meet criteria for an external referral. This finding is consistent with Te Huringa, where the government acknowledges (due to various reasons) MHS are only able to offer an “incomplete response” when people need support (Mental Health and Wellbeing Commission, 2022). In some instances where a referral to a community agency was offered, the suggested support was inappropriate for the whānau’s circumstances and the whānau felt misunderstood. Caregivers had to try and access other community-based support themselves and many whānau said they were not aware of any support available to them. The other concerning issue that was also a barrier, was whānau said they were worried about asking for help. They mentioned concern about being judged and that if they were struggling to control their child's behaviour Oranga Tamariki might become involved and would remove their child. This again, speaks to prior negative experiences of services and the expectation of discrimination influencing service use for tamariki and their whānau for ADHD (as per the Meihana Model) (Pitama et al., 2007).

Facilitators for Treatment

Among participants were those whānau who had tried multiple strategies to support their child, and therefore they had already decided medication would be beneficial. They were prepared to try anything helpful and were open-minded to medication when it was suggested. What was consistent between these whānau was they were clear about what support they anticipated from assessment, and how this would benefit their child. Prior research has said based on personal and cultural values different families seek different outcomes from treatment for ADHD (Fiks et al., 2013). In that research, when the goal was academic achievement, this was associated with medication use and when the goal was behavioural improvement, this was associated with behaviour therapy. Therefore, understanding what whānau aspire to for their child, is important for facilitating treatment. As Durie (1998) explains, addressing inequity and focusing only on access to health services, suggests Māori should have the same aspirations as anyone else with respect to health. This is not necessarily the case and will even differ between whānau. The treatment becomes meaningful because it is meeting a specific need, and one way to identify this need is through case formulation.

As with assessment, whānau were more confident in their decisions about treatment when the clinician collaborated with them and took the time to listen and explain. How to enact this is demonstrated in the Hui Process model, where Māori principles of whakawhanaungatanga and kaupapa are applied to the process of engagement and clinical assessment (Lacey et al., 2011) – connections are made between the clinician and the client, and the purpose of the assessment is shared and agreed upon (as the kaupapa), before this is attended to. In addition, some participants said they had a supportive, empathic support worker involved with their whānau and this helped them to support their child with treatment. The support worker's role was to help the whānau monitor medication effectiveness and side effects, support the family with any ongoing issues, and act as the liaison between whānau and the service. This finding is consistent with previous research where engagement with treatment was improved when staff took time to build trust and showed an interest in the families' lives (Ratto et al., 2017).

9.1.3. Was the support which was available culturally appropriate and relevant; did this influence engagement with services?

As was discussed in chapter two, the link between culture and health has been increasingly recognised in health care, as has the understanding that diverse cultures have different explanations and expectations of health and wellbeing (Durie, 2011, 2017c; Kingi, 2017b). NZ researchers have considered whether a kaupapa Māori approach to health care, may better reflect some whānau and their world view and facilitate service access and treatment (Hatcher et al., 2016; McClintock et al., 2016; Tapsell, 2017). In the AHSB model service characteristics such as the availability of culturally sensitive staff are proposed to influence help-seeking for ADHD (Eiraldi et al., 2006). The Meihana Model also describes several factors which similarly influence how whānau will negotiate their health and wellbeing, and also establishes a framework for assessing both strengths and weaknesses in these areas and how these relate to the client's health (Pitama et al., 2014). Therefore, this research question considers if the support whānau received was culturally appropriate, and whether whānau thought this made a difference to their engagement with services.

In their kōrero, some whānau spoke about their cultural background and how they felt this was relevant to their experience. They spoke about having strong whānau relationships, where grandparents and other family members were significantly involved in caring for and helping to raise their children, and they attributed this to being Māori (or Māori and Pasifika for one family). Where there were issues which meant disconnection from whānau and whakapapa, caregivers attributed their child's behaviour and their difficulty with managing this, to that whānau support having been displaced. The significant role of whānau to wellbeing is seen in Māori models, such as the Meihana Model and Te Whare Tapa (Durie, 1985; Pitama et al., 2007).

Of the participants in this study, only two tamariki (from one whānau) were assessed and supported within a Māori-based CAMHS which focused on them as a whānau Māori. The whānau said they found the service to be a comfortable and inviting space, and they were given the option of karakia to begin their interactions with the clinician. They received wraparound support from the psychiatrist who assessed their tamariki and from a nurse who regularly followed up with them (at the whānau's home). The caregivers said the assessor approached the assessment and the explanations he gave the whānau from a Te Ao Māori perspective. They were offered access to a tohunga, mirimiri, and support for the parents, which was in aid of helping the whānau to support their tamariki; in effect a holistic approach informed by mātauranga Māori. While this was an isolated experience for one whānau, they described their experience of the Māori-based service as entirely positive and agreed this influenced their engagement with the service and with treatment. This demonstrates a possible model of care whereby culture is appropriately considered.

For most other whānau there was no option for a kaupapa-Māori based service which could assess and treat their child for ADHD, or for cultural support within a mainstream service. This was suggested best practice in previous NZ guidelines (which were current at the time each of the tamariki in this study were assessed) (Ministry of Health, 2001). Furthermore, within mainstream services none of the whānau were asked about their cultural background during assessment or treatment. Other than a handful of specialist Māori mental health services in NZ, most kaupapa Māori services are NGOs and primary health care providers. The WAI2575 stage one report highlighted issues of consistent, substantial underfunding for the primary care of Māori patients and Māori PHOs (Came et al., 2019; Waitangi Tribunal, 2019). Therefore, there is limited funding (and scope) for primary care services to have specialists such as psychiatrists, clinical psychologists and paediatricians who could assess, diagnose, and/or prescribe medication for ADHD. This highlights another issue, where the difficulties tamariki are facing must be serious enough that they meet criteria for secondary services before they qualify for assessment and therefore, treatment for ADHD.

However, there were mixed opinions among the participants about whether they would have engaged with a Māori-based service if this were available. At least half of the whānau who were interviewed said they would have opted for a Māori-based service or NGO. The reasons they gave were because they thought the service would be more inviting, the process less confronting, and they would have been understood as Māori. Other whānau said a Māori-based service would not have changed the outcome of their child being diagnosed with ADHD. The advantages of diagnosis (in general) which whānau talked about were a better understanding of their child, validation about their struggles as caregivers, and access to medication. While most whānau wanted additional support, whānau thought this would have been the same in either a mainstream or Māori-based service. This finding adds weight to the idea, Māori should have access to and choice about health services which they can be assured meet their needs and align with their cultural worldview. This means having kaupapa Māori services and mainstream services that are accessible and support whānau Māori as Māori people (Waitangi Tribunal, 2019). In an equitable health care system, whatever option whānau choose should not disadvantage them from quality care or care which allows them to live according to their traditions and worldview (Kingi, 2017a; Waitangi Tribunal, 2019).

9.1.4. What would whānau Māori like to see changed or included in the overall process of treatment for ADHD?

In a sense, for some whānau the diagnosis was the first intervention. As has been mentioned, caregivers learned there was a reason for their child’s behaviour which validated their struggles with parenting their tamariki. Other whānau were sceptical about the diagnosis and whether this significantly helped their whānau’s situation because treatment didn’t address the underlying issue. In either scenario (that whānau did or did not find some benefit from diagnosis) this didn’t necessarily result in the treatment options or support whānau were hoping to have been given.

For most tamariki, it was taken for granted the whānau would try medication. What whānau wanted were options for treatment, perhaps beginning with behavioural and parenting support, and using medication only if there was insufficient improvement. Some caregivers said they had wanted a more holistic treatment approach as they and their children were affected in multiple ways, and they related this approach to mātauranga Māori and to their cultural background. Reviewing Pham's (2015) application of the biopsychosocial-cultural model to the assessment of ADHD, medication has its place in terms of biological features of ADHD and less so for the psychological and social-cultural features. With adequate information and genuine choice (not 'medication or nothing') a holistic approach, by definition, does not inevitably exclude medication from a treatment plan. However, there was an expectation that whānau should alter their preferences and cultural beliefs in favour of the clinical perspective.

While medication was helpful for supporting tamariki with hyperactive, inattentive, and impulsive behaviour, particularly at school, the effect was temporary and so the benefits were not always apparent at home. Therefore, even when medication was beneficial, whānau wanted options in conjunction with medication. Several caregivers said what they needed the most, was support with how to parent a child with ADHD as they felt this required skills beyond typical parenting. This is consistent with established guidelines for ADHD. Especially for younger children (i.e., six and under), behaviour management training for parents is recommended as first line treatment (NICE, 2019; Wolraich et al., 2019). For older children, various guidelines also recommend concurrent medication and non-pharmacological treatment, including parent training (AAGDG, 2022; Wolraich et al., 2019). Despite evidence for the effectiveness of parenting programmes these were not routinely offered (Bolea-Alamañac et al., 2014; Bor et al., 2002) and whānau had to find out how to access these on their own. The main issue of how ADHD-related behaviours were impacting on tamariki and their whānau, was often unresolved by medication.

For the same reason, whānau also wanted ongoing support for their child after the diagnosis which for various reasons, was not always available. The support whānau wanted for their child included therapy or counselling, academic support, access to peer support groups, and specifically help to connect with a Māori-based service. Mostly, it seemed this could not be accessed through the service directly, whānau did not meet criteria for external services, or they had to know about this support in the community and self-refer. Within the AHSB Model, this is referred to as fragmentation of care where help-seeking is compromised by disjointed service provision (Eiraldi et al., 2006). This is again, consistent with findings in He Ara Oranga and other nationwide reviews which highlight a fragmented NZ health care system that is difficult for consumers to navigate (Paterson et al., 2018).

Whānau would also have liked better collaboration and communication between the health service and other social services (such as Oranga Tamariki) or their child’s school. Most whānau relayed information (including the diagnosis) between the service and the school and according to caregivers if the service had communicated directly with the school this would have made access to academic support through the school, more efficient. Guidelines from the AAP recommend the clinician liaise with the school on behalf of the family, and suggest an IEP as part of any treatment plan (Wolraich et al., 2019). The AAP suggest the IEP include environmental modifications for school and behavioural strategies which would ideally coordinate efforts at school and home. As for Oranga Tamariki, one whānau said if Oranga Tamariki had supported the whānau to access the assessment and other support from the beginning of their involvement, they may not have had the delays they experienced.

Finally, it was a common theme that whānau identified a need for support for caregivers and whānau. In whānau kōrero, the reason for seeking the assessment was a combination of tamariki needing help, and of whānau and caregivers needing support. Caregivers acknowledged it was challenging to parent a child with ADHD and the impulsive behaviour was disruptive to relationships within the whānau. Other than wanting support with how to parent their child, whānau thought it would be beneficial if they could access therapy for themselves. This is consistent with a family systems approach where the treatment is focused towards the whānau system in which the child lives;

this also reflects the collective concept of whānau, where support that reinforces the whānau supports individual whānau members (Walker, 2013).

9.2. Implications for Clinical Practice

The current research findings have implications for those working alongside whānau in clinical practice. It was envisaged that an important contribution of this study would be to develop a clearer understanding of Māori perspectives of ADHD and ADHD support and to use this information to suggest how to enhance clinical practice; ultimately, that whānau have access to services that meet their cultural and clinical needs. Understanding factors which relate to problem recognition, service use and help-seeking for whānau Māori means being able to identify ways to improve service responsiveness for tamariki Māori with ADHD.

In NZ's under-funded and necessarily tiered mental health system for youth, care must be prioritised based on perceived severity and impairment (Cunningham et al., 2018), and it would be easy to criticise services for not strictly adhering to best practice. It was beyond the scope of this study to critique whether best practice for ADHD was followed. It would be more pertinent to question whether it was possible for services to deliver best practice in the current service delivery model for ADHD; for not only tamariki and rangatahi Māori, but for all children and adults with ADHD in NZ. Best practice assumes there are resources and capacity to provide the care that is best. In addition, there is an assumption (and reasonable expectation) from the consumer's point of view that once they meet criteria for ADHD or any health or mental health concern, they will subsequently receive the best possible treatment that meets all their needs.

9.2.1. Service Barriers

The primary focus of clinical intervention is to address current, clinical concerns and some of the barriers whānau discussed were related to more systemic issues. Several of the barriers whānau identified (and have already been discussed) were service barriers, such as long wait times for an appointment and difficulty accessing the service post-diagnosis, and clinicians and other staff are not able to individually effect change about some of these issues. These service barriers are consistent with the findings of the Government's Mental Health and Addictions Inquiry and the Health and Disability System Reviews (Health and Disability System Review, 2020; Paterson et al., 2018). Services working with children in health and mental health are in increasingly high demand and this limits who services have capacity to see, how timely they can be seen and the support that can be offered once diagnosis is made. The findings from consumer-led reviews like these, and from the WAI 2575 stage one report (Waitangi Tribunal, 2019) have contributed to policy changes and to the recent health reforms, and it remains to be seen if and how this will affect health care service delivery in NZ. Identifying service barriers and facilitators alongside whānau and consumers is one way to support whānau Māori and to address inequitable service access. The other is to consider how clinical practice might better incorporate the needs of whānau Māori, by first understanding what those needs might be. How those needs might be assessed and formulated within clinical practice - and how clinical assessment could be undertaken with Māori in a culturally-sensitive way - is demonstrated in the Meihana Model and the Hui Process, respectively (Lacey et al., 2011; Pitama et al., 2007).

9.2.2. Assessment

Whānau discussed both negative and positive experiences of the assessment process, and both scenarios have value in identifying ways clinicians might work in support of Māori tamariki and their whānau. To begin with, some whānau approached the assessment with a general distrust of the health care system and felt defensive of themselves and their tamariki. Caregivers were concerned the assessor would judge their parenting and there was whakamā for some whānau, associated with their child having a (diagnostic) label. This corroborates prior research with minority group families in the US where families thought discrimination would compromise the ADHD care provided to their children, and there would be negative connotations attached to their child having the label of ADHD (Alvarado & Modesto-Lowe, 2017). These factors were then complicated if the assessment was rushed, and when the assessor did not take their time to explain the diagnosis or offer support. There were caregivers who were left unsure if the diagnosis was appropriate for their child because of their experience of assessment which then added reason to doubt the appropriateness of medication.

Aspects of assessment that were beneficial for whānau were mostly related to positive interactions and traits of the assessor including: the assessor taking time to develop a relationship with the child and their whānau; an assessor who listened; and an assessor who did not judge the whānau for what they were struggling with. Caregivers said these interactions made the assessment less confronting. Other beneficial factors were having an assessor who was proactive, responsive to any emerging concerns, and who collaborated with the whānau on solutions.

Taken together, this indicates there was value for participants when the assessor took the time to understand the child and their whānau, and what the whānau anticipated from assessment, either good or bad. Establishing interpersonal connection and the parameters or kaupapa of the assessment, resembles whakawhanaungatanga within tikanga Māori. The Hui Process (Lacey et al., 2011) is an existing framework that guides clinicians for how whakawhanaungatanga and other tikanga might be incorporated within assessment. The intent of the Hui Process is to enhance doctor-patient interactions by drawing on mātauranga Māori and based on whānau experience this would apply to clinical assessment for ADHD. More than rapport-building, this lays the foundation for collaboration; the clinician holds the clinical knowledge the whānau have decided they need, and the whānau hold the knowledge about their whānau and what support would benefit their child.

9.2.3. Medication

As has been discussed already, whānau were hesitant about their tamariki using ADHD medication. According to participants, it would have helped if the clinician had better explained ADHD and how this might be affecting their child, and then discussed how medication worked. In hindsight, whānau said they wanted to be told about possible side effects and risks, what was involved with titration, and how to access the medication on an ongoing basis. They felt the assessor could also have explained the process of how medication would be managed by their GP once titrated and would require specialist review every two years.

There were also caregivers who elected not to treat their child because treatment with medication did not align with their cultural values and beliefs. Overall, this represents an opportunity for the clinician to have tried to understand the whānau's concerns about diagnosis and medication, including cultural explanations for those concerns, using the Meihana Model (Pitama et al., 2014). In the clinical setting, the assessor is positioned to gain this information from whānau, and to contribute their clinical knowledge about ADHD towards identifying appropriate and targeted interventions; again, blending cultural and clinical perspectives.

9.2.4. Ongoing support

As discussed in chapter four, there is evidence that supports both pharmacological and non-pharmacological interventions as effective treatments for ADHD (AAGDG, 2022; Molina et al., 2009; Waite & Ramsay, 2010). In this study, whether medication was introduced or not, non-pharmacological treatments were not routinely available to the whānau. Thus, if a child did not use medication there was no clear pathway for ongoing support, despite having met diagnostic criteria. For some whānau there was benefit from medication; however, there was inconsistent support about how to manage the associated functional impairment which did not improve with medication. In most instances, participants noted a lack of support options for caregivers and other whānau, including siblings. Caregivers spoke about needing access to therapy and/or support groups for themselves or their child, opportunities for respite, and support with parenting. Participants also said they needed more information about where they could access other support. Providing whānau with all the information they needed, could feasibly happen after the assessment interview. The assessor could answer initial questions, and then a support worker could answer any additional questions about the diagnosis and assist the whānau to access other support. Of note, some whānau said they were worried to ask for help, concerned about being judged, or scared that if they were struggling, Oranga Tamariki would be involved and remove their children. Therefore, it is important that this information be offered to whānau to overcome this barrier.

9.2.5. Māori based service

For the whānau who were assessed through a Māori CAMHS, the major advantage they described was the sound clinical support they received together with cultural support. Consistent with the He Awa Whiria framework (G. Gillon & Macfarlane, 2017) this is an example of how clinical and cultural understandings can be drawn together; neither was privileged over the other and there was room for both perspectives. Although this was the experience of one whānau, they described being free to express themselves as a whānau Māori as they sought solutions. The outcome was still a diagnosis of ADHD and (one of the children received) medication. The difference was, this was done in a collaborative way, from a Te Ao Māori perspective which left the whānau feeling supported and validated. They were empowered by the process. Other whānau said they would have accessed a kaupapa Māori service if this was available. How Māori-based services, and Māori clinicians and kaimahi might be more available and accessible is an issue that has been raised in He Ara Oranga and the Health and Disability System Review (Health and Disability System Review, 2020; Paterson et al., 2018).

The implication for clinicians operating within mainstream services for ADHD, is to consider their own practice and cultural competence when working with tamariki Māori and their whānau. The norm for many Māori, is that their cultural identity and beliefs are not seen as relevant if they are presenting with health issues, when fundamentally that understanding of health is at odds with mātauranga Māori. As discussed in chapter three, while an illness or disease is defined by a group of symptoms, how someone experiences illness is less readily defined and is partly influenced by their cultural identity and values (Fisher-Borne et al., 2015). As assessment of ADHD is based on clinical interview, it is reasonable for the clinician to also ask how this affects the child and their whānau and the role of culture in that experience. Instead of the responsibility being placed on whānau to engage with health services and to fit in with the system, the system needs to take responsibility for enquiring about and meeting the needs of the person and their whānau.

9.2.6. Case formulation

If a clinician understands how ADHD affects a young person and their whānau, and they can identify the specific goals a whānau has for treatment, then they have a better idea of what support is needed. As Elder (2017) suggests, clinicians need to broaden the scope of what is considered through assessment, beyond a purely diagnostic intent. One way a clinician might develop an understanding of the whānau's experience and needs, is through case formulation.

In simple terms, a diagnosis is the classification of a group of symptoms, and case formulation contextualises the symptoms. For effective and meaningful intervention, it is as important for the clinician to understand what ADHD is and how it can be treated, as it is to understand who the whānau is that has this experience of ADHD and what the clinician needs to know about the whānau to help them manage. Treating a young person with medication without a thorough understanding of the impact of the ADHD-related behaviour potentially contributes to the sense of whānau being misunderstood and not being adequately supported.

As highlighted in chapter five, because diagnostic and treatment practices for ADHD are based on certain social values about expected behaviour, in clinical practice, clinicians must stay mindful of a young person's environment, culture and context (Singh, 2011). Potentially, there are also cultural differences in the outcomes which whānau aspire to for their children. Singh (2011) and Pham (2015) have both suggested models for ADHD that consider the interaction between biological, psychological, and sociocultural factors, specifically for diagnosis and treatment planning with minority cultural groups. The Meihana Model is a similar Māori-specific framework for use in clinical practice (Pitama et al., 2014). What these models share is an overall holistic approach to clinical assessment that seeks to understand the experience and context of the presenting concern. Assessing these aspects of wellbeing to develop a case formulation, also indicates relative strengths and appropriate areas for intervention. The result is a culturally informed assessment and formulation.

9.2.7. Guidelines for assessment and treatment of ADHD with Māori

In 2022, Manatū Hauroa archived the NZ guidelines for the assessment and treatment of ADHD and instead refer clinicians to follow established best practice guidelines from relevant professional bodies. While international guidelines are evidence-based and informed by current research, what is suggested overseas may not always be viable within the service delivery model for ADHD in NZ. Additionally, in the Australian guidelines for ADHD, a specific framework was developed for clinicians working alongside Aboriginal and Torres Strait Island peoples. While there are similarities within that framework, to some of the factors raised by whānau Māori within this study, these are distinct cultural groups with unique histories, ideologies, and beliefs. In the previous NZ guidelines, there was some advice for clinicians about how to support tamariki Māori. This said the assessment should be culturally appropriate, and where possible Māori kaimahi, marae-based clinics and kaupapa-Māori services should be available for Māori children. The NZ guidelines were from 2001, and in the time until they were removed in 2022, these options were still not easily accessible to most of the participants in this study. Therefore, this highlights two issues which would need to be addressed to optimally support tamariki and whānau Māori who are dealing with ADHD: the availability of kaupapa Māori services and clinics that are adequately resourced to support tamariki Māori with ADHD, and the development of guidelines specific to supporting whānau Māori with ADHD which could reasonably be applied in either Māori-centred or mainstream services.

9.2.8. Broader implications of findings

These findings have broader implications when thinking about how ADHD care might best be delivered in NZ. The first implication is how to provide the holistic, wraparound support whānau said they would have benefitted from and preferred. In addition, there needs to be consideration of how with limited publicly funded options, children with attentional difficulties and hyperactive behaviours have adequate opportunity to be assessed for ADHD and to receive appropriate support, and that includes support which is culturally appropriate.

NICE (2019) guidelines suggest that MHS for young people and paediatric services could form multidisciplinary specialist ADHD teams or clinics specifically for the diagnosis and management of ADHD. Such a model, could also allow for a stepped care, stepped diagnosis approach to ADHD, as suggested by Batstra et al. (2014). Batstra et al. suggested this approach partly to mitigate concerns about over-diagnosis of ADHD, and simultaneously, this could also address the possibility of under-treatment by making treatment more accessible. Where there were concerns about hyperactivity, inattention, and impulsivity, this might involve referral to the specialist, multidisciplinary service, as mentioned. Upon referral, whānau could initially be supported with behavioural management strategies and parent training depending on what the child and whānau needed. If there was improvement from these interventions, there may be no need for diagnosis or medication. If there was insubstantial improvement, this would support a more comprehensive assessment through the secondary service (e.g., CAMHS) to potentially diagnose ADHD and prescribe medication. In which case, whānau would already have some behavioural strategies in place, and thus, tamariki would stand to gain the most benefit from medication. This could potentially remove a lot of the management of ADHD from secondary services, thus freeing up a valuable and in-demand resource. In addition, children and whānau would have access to non-pharmacological treatment options, medication if they decided they needed it, and have parenting strategies they could use to support their child, alongside medication. And these services in primary care could also have a kaupapa Māori approach (based on specific guidelines for working with tamariki and whānau Māori experiencing ADHD) where appropriate and relevant for whānau who wished to access such a service.

9.3. Strengths and Limitations of the Current Study

A strength of this research was the primary focus on the experiences of whānau Māori. The Māori-centred qualitative research design resulted in rich information from whānau and added depth to the knowledge that was gained. The meaning of the experiences that whānau shared were constructed through their recount and reconstructed through their interactions with the researcher. This resulted in alternative discourse to the dominant narrative about tamariki Māori with behavioural concerns. The participants were not constrained about what they wanted to discuss by a set of interview questions, or a questionnaire. With minimal research that has considered ADHD treatment practices and Māori, it made sense to begin with a broader, open-ended framework to gain an understanding of how whānau Māori experienced ADHD care in NZ. This could then be used as direction for future research. Because there is a lack of research that focuses on ADHD in NZ, what is achieved is that Māori-centred research based on whānau knowledge is part of the foundation for ongoing NZ-based research.

From a whānau perspective, another strength of this research was the value participants said they placed on being part of the kaupapa. Participants wanted to share their experience to contribute to changes in ADHD service delivery that could benefit other whānau in a similar situation. As there were also positive experiences for the children and their whānau, typically because of skilled, thoughtful assessors and support staff, whānau wanted to acknowledge what was done well as well as what could be done better. One of the key takeaways from whānau about their experiences, was that supporting a child with ADHD was an ongoing challenge and whānau and caregivers also needed support options, as this would allow them to better support their tamariki. Overall, this research holds value as it builds an understanding of the experiences of whānau Māori with tamariki with ADHD and identifies some of the barriers and facilitators to gaining support.

When considering the implications of the findings, particularly the implications for clinical practice, it is important to acknowledge there are limitations. Due to the study design and in-depth interviews, the experiences of only a small group of whānau were represented. To allow for diverse interpretations of whānau, participants decided for themselves who they might involve in the interview. As there were sometimes more than one caregiver at each interview, this produced a lot of data, and the structure of this qualification placed limitations on how much information could be analysed. The cost of the depth of information was the sample size. Therefore, because of the sample size, the findings could not be generalised to represent all whānau Māori. That was also not the intent of this research; the research was exploratory and aimed to build knowledge based on Māori experiences.

Another potential limitation was that all the caregivers who were interviewed, were wāhine. Possibly, tāne Māori may have had different interpretations of their child’s behaviour and how this should be managed and a different experience of the process. However, it was also true even when male caregivers were involved in the assessment, all the female caregivers who were interviewed were also directly involved. In most instances, it was only the female whānau members who were involved. Everyone who was interviewed, therefore had first-hand experience of the assessment and treatment process for their child.

Finally, one of the objectives of this research was to describe how whānau understood the ADHD-related behaviours prior to diagnosis. There was a difference for some whānau where they did not perceive the behaviour to be problematic, or where they said they were able to accommodate the behaviour for a period before there were greater (social) expectations of how their child should behave. In a prior study, clinicians who regularly assessed ADHD in children perceived that a family's culture affected how ADHD-associated behaviours were interpreted and managed by that family (Tipene, 2018). In the current research, whānau gave multiple descriptions of what they attributed the behaviour to and understanding how these explanations were culturally mediated would require more direct questioning. More information may be gained by asking whānau explicitly about their cultural beliefs and how this related to their understanding of their child's behaviours, and their treatment decisions. This would be a beneficial direction for future research and necessary to inform ADHD guidelines for working with tamariki Māori and their whānau.

9.4. Future Research

The findings of this research indicated other areas for future research which might contribute to improving ADHD care in NZ. One of the barriers to treatment was that whānau were not always sure how to access an assessment and support, therefore it would be beneficial to have a consistent pathway for diagnosis and treatment in NZ, so that whānau knew what to expect. The most pressing need would be the development of specific guidelines for the assessment and treatment of ADHD in NZ. While former NZ guidelines have been archived and clinicians are referred to guidelines developed overseas, there are numerous reasons these cannot be assumed to apply in NZ. The health systems in which ADHD care is provided are different between countries, as are the support services and treatment options that are available. Most significantly, these guidelines do not include consideration of working with mokopuna Māori and their whānau. Australian guidelines have incorporated a similar framework for clinicians working alongside Aboriginal and Torres Strait Islander people (AAGDG, 2022). The AAGDG acknowledge there is a need to provide culturally appropriate and competent care to everyone, and so this framework was of critical importance. Similarly, a framework for how best to support Māori would ensure ADHD care that meets the cultural and clinical needs of tamariki Māori and their whānau.

All the tamariki represented by whānau participants in this study had already been diagnosed with ADHD. In discussing treatment barriers for ADHD this should capture the experience of whānau who are trying to access treatment and are unable to. During recruitment, other whānau wanted to participate in the study to discuss the difficulty they had getting help, as although they believed their child had ADHD, their referral was declined by CAMHS or other services which could do the assessment. As prevalence estimates of ADHD in NZ are lower than might be expected (Manatū Hauora, 2021c), a barrier could be that whānau are unable to get their children diagnosed with ADHD in the first place. As discussed, CAMHS are under significant pressure to meet demand with available resourcing and funding (Allan, 2020; Cunningham et al., 2018; Paterson et al., 2018). Therefore, restrictive criteria are necessary to manage referrals which may exclude children from the service, who solely require assessment for ADHD. Primary care mental health options are also not set up to diagnose ADHD. Therefore, there would be significant benefit for whānau needing support for their children and from a service planning point of view if future research considered the level of unmet need for ADHD diagnosis and treatment, for children who meet criteria for ADHD. Our current understanding of prevalence rates for ADHD in NZ is poor, based on incomplete data.

While advocating for the wellbeing of tamariki, rangatahi, and whānau, the experiences this research described are not the direct experiences of the young people who were diagnosed with ADHD. The focus was primarily on the whānau unit and how they were affected, which included discussion of the impact on tamariki. Clinically, particularly for older rangatahi, it is important for the clinician to understand what rangatahi want to gain through treatment and how medication fits with those goals. NICE guidelines (2019) also suggest that clinicians take into account the child's view of their symptoms when determining the clinical significance of functional impairment. It would be an ideal situation that the support available for ADHD in NZ was informed by those with lived experience, including the young people themselves; in much the same way as consumer-led reviews have like He Ara Oranga have contributed to recent health reforms. Therefore, research that explored the views of tamariki and rangatahi Māori about ADHD, would also have benefit.

9.5. Concluding Comments

The aim of this study was to explore the experiences of whānau Māori who support a young person diagnosed with ADHD, and to understand how these experiences impact service use for ADHD. Taking a Māori-centred approach, this was achieved with semi-structured interviews with whānau whose tamariki had been assessed and treated for ADHD. The findings identified several barriers and facilitators for whānau in accessing the support they needed, and it is hoped these experiences might inform a broader, more consistent model of clinical practice and ADHD service provision in NZ.

Mātauranga Māori emphasises a holistic approach to wellbeing, and from this perspective it is counterproductive to continue to separate physical and mental health. This is apparent with a condition such as ADHD; there are behavioural symptoms with a neurodevelopmental explanation, and associated impairment which contributes to (for example) stress and conflict for the child and their family. While treatment with medication is effective, the effect is temporary and aimed at the behavioural symptoms. Even how publicly funded ADHD care is delivered in NZ, reinforces that dichotomy as ADHD is either diagnosed through a paediatric service or CAMHS. Is ADHD a physical health or mental health concern? Is that distinction necessary when an evidence-based, holistic treatment approach which considers cultural and contextual factors, would be beneficial for any young person diagnosed with ADHD?

As mātauranga Māori has been marginalised through processes of colonisation, whānau may not expect their cultural beliefs will or should feature in their dealings with mainstream health services. When Māori people engage with the health system, they do not always have a choice about accepting clinical understandings and practices which do not accommodate their cultural beliefs. In the current research this was seen when whānau were told if they did not accept medication, there were no other options to support them; this suggests the clinical understanding of the child's difficulties as ADHD had precedence over any other explanation. In a sense, whānau with tamariki with ADHD rely on the clinician to have sound clinical knowledge, and trust that resources and support will be available should the whānau need them. Simultaneously, whānau hold their own cultural knowledge and understanding, and however this is represented within a whānau, they shouldn't have to ignore this when they find themselves in the clinical setting. Collaboration between the whānau and clinician, where the knowledge that each hold is included in assessment, case formulation and treatment planning, is an example of blending cultural and clinical knowledge. When genuine collaboration occurs, whānau have autonomy to initiate change in their own lives, on their own terms. Tamariki and rangatahi are supported by their whānau to participate and contribute to their own goals and outcomes. It is my belief that Māori, holistic views of wellbeing are an ideal, which could benefit all New Zealanders.

As there is for other mental health and health concerns, there is potentially a treatment gap for ADHD for Māori. It is well established there are issues within the health system which inequitably affect Māori and the next step is to work towards resolving those inequities. At a systems level this involves strategies and policies to reduce barriers to help-seeking, and to improve service accessibility and responsiveness. For individual clinicians, we need to affirm and incorporate the cultural values, experiences, and aspirations of Māori children and their whānau into practice. This may seem to be an idealistic mentality, but what we are talking about is the ideal of health equity. As the Waitangi Tribunal (2019) note, equity requires a consistent effort.

To conclude, I spoke here about He Awa Whiria and blending cultural and clinical perspectives. This represents my goal with this study for whānau with experience of ADHD and for the benefit of Māori in general in working toward health equity. There was also a parallel process in that this reflects my journey as a Māori clinician working to blend my own cultural and clinical knowledge towards those same goals; to improve my clinical practice and to positively influence the practice of all clinicians who work with whānau Māori.

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Appendices

Appendix A: Study Advertisement

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Blending Cultural and Clinical Perspectives: Attention Deficit Hyperactivity Disorder (ADHD) Amongst School-aged Children in New Zealand

Are you a Māori whānau supporting a child or young person with Attention Deficit Hyperactivity Disorder (ADHD)?
We need your help with our research.

We are seeking participants for our study which considers Māori whānau experiences of services which assess and treat ADHD in the New Zealand context.

This study will contribute both to research about ADHD in NZ and provide insight into how to improve mental health services through better understanding cultural considerations.

Participants are whānau members and caregivers of children and young people who have been assessed for ADHD.

You will be asked to attend an interview of 60 -90 mins duration.

As compensation for your time and as a token of gratitude, you will have the option to receive a $50 petrol or supermarket voucher.

Please click here for information about the study.

How to participate

If you feel you would like to participate in this research, you can take any of the following steps:

Text 0211639651 or email ADHDinNZ@gmail.com with your name and contact details.

Alternatively, click https://www.surveymonkey.com/r/5LQXMXC OR scan the QR code below to submit your contact information and register your interest

For more information, or if you have any questions, please contact:

Charlene Tipene (Researcher)
Ph: 021 163 9651
Email: ADHDinNZ@gmail.com

Appendix B: Participant Information Sheet

Blending Cultural and Clinical Perspectives: Attention Deficit Hyperactivity Disorder (ADHD) Amongst School-aged Children in New Zealand

NGA KUPU WHAKAMĀRAMA/INFORMATION SHEET

Purpose of Research

In 2018, the Government carried out a Mental Health and Addictions Inquiry because of concern about the state of mental health services (MHS) in New Zealand (NZ). He Ara Oranga, the report from the Inquiry, highlighted Māori mental health as an area of concern. Health statistics show worse health outcomes exist for Māori. At the same time health and support services are said to be available but not used by Māori. Research also shows that in general, MHS are not meeting the needs of Māori. Given the claim services are not being used, the current research asks why this happens, and whether this can be better understood by looking specifically at ADHD. Whānau will be asked about their experiences with ADHD services, especially around their cultural needs and what those needs might include. The goal is to understand the cultural needs of whānau, and to then blend cultural with clinical knowledge to inform services for ADHD. This will contribute to both research about ADHD in NZ and suggest how MHS can be improved through better understanding cultural factors.

Introduction to Research Team

Mōtatau tūtei i te ao i te pō, Hikurangi kiekie whāwhā nunui a Uenuku. Ko Charlene Tipene taku ingoa. Nō Mōtatau ahau. Ko au te Kaihautu o tēnei rangahau. Kia Ora, my name is Charlene Tipene, and I am a Clinical Psychology student at Massey University in Palmerston North. I would appreciate your whānau's support of this research. As well as achieving the goals mentioned, this will also meet the requirements of my doctorate in Clinical Psychology. I am supervised by Dr Kirsty Ross and Dr Matthew Shepherd. Dr Shepherd has provided cultural support during the design of this study and ongoing cultural supervision.

Who do we need to take part in this research?

We are seeking the opinions of whānau and caregivers who have a young person who has been assessed for ADHD, and whose whānau identify culturally and/or ethnically as Māori.

If your child/young person is 18 years or under, and:

- they have had behavioural issues consistent with ADHD
- they were assessed for ADHD in the previous 24 months

then your whānau is ideal for this research. Interviews are with caregivers or other whānau who have been involved with the assessment and/or treatment for your child. Please note, your young person does not have to have a diagnosis of ADHD for you to participate.

What does taking part, involve?

Participation involves an in-person interview, of between 60-90 minutes. If you choose to participate, we will arrange an interview time and date which suits you. The interview will be either in your home or another suitable location if you prefer. Interviews will be audio recorded. Before the interview, you will be sent this Information Sheet and sign a consent form to confirm you want to take part. Within a month of the interview, a written copy of your interview will be sent to you and you will be able to make any changes you want. As a thank you for your time, you will have the option between a $50 petrol or supermarket voucher.

Your rights as a participant

Please note, for this study the researcher will not have direct contact with your young person. You are under no obligation to accept this invitation. If you would like to participate, you have the right to:

- Decline to answer any question
- Withdraw your participation from the study any time prior to transcripts being approved
- Ask for the audio recorder to be turned off at any time during the interview
- Ask questions about the study at any point
- Request a summary of the research results, when completed

Confidentiality

The information from interviews will be confidential and will only be used for the purpose of this research. You can provide information knowing that your name, whānau name, and child's name will not be used, and no information which identifies you will be published. The audio recordings will be copied by the researcher and saved as a password protected document.

Your safety and your whānau's safety

In some situations, you and your whānau may feel you want to make an official complaint about services you have dealt with. The researcher will be unable to resolve complaints on your behalf. Should you wish to make a complaint, the researcher will ensure you have information about how to do so. Should you or anyone in your whānau experience distress during the research process, please discuss this with the researcher and refer to the list of support services on the final page.

How to participate/what to do next

If you would like to take part in this research, you can take any of the following steps. Contact the primary researcher by the email or phone number below. Alternatively, scan the QR code, or click https://www.surveymonkey.com/r/5LQXMXC and submit your contact information.

NGĀ KAIRANGAHAU/RESEARCH CONTACTS

If you have any questions or would like more information, please contact the primary researcher, or research supervisors at any stage.

Charlene Tipene (Researcher)	Dr Kirsty Ross (Supervisor)	Dr Mathew Shepherd (Supervisor)
Telephone: 021 163 9651	Email: K.J.Ross@massey.ac.nz	Email: M.Shepherd1@massey.ac.nz
Email: ADHDinNZ@gmail.com		

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application SOB 20/59. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz

Appendix C: Consent Form

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA
UNIVERSITY OF NEW ZEALAND

Blending Cultural and Clinical Perspectives: Attention Deficit Hyperactivity Disorder (ADHD) Amongst School-aged Children in New Zealand

KUPU WHAKAAE/CONSENT FORM

I have read the Information Sheet and have had the details of this research explained to me. I have had the opportunity to ask any questions and understand that if I have any further questions or concerns, I am able to raise these with the researcher or research supervisors.

I understand my participation involves meeting with the researcher in person to discuss our whanau's service use experiences, relating to our child or young person being assessed for ADHD.

Taking part in this study is voluntary, and I may withdraw my participation at any time, by letting the researcher know.

I understand that my identity and any other potentially identifying information about myself, my whānau and our child/young person will be kept confidential.

I agree to the interview being audio recorded and transcribed. I wish / do not wish to have the transcript returned to me prior to being used in the research.

I agree / do not agree to participate in this study under the conditions set out in the Information Sheet.

Full name: ______________________________

Signature: ______________________ **Date:** __________

If you are willing to share the following demographic information, please specify:

CHILD/YOUNG PERSON'S DETAILS

DOB: ______________________ **Gender:** __________
Ethnicity: ______________________________
Current year at school: ______________ **Age at assessment:** __________

CAREGIVER/WHĀNAU MEMBER'S DETAILS

Caregiver's age: ______________________________ **Gender:** ______________

Ethnicity: ____

Average annual income (estimated): $0-$19,999 / $20,000-$39,999 / $40,000-$59,999 / $60,000-$79,999 / $80,000-$99,999 / $100,000+ / Prefer not to say

Your participation in this study is completely voluntary. In deciding whether participation is right for you, we would encourage you to talk with your whānau, kaumatua or kuia, or other support person who might help you in making a decision about taking part.

NGĀ KAIRANGAHAU/RESEARCH CONTACTS

If you have any questions or would like more information, please contact the primary researcher, or research supervisors at any stage.

Charlene Tipene (Researcher)
Telephone: 021 163 9651
Email: ADHDinNZ@gmail.com

Dr Kirsty Ross (Supervisor)
Email: K.J.Ross@massey.ac.nz

Dr Mathew Shepherd (Supervisor)
Email: M.Shepherd1@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application SOB 20/59. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz

If after talking about your experiences with the researcher, this raises concerns or results in distress for you, or your whānau, the following services may be of benefit to you:

Māori health support

Manawatu: **Oranga Hinengaro Māori Mental Health** – Midcentral DHB. Phone (06) 350 9155 or email oranga.hinengaro@midcentraldhb.govt.nz. Mon–Fri, 8:00 AM – 4:30 PM. After hours, call 0800 653 357.

Te Wakahuia Manawatu Trust: Whānau care and support service – for whānau in the Highbury, Westbrook and Cloverlea areas of Palmerston North. Phone 06 357 3400, Mon–Fri, 8:30 AM – 5:00 PM

Taranaki: Tui Ora – Kaupapa Māori Mental Health & Addiction Services

Whanganui: **Te Oranganui** - Mental Health & Addictions www.teoranganui.co.nz

National helplines

Need to talk? Free call or text 1737 any time, for support from a trained counsellor

Lifeline 0800 543 354 (0800 LIFELINE) or free text 4357 (HELP)

Suicide Crisis Helpline 0508 828 865 (0508 TAUTOKO)

Samaritans 0800 726 666

Helplines for children and young people

Youthline Free call 0800 376 633, free text 234, email talk@youthline.co.nz or Web chat

thelowdown.co.nz or email team@thelowdown.co.nz or free text 5626

What's Up 0800 942 8787 (for 5–18 years). Phone counselling is available every day of the week, 365 days a year, 11am–11pm. Online chat is available from 11am-10.30pm 7 days a week, including all public holidays.

Help for parents, family and friends

Parent Help 0800 568 856 for whānau seeking support, advice and practical strategies on all parenting concerns. Anonymous, non-judgemental and confidential.

Family Services 211 Helpline 0800 211 211 for help finding (and direct transfer to) community-based health and social support services in your area.

Yellow Brick Road For families and whānau supporting a loved one experiencing mental health challenges. Find regional contact details here.

Appendix D: Semi-structured Interview Guide

Broadly, the research questions will consider:

- How is the current process for ADHD diagnosis and treatment experienced by Māori?
- Are Māori whānau able to access services and support for ADHD when they need to?
- If support is available, do Māori whānau access these services? Why, or why not?
- Is the support culturally appropriate and relevant for Māori whānau?
- What thoughts and preferences do whānau have about treatment options?
- Would Māori whānau like to see anything changed or included in the assessment and/or treatment process?

<u>Background Narrative:</u>

Tell me the story about how your child/young person first came to be diagnosed with ADHD?

Prompts:

- What were the behaviours you noticed/the school noticed?
- Were you concerned about your child and these behaviours?
- At the time, what did you think was happening for your child?
- Do you think your child was concerned about their behaviour? What did this mean for you as a whānau? What explanation did you or your whānau have for the difficulties your child was experiencing?
- Did you want to have your child assessed?
- What about your child, what did they think about going for the assessment?
- What influenced your decision to move forward with having your child assessed?

<u>Diagnosis:</u>

Tell me about your experience of the assessment process for your child/young person?

Prompts:

- Was there a referral?
- Was there anything that helped or made it more difficult?
- What service were you seen by? What kind of health professional did the assessment?
- What did the assessment involve?
- Was the process explained well?
- Was it easy to access the service in the first place? Why, or why not?

What was your impression of the services/professionals you engaged with?

How do you feel your young person engaged with the clinician?

How did they engage with and respond to you as a Māori whānau?

- Were you asked any questions about your cultural background?
- Would this have made any difference?
- How would you like them to have engaged with you?
- What was your overall impression of the diagnosis process?

Was there anything you would like to see changed about the process of diagnosis?

Treatment:

What treatment options were offered to your child and your whānau?
Prompts:

- Was this a suitable plan for your whānau?
- How did it work out for you?
- What was your preference about treatment options?
- Have you made any changes or decisions yourself about treatment?
- What kind of support were your child and your whānau offered?
- Did you access these services? Why, or why not?

In your opinion, was the service you were offered culturally appropriate and relevant for you as a Māori whānau? Why/why not?

Was there anything you would like to see changed about the treatment process?
Prompts:

- Has it been useful for your whānau or your child to receive the diagnosis?
- Has anything made the symptoms worse? Has anything made them better?
- How was it for you and your family to receive the diagnosis?

- What do you think affects a particular family's acceptance of an ADHD diagnosis? What do you think their concerns might be about such a diagnosis?
- Do you think there are differences with how Māori whānau might deal with an ADHD diagnosis?

Guidelines:

Begin by briefly describing NZ guidelines for diagnosis and treatment of ADHD, with emphasis on the guidelines discussion of working with Māori clients
What are your thoughts about those guidelines? Do they seem appropriate? Are they necessary?

- In your experience, were these guidelines followed?
- If they were followed, how did this influence your experience? OR If they had been followed, would this have changed your experience, and how?
- Is there anything you would add to these guidelines?

Final Questions:

How do you understand your child's difficulties now?

Did you think the psychiatrist/paediatrician/psychologist you saw understood your whānau and your concerns?

- Do you think the specialist worked well with you as a Māori whānau?
- If not, what do you think they could have done to better support you?

Were there any additional considerations you wanted support with?

Were you offered any cultural support?

Do you have any other thoughts or comments you would like to make?

If you would like a copy of your transcript, please let me know.

Appendix E: Transcript Release Form

MASSEY UNIVERSITY
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UNIVERSITY OF NEW ZEALAND

Blending Cultural and Clinical Perspectives: Attention Deficit Hyperactivity Disorder (ADHD) Amongst School-aged Children in New Zealand

AUTHORITY FOR THE RELEASE OF TRANSCRIPT

I have had the opportunity to read the transcript of the interview I had with Charlene. I have made any changes I would like to make.

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

I understand that any extracts from this interview will not identify me, my child or young person, or our whānau.

Full name: ____

Signature: ______________________________ **Date:** ______________

Appendix F: Synopses of Whānau Narratives

Amohia and Awhina talking about experience with Īhāia

Amohia is a 39-year-old mother to three boys, aged 13, 7 and 4. Our discussion centred around 7-year-old Īhāia. Amohia worked in education and was knowledgeable about child development and how to access support for her children. The boys' father, Hami was also involved with the assessment for Īhāia although he and Amohia were no longer a couple. As well, the whānau had a support person, Awhina who was involved with care for the children and participated in the interview.

When Īhāia was two, Amohia noticed he had a lot of energy. She wasn't concerned at first, until the behaviours became unsafe. His behaviour was impulsive and risky at home and at day care. Given her training and employment background, Amohia started to think Īhāia might have ADHD.

To support Īhāia, Amohia introduced multiple behavioural strategies at home. However, the strategies were largely ineffective. To Amohia and Awhina it seemed Īhāia couldn't slow himself down enough to take these strategies on board and use them. Amohia was conflicted as she didn't want to assume something was going on when there was nothing or diagnose her own child. Hami also said there was no issue other than "boys being boys" and the behaviour was due to Amohia's parenting style.

Amohia discussed her concerns with their family GP and trusted his judgement when he said they should wait to see what happened when he went to school. Amohia had always felt well supported by the GP and said he was proactive and efficient in their dealings with him.

When Īhāia went to school, Amohia was careful about school selection. The transition did not go well. Īhāia's behaviours strained his relationships with peers and he was easily overwhelmed. Īhāia did not manage full days at school for most of the first year. Amohia said she wanted to protect her son from the consequences of his behaviours with his peers. She also wanted people to understand him and so was keen for him to be assessed. However, Hami was not on the same page, and he thought Amohia was overreacting.

There were also other issues in the whānau's life at the time. Amohia's mum had a massive stroke and Īhāia was very close to her. The whānau chose to care for her at home and they moved into the same house. Amohia was therefore questioning, is this my parenting, trauma, the environment or because she and Ihāia's dad had separated. While knowing it wasn't normal behaviour, Amohia lost confidence in her parenting. She almost wanted there to be an issue other than parenting because it was such a struggle.

Amohia and Awhina said things were at breaking point at home as they tried to keep Īhāia safe. The unsafe behaviours then started at school. Īhāia had multiple accidents at school. There were also aggressive, reactive behaviours towards others.

When Īhāia was five, Hami agreed to the assessment as he then had some experience of parenting Īhāia on his own. They were referred by their GP to the local CAMHS service, and the whānau chose to go through Māori mental health over mainstream CAMHS. Īhāia was assessed by a psychiatrist. The psychiatrist based the assessment on lots of information from Amohia, Hami, the school and GP and diagnosed Īhāia with severe combined ADHD. To begin with Hami was shocked by the diagnosis. Amohia thought he felt a lot of whakamā. Amohia was relieved by the diagnosis.

The psychiatrist talked with the family about ADHD and discussed treatment options. He explained the benefits and risks of medication, and the need to monitor blood pressure and growth. As Amohia had tried behavioural strategies, the whānau had already decided Īhāia needed medication. When Īhāia started medication, he had regular appointments with the psychiatrist every three weeks. A nurse from the service also supported them and did home visits. It took two years to optimise medication and Īhāia now takes a mix of stimulant and non-stimulant medication.

The diagnosis of ADHD has been beneficial from Amohia's perspective, as the whānau could understand Īhāia better. Having ADHD also meant there was funding for teacher aide support, and Īhāia was able to go back to school fulltime. She realises that she and Hami had different approaches to parenting before the diagnosis. Hami reacted to the behaviour, whereas Amohia and Awhina made changes to the environment. Hami understands his sons better now he has learnt what ADHD is.

The experience of Māori mental health was a good one for Īhāia and the family. The service took a holistic approach supporting not only Īhāia, but the whole whānau. The psychiatrist described to Amohia that parents were the "pou" of the whare, and therefore the pou needed to be strong to support the whānau. He prompted Amohia to prioritise her own self-care. With his support, Amohia was also diagnosed with ADHD during this process. With experience of both mainstream CAMHS and the Māori MHS, Amohia said she would recommend the Māori service to whānau if this was available. This was for lots of reasons such as karakia being offered, a more relaxed, less clinical space and feeling more comfortable in that environment.

Amohia said the psychiatrist was amazing. Every suggestion he made he would draw it up or write it out and Amohia felt safe in his knowledge and skills. He also took their concerns seriously and acted on them. The nurse was also very supportive and got to know Īhāia. She reassured Amohia she was doing a good job and validated this was a difficult situation. Amohia said she felt they were listened to.

Currently, while the ADHD is managed as well as can be there are ongoing difficulties. Amohia explained that when the medication calmed the impulsive, reactive behaviours, sensory issues became more apparent. Īhāia was then referred to the Child Development Service and assessed as having sensory processing disorder. As ADHD is not classified as a neurological condition in NZ, one of hardest issues for Amohia was being able to access funding. The sensory processing disorder diagnosis meant Amohia could request a Needs Assessment Service Coordination (NASC) assessment. She pushed for a NASC assessment, and because she knew the system, she was able to secure some funding to help pay their support worker. Īhāia is now going through process to be assessed for autism spectrum disorder.

Amohia also sought out additional support for herself and Īhāia from local social service agencies. At one stage there was a team of 15 involved. Amohia recognised she was able to push for these services to be involved because of her experience and knowledge from her job and that not all whānau were in the same position to seek support for themselves. She felt that some Māori whānau might feel shame about their child having a diagnosis and be concerned that they would be treated differently by services. She thought too there may be a lack of understanding among some whānau about ADHD.

Amohia noted that in the future she would like a job where she supports parents, whānau and siblings who support someone with ADHD, as in her experience this was lacking. She thought this would resemble a holistic approach to well-being with access to services like mirimiri, rongoa and options for support for mental health issues within the whānau.

Tui talking about experience with Ururangi and Waita

Tui aged 37, shared an insightful yet challenge-filled narrative. The family had experienced interpersonal violence, trauma, grief, loss, drug addiction and mental illness. Tui had trained as a social worker although circumstances meant she was unable to work. She had three sons, and our discussion focused on the younger two, Ururangi (11) and Waita (10). Both boys had been diagnosed with ADHD, as had Tui. Ururangi was diagnosed at 7, and Waita at age 10.

When we met, the boys' (paternal) koro had passed away the day before. Tui purposefully didn't tell me as she knew I would postpone the interview. She felt their experience around ADHD might be useful for other Māori whānau who were struggling, and Tui said it was important to her to have a voice.

Tui described how her oldest son was raised in a much different context from the younger boys. He was brought up by the whole whānau. They had a big whānau house and their koro and nanny looked after all the babies in the whānau and helped raise them, while the parents worked. When their nanny died at age 46 from skin cancer (she didn't trust the medical system), their support system was lost. Tui thought their situation would have been much different if her sons had grown up in that whānau environment.

There was a time when Tui had addictions, and her mental health impacted her ability to care for her children. Ururangi and Waita witnessed a lot and Tui questioned the impact this had on their behaviour. After their dad was charged with assault against Tui and her oldest son, Tui and the boys tried to move away. However, the Courts made them return to be closer to their dad and other family. The moving and periods of homelessness were disruptive. Tui said Ururangi was playing out the violence he saw at home. He had also always been "full on" from a young age. He couldn't sit still and focus and was constantly in trouble at school for breaking property and being disruptive. Tui thought something was up, though she didn't know what ADHD was at that time.

Tui did not think that Waita had ADHD. She said at age five, Waita had a traumatic experience and then there was a distinct behaviour change. This involved a situation where Tui was hospitalised and while she recovered, Oranga Tamariki (OT) put the boys into a foster care home, where they were mistreated. Waita started to behave angrily after this. While Tui was still in hospital, she said the school rang to say Waita had smashed a window, and she thought they had the wrong child as it was so out of character. It wasn't until six months later, Waita told her what happened in foster care. Tui told CAMHS she didn't want Waita diagnosed with ADHD, as he had been traumatised and needed support for that. During the assessment, Waita refused to talk as he didn't trust anyone.

Both boys were assessed through CAMHS. It was not Tui's decision to have them assessed. With Ururangi she said the Courts, the school and social workers who were involved with the family were saying his behaviour was a problem. She said OT insisted she have the assessment done, and she had no real choice as she had to prove to OT, they shouldn't remove the boys from her care. There was also so much going on Tui just wanted help and so she agreed. With Waita, the school and CAMHS said he should be assessed for ADHD. The main issue was that Waita kept running away from school which Tui said was because he didn't feel okay there. Tui said everyone else involved with the boys wanted them assessed. She thought they wanted the Western medical system to “fix” them with medication.

From Tui’s point of view the boys were not coping with school because she was not coping and because whānau were not there to support them. With the right support she was sure some of these behaviours wouldn’t be happening. Tui said both her sons have different strengths, just not in the classroom. They were fine when they were out fishing or in nature. She thought other explanations for their challenging behaviours might be anxiety, trauma, and growing up feeling they had nowhere safe to live.

Having moved several times, the whānau had experience with CAMHS in three different regions. Tui said CAMHS were all run differently. One CAMHS (which worked the best for their whānau) didn't initially diagnose Waita with ADHD. The whole whānau was supported by a CAMHS social worker and the social worker listened when Tui said she didn’t think Waita had ADHD. Instead, the social worker helped Waita get therapy. Tui said the social worker understood the whole whānau unit needed support. As Tui was with CMH and both boys were with CAMHS, the social worker organised hui with all the whānau and their support workers. This experience restored the boys' trust in social workers. They had lost trust in the system which told them they would keep them safe and yet had removed them from their home to a situation in which they were harmed. It was this one social worker who brought them all together and Tui said having a good experience like this depended on who was supporting you.

In terms of treatment and support for ADHD, Tui thought there were few options available for Māori children. In her experience, her children needed opportunity to connect with Te Ao Māori without the pressure of being in a kura kaupapa. At 10 and 11 years old, the boys could not speak Te Reo Māori, and so kura was not an option for them. She felt while they might fit better within kura kaupapa, this only catered to whānau with a strong sense of where they were from. Alternative education programmes were only available once a child turned 13 and schooling options like Rudolph Steiner or Montessori were expensive and elitist. The only other option was mainstream school and Tui said she couldn’t support her sons with school, as while she knew other stuff she didn’t know about school. Tui thought some children with ADHD might do well in mainstream education because their parents could keep them in sport. While her sons were gifted sportsmen, she couldn’t get them into sports because they couldn’t afford or manage it. So, Tui said the education system missed children in the middle who didn't fit in because of loss of whakapapa and reo. And the system was trying to force her boys to fit in at school.

Overall, Tui wasn’t sure the diagnosis of ADHD for her, or the boys was helpful. They still didn’t have access to what they needed to be well. Tui was also unsure about the medication. It was somewhat helpful although this was temporary, so Tui was aware it wasn’t healing anything. Mostly, the medication was helpful from 9am till 3pm and the boys were okay enough to be at school. Ururangi was like a zombie, but they were okay with him in school because he was quiet. So, the medication was necessary to fit in. It also affected all their appetites and Ururangi had lost a lot of weight since he started medication. Tui was also adamant medication was not right for Waita, and so she hadn't been giving it to him very often because she didn’t think he needed it. She thought if she refused, a notification might be made to OT. Other issues around medication were that at times Tui couldn’t pick up her own medication from the pharmacy because she couldn’t pay her bill. That would mean she didn’t function very well. Also, as she was recovering from addiction, Tui was also struggling to manage the medications for her and the boys and was trying to get medication support.

Taranga talking about experience with Māui

Taranga is a 45-year-old mental health nurse and sole parent to two children. The experience she discussed centred around her 10-year-old son Māui, who was diagnosed with ADHD when he was 5.

Māui was born very small, and he was also deaf. Multiple services were involved to support Māui with his speech and hearing. When Māui was three, it was discovered he had a cleft palate and by the time Maui was 5, he had 8 operations. He also had mild developmental delay. So, when questions were raised about whether Māui had ADHD, Taranga thought maybe because he had so many challenges, she had babied him. Initially, she said she didn't notice any out of the ordinary behaviour as Māui was so precious to them and that was just who he was.

As a toddler, Māui was not overly hyperactive although this became more obvious when Māui went to day care. When Māui was about to go to school, his day care told Taranga they thought there was something going on with Maui. Taranga had heard similar concerns when his older sister was the same age and she thought he would slow down and grow out of it like his sister had.

When Māui started school, he was still having an afternoon nap and was finding it hard to concentrate. He would go to school, be hard out all day and fall asleep in the classroom. This was despite Māui going to bed at 7pm every night. The school suggested having Māui tested for ADHD and Taranga said no. Māui was in class with another child with ADHD who was aggressive and would bite. So, in comparison Māui was an angel and his behaviour wasn't a problem.

When Māui was assessed, he was already with the Child Development Service and so a referral was not needed. They were at an appointment and Māui was not able to sit still, and the paediatrician asked Taranga if she thought Māui had ADHD. The paediatrician asked if he could assess Māui and explained he would send a letter to the school, and he and Taranga would work together through the assessment. Taranga agreed. When the school were asked to contribute Taranga said they were very good and explained everything they said and why and asked if that was okay. She recalled the school talked about Māui having a short attention span and difficulty following more than one direction at a time. Taranga also did a questionnaire and it turned out almost the same.

Māui was diagnosed with ADHD and the doctor asked Taranga if she wanted to trial medication; she was not keen. Taranga decided to do her own research before deciding, as she was not against medication if it was helpful. She wanted to try other things first, such as fish oil tablets, but Māui wouldn't take them. Taranga also asked other people about their experiences, and they were all anti-medication. It took 3 or 4 months for Taranga to agree to try medication. She told the doctor she would trial the medication and if she didn't like it, she didn't want the paediatrician to persist. Māui started Ritalin just at school. Two weeks later, Māui was engaged, and made massive gains in reading because he was able to sit and learn.

Taranga's concerns about an ADHD diagnosis and medication were about other people's comments. As a nurse she knew the facts about kids with ADHD and said outcomes weren't good. She didn't want Māui to be labelled as naughty or known as the "Ritalin kid" at school. She had heard negative comments about children with ADHD as being naughty and aggressive. She was also scared the medication would have side effects and would affect Māui's growth when he was already small for his age. Another concern Taranga had was she didn't want Māui get to 18 and resent Taranga for having been on medication. She also didn't want him to have struggled all the way through school and wonder if medication may have helped.

Taranga now feels the ADHD diagnosis was helpful and is happy with the decision to give Māui medication. Her decision was helped by having a paediatrician who listened, and he gave Taranga a lot of information about ADHD and the medication options. Māui understands the medication helps his brain at school. At first Māui said he liked medication because he could learn more at school. Now he doesn't want to take it anymore because the other kids in class don't. As his appetite is affected, Māui has a medication break in the school holidays. To help with the side effects, Māui takes a long-acting formulation for school and short release in the weekend.

In hindsight, Taranga didn’t know which behaviours were potential signs of ADHD. Some behaviours were a problem for family, they were just used to Māui being hyperactive. For example, Māui was very impulsive; he had an expensive hearing aid, and he threw it out the window, or he would be very unsafe around cars. He would become overwhelmed easily by noise and people, and Taranga now sees these are part of his symptoms.

The whānau’s cultural background was not asked about during the assessment for ADHD. Maui's dad's family who are also Māori have taken a long time to understand what ADHD is, but Taranga thought they wouldn't have appreciated someone explaining it to them. Maui's dad was not involved with the assessment and was happy for Taranga to make health decisions, especially as she is a nurse. When Taranga told Maui's dad Māui was trialling ADHD medication, he didn't really understand or listen. Then a couple of years later he said he had read a book about ADHD. Maui's dad does notice the difference when Maui is taking a medication break, as he is a lot of work and gets overwhelmed easily.

Taranga didn't feel that a kaupapa Māori service or home visit would have made a difference to their experience. She said they were well supported by the school, because it was a small, predominately Māori school. What was more important to Taranga was that Māui felt happy about going to school, even more than his academic performance (though still important). Taranga thought some Māori whānau might look at ADHD as a shame, and as something they had done wrong.

Taranga would have liked more information about how to manage ADHD which was specific to Māui. Like understanding struggling with his attention, could be why he was overwhelmed when there was too much going on and it was too loud. Overall, Taranga was given a diagnosis and only options were medication or no medication. Some other advice, treatment options and support would have been helpful.

Kiri talking about experience with Kura and Hamua

Kiri, aged 42, had two sons Kura (13) and Hamua (17) who had been diagnosed with ADHD, and 2 daughters. Kiri and the children’s dad, Papara had separated two years prior, and had shared care. Kiri was of Cook Island descent and Papara was Māori.

Kura was diagnosed with ADHD when he was 11. Kiri said his difficulties became apparent toward the end of primary school. Kura would interrupt, was disruptive in class, he couldn’t sit still, was always talking and he would leave class. He couldn’t do assessments at school because he couldn't sit still long enough to do a test. Kura was also disrespectful to people at times which was very frustrating for Kiri.

In year 7, the school suggested Kura had ADHD. Kura had multiple suspensions from school and the school reduced the days he could physically attend school. Kura had schoolwork to complete at home but wouldn’t do his work when Papara had him. An RTLB was also involved and very supportive of Kura. By end of the year, Kura had not technically been expelled, but he did all his schoolwork from home.

In that same year, Kiri and Papara separated and went through mediation and family court. Kura was a “daddy’s boy” and wanted to stay with his dad more often. Overall, it was a difficult time, and Kiri thought this might be contributing to Kura’s behaviour. Kiri thought some of the issue was that Papara let Kura do anything and there was no consistency in the rules between homes. Also thought maybe Kura was adjusting to moving from primary to intermediate and was trying to make friends or show off.

Kiri requested a referral for Kura from their GP and provided supporting information from the school and RTLB. He was referred to the Child Development Service. The RTLB and Kiri completed forms for Kura, and the RTLB tried to have the appointment hurried along because Kura was getting in a lot of trouble. They waited for the first appointment for 3-4 months, then had to get another form completed by teacher (rather than RTLB) and wait for another appointment. Kiri said by then, they were desperate. Nothing was explained about the assessment process. Kura was weighed and measured, and then the paediatrician said they read the forms and agreed he had ADHD. They didn't talk to Kura and briefly touched on what Kiri had written. Kiri felt the assessor rushed them and just prescribed something.

In year 8, Kura was offered a scholarship for a private preparatory school, and Papara said “no.” As Kura and Papara couldn’t agree on a school, they went to family court to decide. Papara wanted to send Kura to a school where culturally, he might feel more accepted, and the Court agreed with his choice. At the new school the teacher didn't want the RTLB support. Kura continued to get in trouble. His ADHD medication was still being adjusted, and Kura was not taking the medication when he was at his dad's. In the last term of Year 8, Kura’s behaviour escalated, and the school felt the medication was ineffective.

As Hamua was diagnosed previously, Kiri knew some information about ADHD which helped when it was suggested Kura had ADHD. Some of Kura and Hamua’s behaviours were similar, such as talking non-stop, being impulsive and not sitting still. Hamua’s worst punishment was being made to stand still because he couldn't. Kiri would tell Hamua to think before he did something without realising that was difficult for him. She would have to repeat herself, even with simple instructions and Kiri couldn’t understand why Hamua wouldn't get it. It wasn’t until she did an introductory mental health course through her work and learned about ADHD, that she realised he met the criteria.

Kiri suggested ADHD to their GP, and he said Hamua was fine and “just being a boy.” Kiri thought the doctor must know, though she had seen her nephews raised and knew this was different. Hamua continued to get in trouble. The third time she went back to the GP with the same concerns she insisted on the referral. His behaviour made a lot of sense once he was diagnosed, and Kiri was more patient with him as she learned more about what was difficult for him.

In contrast to Kura’s assessment, the paediatrician who saw Hamua took his time, and spoke with Hamua. He didn’t really explain much about ADHD, and Kiri had to do her own research. Once medication was prescribed, Kiri said they were left to figure it out. Hamua hated how the medication made him feel. He didn’t like that it affected his appetite so he would lie and say he had taken his pills. Hamua knew the medication would help him at school, but he wasn’t worried about school. When Hamua was 16, he was then transferred to the adult service, and was still waiting to see a psychiatrist. Kiri is wondering what the point is if they will only offer medication which isn't helpful for Hamua.

Medication management has also been difficult for Kura, and Kiri still doesn't think it is right after nearly two years. Kura has been seen by four different doctors, and there have been lots of issues communicating with the GP about what should be prescribed. When the hospital makes a change, they don't tell the GP and the GP can then only repeat the last script. Then the GP has to go back to the hospital which can take over a week or they don't answer the GP and Kiri has to contact them. In the meantime, on occasion Kura has gone without his medication.

While Kiri didn't want either of the boys to need to take medication, her main concern for them both was school. She said she was able and willing to deal with whatever happened at home but wanted them to be able to concentrate enough to do schoolwork and be successful. Unfortunately, other than medication they weren't offered other options and no strategies were discussed. Kiri wasn't too sure what else would help but it would have been good to have something else to try.

For both boys' assessments, there were no questions about their cultural background or how the whānau managed care between two households. Kiri said they were never asked who they lived with or the extended family who were involved. Because other than Papara, that included Kiri's mum, her dad and his wife, and Kiri's other family members. Kiri said her parents do everything with their grandchildren and have major roles in their lives. They frequently have family meetings when the boys are misbehaving so everyone is on the same page. Kiri thought it should be acknowledged that for Māori and Pacific Islanders, often not only parents are involved in raising children. Kiri said it was important for the doctor to know what their life looked like, to know what was going on for their family.

Toward the end of 2021, Kiri asked the service if Kura's medication could be reviewed as he had lost lots of weight from not eating. They recommended taking him off his pills as he was already misbehaving at school and the medication wasn't helping anyway. They confirmed Kura was okay health wise and said they would book an appointment for January to get him back on medication before he started high school. That never eventuated and Kiri had to contact the service more than once with no response or appointment. She rang again two weeks before Kura started school and was told his doctor (who he had never met) was on leave. Kura started high school and five days later he was expelled. Kura is not at school currently and is in alternative education until he can transition back to mainstream school.

One of Kiri's main issues has been not being able to access the service when she needed to. It can take over three weeks to be seen when the medication hasn't been right and by then Kura would need a repeat and so would have to repeat the same prescription.

Overall, the diagnosis of ADHD for both boys has been useful for the family. Initially, Kiri felt bad when she found out as she had thought they were being deliberately naughty and difficult. The diagnosis is helpful for Kiri to understand them more and why things are difficult for them. She feels there is still a lot more that she needs to know to be able to help her sons. Kiri said continuity would have helped their situation, seeing the same person so they were not always having to repeat the same information to new doctors. Kiri also wishes there were other options, as she is at a loss what else to try as she continues to try and support the boys.

Emere talking about experience with Hina and Pua

Emere and Kingi had three children and were mātua whāngai for their biological niece and nephew. Hina (13) and Pua (12) were removed from their parents by Oranga Tamariki (OT), and the wider whānau asked Emere and Kingi to care for them. They represented themselves in court to gain custody, and Hina and Pua had been with them since 2014. Emere discussed how both children were assessed for ADHD.

When Hina and Pua came into their care, their behaviour was immediately challenging. To begin with, it was hard to know if this was the result of neglect. Both parents had used drugs and there was domestic violence in the home. Everyone was hoping the behavioural difficulties would resolve with time. The whānau decided to focus on providing security and see if that helped.

Out of concern, Emere took both children to a paediatrician who said they were fine and there was nothing abnormal happening. The doctor said all they needed was love and a stable life. Emere wasn't sure that was the case. They seemed happy but she thought there was something else going on.

Looking back, Emere now recognises Hina and Pua were both hyperactive, inattentive, and unorganised. Pua was only four, so his behaviour was less noticeable. He would run away, and have difficulty sitting still, but was very quiet while he did it. Hina's behaviour was complex and overtly different. For example, she would say things over and over and talk in a continuous stream. She craved attention from anyone, including strangers. The whānau were more worried about Hina at the time, as those behaviours were the most difficult to manage. Although still unsure what was happening, Emere decided to find out.

Hina was seen by a paediatrician, occupational therapist and speech language therapist and they all told Emere there was nothing wrong. Emere kept being told, “it's not something I deal with.” At one point, specialists said Hina was deaf, and they convinced Emere, Hina needed surgery. Right before surgery, the surgeon did a final test and realised she wasn't deaf at all. When they first tested her, Hina had answered in her own unique way and not as expected, and they assumed it was because she was deaf.

Eventually, in 2016 their GP suggested Hina be assessed for ADHD. Emere still didn't know what the issue was or what ADHD meant, but she went back to the paediatrician with an open mind. Hina saw the paediatrician three times, and as well as ADHD they assessed for multiple factors, including intelligence.

It took two years of getting knocked back and fighting, for Hina to be diagnosed with ADHD. Emere persevered to gain the best possible support and outcome for Hina. Emere said with their own children they had focused on happiness, living in line with their values and providing an environment where they could thrive. With Hina they realised, let's just focus on her being happy. By choice, Hina is now living with other whānau in Australia. She is undergoing assessment for ASD.

While focused on helping Hina, the whānau had remained hopeful the situation with Pua would resolve. However, there were reports from school about his not concentrating and he was being labelled the "naughty boy" which Emere did not want to happen. Pua had his adenoids and tonsils removed to eliminate sleep issues and snoring, however his behaviour didn't change.

With more knowledge, Emere recognised Pua’s behaviour was consistent with ADHD. As she didn't want to wait two years before Pua was diagnosed, Emere had a game plan about how to get the referral to CAMHS. Having done it with Hina, she knew to be very firm with the doctors and she spoke a lot to the GP about risk, e.g., Pua had opened the car door while they were driving.

Pua was diagnosed with ADHD in 2019. The assessment involved Emere and Kingi each completing a questionnaire. They also asked Pua’s teacher to do a questionnaire which Emere said was hard because the teacher didn't like Pua. The paediatrician also interviewed Emere to gain background information.

For both children, the available treatment options were medication or parenting strategies which they were already using. Emere and Kingi wanted to consider all options and decided to try medication. As Hina took medication at school, the school obviously knew. Emere said the school was negative about the medication and there were comments from some older teachers about parents “drugging” their children to make them behave. There were also people within the community and their whānau who were anti-medication. On one occasion a whānau member was looking after Pua and Hina and refused to give them the medication. Other people’s concerns were, they were drugging kids and kids should be free to be kids. When Pua was diagnosed they were more conservative about who they told.

The change in Pua and Hina’s behaviour from the medication was obvious and both performed better at school. Pua improved so markedly, the teacher thought he cheated on a test. Their appetites were reduced as a side effect, so Emere made regular eating part of their routine. Emere is happy with the decision to medicate as Pua and Hina function better, and it helped relationships with siblings at home.

As Pua’s caregiver, Emere noticed she was treated very differently by teachers then she was with her own children. Her own children were top performers academically and well behaved in class. When Emere approached Pua’s teachers she found she was “steeling herself” and it was difficult to ask for support. She said she didn’t behave any differently as a mum to Pua, and yet was treated like part of the problem. When Emere asked the teacher to fill in the questionnaire, the teacher wasn't convinced it was ADHD. Emere thought there was bias toward Pua, and he had been labelled as “the naughty Māori boy.”

Overall, the ADHD diagnosis was helpful because it meant they could access the medication and that helped whānau relationships develop. Emere thought some Māori whānau might not know what ADHD was and/or mistrust the system. Nobody wants their children to be labelled. However, Emere was more concerned about other negative labels that come from being hyperactive and impulsive in the classroom and how that might impact on the children’s happiness.

During assessment, there were no questions about the whānau’s cultural background. Recently Emere saw the GP to have Pua’s medication reviewed, and the GP asked, "do you think it's a cultural need?" Emere said, "can you explain that a bit more?" and the doctor didn’t elaborate. The next doctor asked Emere who they could connect her with, within the local Māori community. Emere’s perception was they were saying, ‘we don't have a Māori service available and maybe you might know one.’

On reflection, a kaupapa Māori service may have felt more welcoming and understanding for Emere, Pua and Hina. Mostly, Emere said access to the services was hard and she had to fight when she is typically a peaceful person. It wasn't something she was comfortable doing. Her motivation was the health of their whānau. In hindsight, it would have been useful if OT and the health system overlapped and worked together. OT didn't tell them about any behavioural or heath concerns for Pua or Hina. It would have been helpful if OT had worked with them to get the assessments Pua and Hina needed. Also, would have made a difference if the first assessment took a bit longer and the doctor had understood better the context of the whānau, from OT. As it turned out, Emere had been right from the beginning and those initial three years would have been very different if they had been adequately supported.

Katrina talking about experience with Nikora

Katrina is a 37-year-old mum to three sons, aged 5-14. The boys spend their time, a week with their dad and a week with Katrina. Katrina discussed the whānau's experience of assessment with Nikora (7). At day care, there were no concerns with Nikora's behaviour. He had a group of friends, who played together and went to each other's birthday parties. Nikora was sociable, and he had friends.

Once he started school his teacher kept saying Nikora wasn't engaged and couldn't focus. Katrina struggled to get Nikora to go to school, and he would cry and say the teacher was mean. Katrina had to pick Nikora up multiple times because he had punched or tripped another child. He would sit out every lunch time, wasn't allowed to touch anyone and sat on his own in the back corner during mat time.

Nikora's teacher pulled Katrina aside and told her his behaviour would not be tolerated and Katrina would need to find a new school if she didn't figure it out. The teacher said she thought Nikora had ADHD and should be seen by a doctor, which Katrina thought was drastic though she was concerned. Then Nikora started lashing out at his brothers at home. She had no idea about ADHD so did some research and the more Katrina found out she thought ADHD described Nikora's behaviour.

When Katrina spoke with Nikora's dad about these concerns, he said he did not want Nikora labelled because it would bring shame on the whānau. He said he did not want to be told his son was a "retard." He said the school should be more accommodating and it must be Katrina's parenting style because those issues weren't happening at his house (though eventually they did).

Katrina wondered if the issues were because of something she was doing, or if she wasn't strict enough. However, her other sons didn't have similar difficulties. In comparison, Nikora was erratic and impulsive. He was not bothered by getting in trouble and had no respect for authority. When Katrina put in a consequence, Nikora would "rage" for one to two hours. What really struck home was when Katrina's own family who have children the same age, started to ask Katrina not to bring Nikora to family events.

As the behaviour continued, the school became more insistent. They said they couldn't expel Nikora because he potentially had ADHD. However, because of the number of complaints and concerns having him around other children they urged them to go ahead with the assessment. Katrina was open to the assessment as she thought they should explore every option. Eventually, Nikora's dad agreed.

The whānau went to their GP as that is what the school told Katrina to do. The GP referred them to the Children's Health Clinic at the hospital, and Katrina, Nikora's dad and the school were sent forms to complete and then send back to the hospital. They had a lot of issues dealing with the clinic. The clinic lost the forms, located them weeks later and then gave them a first appointment several months later.

At the appointment, Katrina remembered Nikora was well-behaved in the waiting room and sitting quietly, talking to his parents. When they walked into the paediatrician's office, he immediately said Nikora had ADHD. Katrina asked if he wanted to assess him or ask questions and he said he could tell by walking past him in the waiting room. He told them he knew from the assessment forms and not to panic, Nikora would be fine and could live a normal life. He prescribed medication which Nikora could start the following day. He said Nikora might feel sick and have headaches but should be fine and have good results. He told them to come back in a month and if the medication was effective, he would write a script for another 30 days. The entire appointment was a few minutes long.

Katrina and Nikora's dad were in shock. They were given no information about the medication or ADHD. Katrina had no idea who to contact if there were issues and no one else from the clinic contacted them. There were no alternatives to medication, and no support services were recommended or offered.

A month later, the medication ran out and no appointment had been made. This was during COVID, and the clinic told Katrina, Nikora wouldn't be seen and to get the script from their GP. However, while he was more focused at school with the medication, there was no change at home. Nikora was aggressive and had threatened Katrina and his brothers with knives and garden tools. Desperate for help, Katrina went to the GP, but he could only issue the same script and said they had to go back to the hospital.

The GP made another referral, and the Children's Clinic still said they would not see Nikora unless it was an emergency. Throughout this period, the medication made no difference to the rages and Katrina was no longer sure it was ADHD. When the situation deteriorated, they went to the GP again and insisted on an appointment. The GP did another referral, and after waiting since August they finally got an appointment for the following March. They were seen by the same doctor, and Katrina told him they wanted a full review and assessment, and they were not leaving unless they were happy with the outcome. The doctor sat down with them and asked them and Nikora questions. He agreed the medication was not helping and they would try another type.

Since changing medications, Katrina said it was like having her son back. The rages stopped, and Nikora would have a full conversation with Katrina which had never happened before. The medication made the difference, but Katrina had to really push for that to happen. Even with the medication change the paediatrician never explained about possible side effects or when he would see them again.

Nikora's diagnosis has been useful as his whānau now understand Nikora isn't just being naughty, and his extended family are more empathic towards him. At first Katrina was concerned to tell her family about the diagnosis. She thought she would be judged and blamed for the situation. She now feels the "true Nikora" is here as a part of the family and all their relationships have improved.

Overall, the assessment process was difficult and not well handled. The assessor never asked about their cultural background. They also never had the opportunity to explain the aggressive behaviour at home. The whole assessment was rushed, and they felt they didn't have a voice. At the follow-up Katrina asked if there were support groups or parenting courses. The doctor was not aware of any groups and said there was a parenting course, but he didn't know who it was through or what it was called. Ideally Katrina wanted the doctor to have asked how things were at home and given them information about ADHD and how to get support.

Katrina thought other Māori families might also feel like they would be judged or stereotyped. She was also concerned that while the medication is free, there are costs associated with regular phone calls to the GP for the repeats and having to drive to the pharmacy with all the children. It was also difficult having to access medication regularly. They were only given 30 days' supply and had to make a phone appointment with the GP for every repeat script. Katrina would ring when there was a week left and be told no phone appointments for two weeks. Then when she made a phone appointment, the doctor wasn't always able to ring at an exact time and Katrina might miss the call. Then she would have to wait another few days for another appointment, all the while Nikora had no medication. As they had no intent to sell the medication or misuse it because Nikora needed it, she was hopeful eventually they would be trusted enough to get the prescription, without an appointment being needed.

Kahukura talking about experience with Matiaha

Kahukura is a 35-year-old sole parent to her son Matiaha (10). Matiaha's dad is Brazilian, and he was not involved with Matiaha’s care. Their whānau were supported by Kahukura’s parents. Kahukura was a trained early childhood teacher, although not currently working.

When Matiaha was three or four, minor behavioural issues started at day care and home. Kahukura initially attributed this to Matiaha’s koro and kuia moving away. Before starting school, Matiaha had a B4 School check and there were differences between what day care reported, and Kahukura's report. The day care said Matiaha would get angry, talk back, and was hitting, which was news to Kahukura.

Kahukura decided to see how Matiaha went at school, and the behaviours continued. In the meantime, through her own research Kahukura thought Matiaha’s behaviour resembled symptoms of ADHD. She knew the behaviours would be happening in more than one environment if it was ADHD. So, Kahukura spoke about her concerns with his teacher, who said they thought he was fine and brushed it off.

When Matiaha was six, they moved closer to Kahukura’s parents again, yet the behaviours increased. Kahukura decided to have Matiaha assessed for ADHD. She was not sure how to go about this, and said it was difficult to find information. She found a clinical psychologist who specialised in assessments for children, and she paid for the assessment to be done privately. The psychologist was thorough and tested Matiaha for other things, diagnosing him with ADHD and auditory processing issues.

Once diagnosed, they were referred to a psychiatrist to discuss medication. The psychologist also wrote a report with strategies to support Matiaha at home and school. Such as, making eye contact when talking to Matiaha, only giving a maximum of three instructions, and having a routine. At school, she said he should sit at front of class, be given more time to finish tasks, and one-on-one instruction when possible. Medication was the only treatment offered. Kahukura wanted to try other options and asked about therapy or a behavioural specialist but was told this was unlikely to help.

It didn’t sit well with Kahukura that neither the psychologist nor psychiatrist could offer another option. As they lead a typically holistic lifestyle, for Kahukura medication was a last resort if things became worse and if it would be helpful for Matiaha. The psychiatrist did not explain how the medication worked or side effects, other than it was the best option for kids with ADHD. When she declined medication, Kahukura was left feeling she didn’t know how to support Matiaha as his mum. She had to figure it out, doing her own research and joining online groups to learn from other people's experiences. Kahukura’s parents wondered if Matiaha should at least try the medication.

Kahukura enrolled Matiaha at a Steiner school. Mainstream school had too many expectations about how things needed to be done and focused on schoolwork. Whereas the Steiner school was holistic and looked at the whole child and what they were good at. It was hands on, so Matiaha was stimulated because of how the material was presented. While he still had issues with behaviour like talking back and leaving the classroom, he had a teacher who Kahukura said saw Matiaha for who he was and not as the diagnosis of ADHD. This made a difference. The teacher genuinely liked Matiaha and took on board what the psychologist had written. She communicated well with Kahukura which helped.

When Matiaha turned 9, the behaviours became more frequent and intense at school and home. Matiaha would get angry and sometimes hit or punch his mum. Kahukura found a local art therapist and Matiaha went to art therapy for about six months. The therapist also recommended someone who could provide natural medications. Kahukura noticed an improvement with these treatments and Matiaha enjoyed them. This treatment stopped as Kahukura couldn’t afford to pay for this anymore.

Kahukura is still happy with her decision not to medicate Matiaha. He continues to take magnesium for sleep, and zinc and vitamin D to support brain function. These work well for him and Kahukura doesn't think other medication is necessary currently. She has also focused on his eating, as she was told there are additives in food which can trigger ADHD. They have good routines around bed and getting ready for school. Kahukura is mindful of his environment, his mental health and how he feels. She makes sure he gets regular exercise, and they do yoga and medication for focus and relaxation

Currently, Matiaha’s still struggles to regulate his emotions. He becomes upset over small issues and being told "no." He is very sensitive if she even slightly raises her voice. Kahukura has reflected on how she parents Matiaha as “normal parenting strategies,” have not worked for him. This has been hard for Kahukura because there is not another adult at home to support her. If Kahukura is stressed or Matiaha is acting out, she can't leave. If she goes to her room, he will follow her, and bang on her door.

Throughout the process of Matiaha’s diagnosis, Kahukura did not approach the GP. She recently asked them to complete a form for Child Disability Allowance. The GP suggested Kahukura try CAMHS, however Kahukura was put off by other people saying they had long wait-times and it was hard to get support for ADHD. Therefore, Kahukura decided to manage things herself. She didn't think she needed to see the GP as she said they weren't trained to understand ADHD. The GP wasn't very helpful and didn’t have any other support to offer. They also said as Matiaha got older, it was unlikely he would continue to get the Child Disability Allowance.

Diagnosis was useful, however there was no ongoing support. Kahukura didn't really know what to do and had to continue to send him to school. She invested her own time and money to find support. The diagnosis helped Kahukura understand Matiaha more and what was difficult for him. Then she was able to figure out how to support him. She is still finding out new things about ADHD and it would have been useful if someone had worked with her and told her these things up front.

The other problem Kahukura had noticed was a lack of support for parents; helping parents to support their children. She felt support groups for parents would be useful, especially ones that don't cost. Also, helpful to have mentors for young boys, as often teachers and for example his therapist was all female.

Cultural considerations didn't feature as part of the assessment. Kahukura would have considered a Māori based service if one had been available. She thought this service may have looked at the situation in a different way. A Māori psychologist may have taken a more holistic view and been more receptive to identifying other ways to support Matiaha in the community. Kahukura said Māori tended to look at issues like this through a holistic lens, and she wanted to support Matiaha as a whole person.

Miriama talking about experience with Luka

Miriama, 40-years-old, is a social worker and mother of three sons. Miriama and the boys live with Miriama's sister, and they care for the boys between them. Miriama and her two older sons had all been diagnosed with ADHD. We spoke about Luka (11), as Miriama's oldest son Scott (21) is an adult, although Miriama did reflect on and compare their experiences.

When Luka started school, Scott had been stood down from the same school a month earlier. Luka had behavioural issues at school however Miriama thought these were learned behaviours and might settle. Concurrently, Miriama separated from the boys' dad and Scott went to live with his dad. As the whānau lived in a small town, everyone knew about the separation, and Miriama thought that had affected Luka.

At school Luka would not participate and ignored his teacher. He refused to do testing or reading, was easily distracted, couldn't sit still, and had poor emotion regulation. There was an incident when Luka left school and walked home. He said he didn't want to be there because his teacher didn't like him, and he wanted his jacket. The school met with Miriama, and told her Luka had to be medicated. At that time Luka had not been assessed or diagnosed with anything, so Miriama was shocked. She felt the school typecast Luka because of Scott's behaviours, so she withdrew Luka and moved him to another school.

Scott (then 15) had been diagnosed at age 9 with ADHD, ODD and other concerns. Scott's behaviour was violent so comparatively Miriama thought Luka's teacher was calling her over minor issues. Luka was never violent he was just distracting others. She told the teacher, this is just “kids being kids” stuff.

The behaviours the school were concerned about, weren't an issue at home. Miriama was more focused on no violence and treating other people well, than Luka sitting still. Miriama wanted her children to succeed at school but felt defensive because of the school's approach to Luka.

At the new school, Luka's teacher took a genuine interest in Luka and Miriama's lives. They were in regular contact, and the teacher acknowledged Miriama was overwhelmed and needed help. The teacher being concern was a new experience for Miriama, and she felt comfortable enough to accept help. The teacher referred Miriama to a local Māori NGO who could support the whānau.

Miriama then decided to have Luka assessed through CAMHS. Looking back her initial reluctance was in response to how the first school approached the situation. They said medicate him or he cannot remain here, which concerned Miriama as she didn't think he had ADHD.

As Scott had an ongoing relationship with a psychiatrist at CAMHS, Miriama contacted the doctor directly to ask him to see Luka. CAMHS did a full assessment: they observed Luka in class, the nurse spoke to him, Miriama and his teacher completed forms and then Luka met the psychiatrist. The psychiatrist said Luka had ADHD. Miriama still did not agree, as she saw none of the same behaviours as Scott. With her own research she now realises ADHD symptoms can present differently. She thought the doctor was quick to medicate Luka. The doctor asked Miriama why she didn't want to try medication and then explained how the medication worked, to support her decision.

In comparison, the experience with Scott was horrible and this contributed to Miriama's “hang ups about the system” with Luka. Initially Scott had a different psychiatrist who Miriama found difficult to deal with. He directly blamed Miriama and her parenting. Scott was in a lot of trouble and was very violent and the doctor told her to ‘put her foot down.’ His comments made Miriama feel powerless to change the situation. She thought he saw Miriama as fitting all the negative stereotypes about Māori. At first, the doctor said Scott’s behaviour was all a parenting issue until he saw Scott and Scott couldn't sit still to answer any questions, then he considered ADHD.

When Scott was diagnosed, Miriama asked CAMHS for help, other than medication. She was told waiting lists for support services were horrendous or they did not meet criteria as issues not serious enough, or too serious. She told them she was at a loss and wanted help with how to parent Scott, and CAMHS made a notification to Oranga Tamariki (OT). Miriama was scared OT would remove Scott They met with Miriama and offered respite care. As no family members were prepared to take him, nothing came of it.

Comparatively, Luka’s experience was better because of the existing relationship with the psychiatrist. He had a personable approach, as did the nurse who worked alongside him. He was empathic to how difficult the situation was, and easy to understand. The nurse spoke with Miriama every week. Miriama thought they recognised their whānau was in crisis.

Meanwhile, the Māori NGO supporting the whānau, insisted Miriama attend their women's group. They recognised she was isolated and told Miriama they would consider a notification to OT if she couldn't join. They were clear the issue wasn't her parenting, there were multiple stressors, and they were concerned the whānau needed support. Their approach meant Miriama didn't feel criticised and she accepted their help. They were transparent about how they could support them, and it felt like a collaboration. According to Miriama their involvement with the NGO changed things for their whānau.

In respect of medication, the boys’ dad did not want them medicated and took Miriama to court. It has also affected their appetites. Given the side effects, the medication was worth it to the school. Luka only takes the medication on school days as it makes him feel “gross.” Miriama would be unable to keep Luka at school without it, though she worries he isn’t developing skills to manage without medication. She would prefer supports that worked alongside the family, as “that is where the doing is.”

Miriama accessed some social support herself through the community. She knew where to access help because of her work as a social worker. Her opinion was other whānau wouldn’t know where to go and would be scared to ask for help. She thought they would be concerned once you start asking for help, people will think you are not coping and then OT might get involved, even though it isn't like that.

In either assessment there were no questions about their cultural background. None of the assessment by CAMHS considered them as a Māori whānau. Miriama said for the most part she wasn't a "very good Māori" and was on her journey to learning more. Would have like to have been able to connect the boys with a service that had a more Māori-oriented way of working, like the NGO they worked with. In Miriama’s opinion it can be helpful sometimes when the person sitting across from you is a bit like you.

Overall, Miriama having both boys diagnosed with ADHD had not been entirely useful. She thought other whānau might resist diagnosis as they are put under the spotlight by all the people who become involved. Would have been helpful if as guidelines suggest there had been some home visits. Miriama felt CAMHS didn't really understand how the boys were at home and at school. It was just another appointment to them, and for the whānau it was their lives. As a social worker, Miriama now has an interest is in supporting parents with children with ADHD. She doesn't know any parents with children with ADHD who are still together because home life is so seriously affected.

Appendix G: Case Study

Case Study Four: Assessment for Attention Deficit/Hyperactivity Disorder

This research case study represents the work of Charlene Tipene during the period of an internship in partial fulfilment of the degree of Doctor of Clinical Psychology.

In accordance with the Code of Ethics for Psychologists Working in Aotearoa/New Zealand, client confidentiality is maintained by using pseudonyms and adapting identifying information

Abstract

This research case study demonstrates how my doctoral research influenced my practice as an intern psychologist, and how my practice has informed my research. My honours and doctoral research, have (in part) considered factors which are relevant to the assessment, diagnosis, and treatment of attention deficit-hyperactivity disorder (ADHD). The case study presents the assessment for a 59-year-old woman, originally from South Africa, suspected to have a diagnosis of ADHD. As my research is around understanding the process of assessment from both the clinician's perspective, and the perspective of the individuals involved, it was important to gain first-hand experience of assessment during my internship. The discussion and reflection sections indicate the many learnings I take from this assessment. The challenges of assessing an adult for ADHD are discussed. This case also highlighted a benefit of working within a multi-disciplinary team.

Literature Review

Introduction

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterised by deficits in the control of executive functions (Diagnostic and Statistical Manual fifth edition (DSM-5)) (American Psychiatric Association (APA), 2013). This results in core behaviours of inattention, disorganisation, hyperactivity, and/or impulsivity. These behaviours are inconsistent with developmental level and interfere with social, academic and/or occupational functioning and people with ADHD often experience significant difficulties resulting from their behaviour.

Behavioural symptoms of ADHD can interfere with a person's ability to learn and to develop and maintain social relationships. ADHD is also highly comorbid with anxiety, conduct and mood disorders (Williamson et al., 2014) and children who experience ADHD also often have reading and learning difficulties (Rucklidge, 2006). Aside from behavioural symptoms, ADHD is associated with several outcomes later in life, including an increased risk for social and emotional adjustment difficulties, alcohol and drug abuse, and suicidality (Williamson et al., 2014).

This case study presents the neuropsychological assessment of a 59-year-old South African woman, named Jess. The purpose of the assessment was to determine if Jess met criteria for ADHD. Jess had a primary diagnosis of schizoaffective disorder, first diagnosed in her 20s. Jess had been with mental health services (MHS) since then and had required significant support for periods of psychotic episode, low mood, and suicidality. Alongside these concerns, Jess was in a perpetual state of disorganisation; Jess was unable to finish projects, keep on task, concentrate, follow conversation, keep track of the time and she was unable to establish or maintain a routine. At times these difficulties would overwhelm her and contribute to decompensation. Jess' mood had remained stable on her current medication regime, with no recent episode of psychosis. While Jess had symptoms which resembled the inattention seen with ADHD, there are clinical concerns that Ritalin (methylphenidate), the main medication used to treat ADHD, may increase the risk of psychosis particularly for people with a history of psychotic episode (Cressman et al., 2015). Jess was therefore referred for assessment to confirm (or not) if a diagnosis of ADHD was met.

ADHD in Adulthood

While typically diagnosed in childhood, ADHD also occurs (and can be first diagnosed) amongst adults, though there is mixed evidence about whether this is a continuation from childhood or a specific syndrome (Moffitt et al., 2015). During adolescence symptoms of hyperactivity such as excessive running about or climbing may resolve and become more an internal feeling of jitteriness, impatience, or restlessness (APA, 2013). In adulthood, symptoms of inattention and impulsivity are increasingly recognised as persisting, even when the hyperactivity may have diminished (Goldman et al., 1998). Inattentive symptoms show less recovery than hyperactive-impulsive behavioural symptoms (Bramham et al., 2012).

Prevalence of ADHD in New Zealand

There is a lack of solid data about the current prevalence of ADHD in New Zealand (NZ), in fact there is a dearth of research relating to ADHD in the NZ context (Tipene, 2018). Estimates are unable to be made from pharmacological data from the Ministry of Health, as Ritalin is also the first line treatment for conditions other than ADHD. Furthermore, while there is data on the total number of prescriptions for Ritalin, this does not differentiate between multiple prescriptions for the same individual. This also misses prescriptions which are issued by a doctor, and then not filled. The DSM-5 (APA, 2013) states that ADHD occurs in about 5% of children and 2.5% of adults. Studies in other countries have comparable estimates of ADHD among adults with prevalence rates between 2% and 5% (Fayyad et al., 2017; Wilcutt, 2012).

Assessment

The onset of ADHD is in childhood and diagnostic criteria specify several symptoms be present before the age of 12 years (APA, 2013). The DSM-5 increased the age of onset from 7 to 12 years to reflect the difficulty of establishing precise onset retrospectively, especially for adults. Adult recall of childhood symptoms tends to be unreliable, so it is important to gain collateral information whenever possible. According to Ramsay (2017), when assessing an adult for ADHD, there are three key questions: is there evidence of ADHD as a child, is there evidence of ADHD as an adult, and is there a better explanation for the difficulties?

Assessment can be a complex process for several reasons. The assessment process needs to carefully rule out other conditions that may be causing inattention, hyperactivity, and impulsivity. For example, Goldman et al. (1998) describe how traumatic brain injury, epilepsy, anxiety, and mood disorders may also lead to deficits in attention and/or activity level. Assessment is also challenging, as ADHD is highly comorbid with other mental health diagnoses and difficulties. It can also be challenging to decipher distractibility and tangential conversation from inattention which causes functional impairment. Inattentive symptoms are not always obvious and will often go unnoticed (especially in childhood) as they are not as disruptive to others as hyperactive symptoms. Therefore, a thorough and methodical evaluation is essential, to identify differential diagnoses and comorbidities (Efron et al., 2013).

In NZ, diagnosis of ADHD is based on clinical assessment and clinical interview either by a paediatrician, psychiatrist, or psychologist. Once diagnosis is confirmed only specialist paediatricians or psychiatrists may prescribe or authorise the prescription of stimulant medication for ADHD (Ministry of Health (MOH), 2001). The Royal Australian and NZ College of Psychiatrists (RNZCAP) (2014) recommend assessment based on comprehensive multimodal assessment, including accounts of the individual’s functioning in a variety of situations. In relation to the present case, the psychiatrist wanted confirmation a diagnosis of ADHD was supported, before making decisions about treatment. The assessment report is presented here.

Neuropsychological Assessment – ADHD

Private and Confidential[4]

Name: Jess H **Age**: 59	**General Practitioner:** Dr GP **Referred By:** Psychiatrist

Dates of Assessment: 26 May, 16 & 23 June 2021
Assessing Clinician: Charlene Tipene (Intern Psychologist)
Date of Report: 10 August 2021

Referral

Jess H is a 59-year-old woman, originally from South Africa (SA). She was referred for assessment for attention-deficit/hyperactivity disorder (ADHD) and an evaluation of her memory abilities. This was to understand if Jess' chronic inability to manage her time, sleep regularly, organise her home, and complete everyday tasks were indicative of ADHD.

Jess has a long-standing diagnosis of schizoaffective disorder, depressive type and has been well maintained on her current medications, together with significant support from Community Mental Health (CMH). Specifically, the referral requested neuropsychological assessment to confirm if Jess met criteria for ADHD.

This report is based on the following information:

- Clinical interview with Jess on 26 May and 16 June 2021 (3 hours)
- Phone interview with Sheryl (Jess' sister) on 19 July 2021 (1 hour)
- Referral information from psychiatrist, dated March 2021
- Review of file information as follows:
    - Psychiatric inpatient admission notes, dated May 2004
    - Previous clinical notes from CMH involvement, May 2003 – March 2021
    - GP referral to CMH dated March 2012, September 2013, December 2015, July 2015, and October 2015
- Results from current assessment; carried out over 3 sessions on 26 May, 16 & 23 June 2021 (total 7.5 hours)

Presentation

Jess attended the assessment sessions on her own (accompanied by her dog, Kuri). She readily conversed with the clinician, and rapport was easily established and maintained throughout the sessions. Jess made appropriate eye contact and engaged in reciprocal conversation. She reported her mood as generally being good and her affect was congruent. Jess' thought content was mostly relevant to topics discussed, though she was easily distracted and would frequently lose her train of thought. No perceptual disturbances were evident. Jess knew her behaviour was disorganised and chaotic though lacked insight into how this could be improved. The clinician's impression was that Jess would be unable to organise herself or her home without support. Jess was oriented to person, place, and time. She explained her understanding of the referral was to consider if another medication would be beneficial and worth the risk of disrupting her stable presentation. Safety was assessed and there was no risk noted.

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Background Information

Presenting Problems

Jess has a longstanding diagnosis of schizoaffective disorder and schizoid personality. She has a history of anxiety and chronic low mood. Since moving from SA to New Zealand (NZ) in 2001, Jess' mood has at times deteriorated and led to psychotic episode and suicidal ideation. While Jess says she recognises the importance of medication, she has a history of non-adherence because of her inability to manage her time and follow a routine.

Jess has been supported by the same psychologist through CMH since 2017. The psychologist questioned whether Jess' attentional difficulties were a symptom of ADHD. Dr S (psychiatrist) requested a neuropsychology assessment to confirm if diagnostic criteria were met for ADHD, before considering medication.

Jess reports being significantly functionally impaired by her inability to focus and stay on task. Throughout her involvement with mental health services (MHS) there is note of erratic sleeping patterns, disorganisation, inability to complete tasks and meet deadlines, anxiety, poor concentration, and compulsive coping strategies. Jess mostly tolerates these difficulties until she decompensates and then feels overwhelmed by her disorganised behaviour.

Current Functioning

This description of Jess' current functioning represents a pattern which has existed for years and is not a recent change.

Adaptive Functioning

Jess is an artist and has previously exhibited and sold her art. She is involved with an art group through (community support group). Her home is cluttered with art material and Jess also says she hoards newspapers, receipts, and other paperwork. Notes from previous home visits, indicate it has been this way for years. Her living spaces are so full and disorganised there is no space for Jess to do her artwork. This is distressing to Jess, so she spends all day sorting her home. However, she doesn't make progress because she is constantly distracted off-task. Jess' aim each day is to paint and because she rarely gets to, this contributes to ongoing low mood. When Jess has a deadline for her artwork this often results in her mood deteriorating.

To be more productive with her time Jess has strategies such as to-do lists and keeping diaries of various activities. Jess acknowledges her list making is unsuccessful as she plans too many tasks and gets overwhelmed. There is a compulsive quality to the list-making. For example, Jess feels compelled to make a to-do list every morning. Every night she tries to complete the list before she can go to bed or start her artwork, which is unsuccessful. Jess said she feels unable to discard her to-do lists if they are incomplete. As a result, some lists have been in her home for 20+ years. Jess has never referred to them again.

Sleep

Sleep is the function most affected by Jess' issues with monitoring time and managing daily tasks. Numerous sleep hygiene interventions have been attempted. Jess' main concern is she is unable to manage a consistent bedtime and goes to bed in the early hours of the morning. Jess reportedly becomes hyper-focused when engaging in a new or interesting activity and will not notice how much time has passed. This sleep pattern is problematic because Jess feels guilty if she sleeps during the day however, she is up all night trying to be productive. She also, eats when she wakes and if sleep is irregular, Jess eats irregularly.

Not having a regular sleep routine also impacts Jess taking her medication. Jess is supported by (community support group) to take her medications every day. When this support was previously withdrawn during weekends, Jess was unable to remember to take her medication on her own and became unwell with suicidal ideation, presenting to the emergency department.

In April 2021, Jess underwent a sleep study which identified minor respiratory issues and recommended a CPAP trial. While Jess struggles to organise herself to go to bed, once in bed she has no issues going to sleep.

Interpersonal

Jess lives alone in her own home in New Plymouth. Her closest companion is her dog Kuri, and Jess takes Kuri everywhere. Jess' sister, Sheryl lives locally and offers practical support to Jess. Jess feels Sheryl can be impatient and has strong opinions about what Jess should do to support herself. Sheryl said she gets frustrated with Jess' hoarding and lack of routine.

Aside from her sister Sheryl, Jess has limited ongoing social relationships. Jess has a friend Dale who she meets with regularly, though Jess says their relationship can be difficult as Dale is opinionated about what Jess should do. Jess is vulnerable as she struggles to set boundaries in her relationships with others.

Alcohol and Drug History

Jess has a history of problematic alcohol use/abuse. She was previously referred to the Alcohol and Other Drug Service and attended a Women's support group, individual counselling and was treated with Naltrexone. Jess drinks wine occasionally and more often when stressed. She does not use other illicit drugs.

Collateral Information

According to Sheryl, Jess' memory and attention have always been an issue and have become worse in the last year or so. Recently Jess has been asking Sheryl to slow down and not talk so fast because, "I can't keep up with what you are saying." To Sheryl Jess seems like she is not coping, and she has wondered if Jess needs more support. She says Jess struggles with everyday life, because her "house is full, and her head is full." Sheryl says Jess becomes focused on unimportant details, and therefore never makes significant progress.

Relevant Background History

Mental Health History

Jess has been involved with MHS in SA and NZ since her 20s. In 1996 (aged 34) Jess attempted suicide by overdose and was admitted to a psychiatric hospital in SA, where she was an inpatient for 9 months. Jess made another suicide attempt in 1998.

While she was an inpatient Jess received Electroconvulsive Therapy (ECT). Jess feels while it was always difficult for her to concentrate, this was worse following ECT. For example, Jess could read a textbook (with considerable effort) prior to having ECT and since treatment could no longer sustain her attention to read a book. Sheryl also agreed Jess' concentration and attention declined further after she received ECT.

Family and Social History

Jess was born in SA and grew up with her mum, dad, and sister. Sheryl and Jess both described their mum as meticulous. Jess said mum was always making to-do lists, and she never got to the end of these lists. Sheryl agreed their mum was a perfectionist and would repeat things over and over until they were right. As this was time-consuming, their mum struggled to keep up. Jess and Sheryl recognise some of Jess' strategies, while ineffective, are behaviours Jess learned from their mum.

As a young child Jess recalls daydreaming and being stuck in her own thoughts. Sheryl also said, Jess would run everywhere and would not sit still when she was young. Jess reportedly played a lot of sport growing up and as a teenager and young adult she would obsessively run, bike, swim and play tennis daily. Jess said this helped to burn off all her energy.

Jess didn't have many friends of her own age as a child, though she says she wasn't lonely as she preferred to play on her own. Jess did make friends with adults through playing tennis. Sheryl said Jess struggled to make friends because she was shy and "different." She said Jess had a hard time at school because she didn't talk and didn't socialize.

Educational History

Jess reportedly struggled in all subjects, particularly math. She was unable to understand the teacher's instructions. Jess would daydream and not pay attention, and if the teacher asked her a question, she would not know what was said and the other children would laugh at her.

It would reportedly take Jess a week to do work other children did in a day because she couldn't concentrate or follow instructions with multiple steps. Jess said often her mum did her homework for her. Sheryl remembers their mum making Jess do schoolwork for hours every day, late into the evenings. This made Sheryl realise Jess was always going to find life difficult because she didn't have the same abilities as other people.

When Jess finished high school at 18, she initially failed the university entrance exam and went to art school instead. Jess eventually attended university and earned a Bachelor of Fine Art's degree. Given her difficulties with attention and focus, Jess said she did this with significant input from her mum with the bookwork. Her mum would write the assignment essays for Jess. Over the course of her degree Jess learnt a strategy about how to write an essay which was "good enough to pass an exam," though this remained a struggle.

Employment History

In SA, for five years Jess worked as a rock art researcher, through a university. She enjoyed this job as she worked alone, and the tasks were repetitive and mundane. When Jess moved to NZ, she worked in a restaurant for four years doing food preparation in the mornings. Jess reportedly found this challenging because she had multiple tasks, with multiple steps. To manage this Jess had a folder in which she wrote out every activity in step-by-step detail. Jess would refer to this folder for every task. The tasks had to be done in the same order and if anything disrupted this, Jess would not know where to start next. Jess also worked as a children's art tutor and looking after animals. She found work stressful especially with competing demands and when the work was not predictable and structured. Jess is no longer in paid employment.

Neuropsychological Assessment

This report is based on the following information:

Self-Report Questionnaires

- Diagnostic Interview for ADHD in adults (DIVA 2.0)
- Depression, Anxiety Stress Scale (DASS-21)

Tests Administered:

- Test of Everyday Attention (TEA) Version A
- Rey-Osterrieth Complex Figure Test (RCFT)
- Rivermead Behavioural Memory Test – Third Edition (RBMT-3) Version 1
- Subtest of Delis Kaplan Executive Functioning System (DKEFS): Colour/Word Interference Test
- Addenbrooke’s Cognitive Examination (ACE-III) NZ Version B
- Test of Memory Malingering (TOMM), as a test of Jess’ effort

Test Behaviour and Motivation

Jess consistently gave her best effort on all tasks administered and engaged well with the clinician. The TOMM is used to discriminate between memory impairment and malingering, and this showed Jess was putting forward her best effort. Instructions or tasks with multiple components were most difficult for Jess, as were tasks which required divided attention. On timed tasks Jess wanted to do well and sacrificed speed for accuracy. Where possible, Jess required repetition and careful explanation of instructions to facilitate her best effort to respond. Overall, Jess demonstrated difficulty with attention throughout assessment. She was distracted by minutiae not relevant to the task and struggled to focus. Jess would talk about unrelated topics, and it was effortful to re-direct her back on task.

<u>**Please note:**</u> The following psychometric results can be understood using the following figure, which indicates where most of the population lies according to their level of functioning in the different cognitive domains:

Well Below Average < 2nd	**Below Average** 3rd – 8th	**Average Range**			**Above Average** 92nd– 97th	**Well Above Average** > 98th
		Low Average 9th – 24th	**Average** 25th – 75th percentile rank or 50 of every 100 people score in this range	**High Average** 76th – 91st		

Summary of Psychometric Assessment Results:

General Intellectual Functioning	Estimated intellectual functioning Based on educational and occupational history and brief cognitive screen – ACE-III, NZ Version B	Low average
Attention **Test of Everyday Attention (TEA)**	Sustained attention	**Well below average**
	Visual selective attention	**Well below average**
	Attentional switching	Well below average to below average
	Divided attention	**Well below average**

	Working memory	Well below average to below average
Memory and Learning Rivermead Behavioural Memory Test – Third Edition (RBMT-3)	Overall level of memory functioning RBMT-3 (General Memory Index)	**Well below average (0.2 percentile)**
	Verbal Memory	
	Immediate verbal memory	Below average
	Delayed verbal memory	Well below average to below average
	Visual Memory – RBMT-3	Below average to low average
	Immediate visual memory – RCFT	Low average
	Delayed visual memory – RCFT	**Well below average**
	Spatial Memory	**Well below average**
	Prospective Memory Remembering to do something in the future	Well below average to below average
	New Learning	
	Immediate recall – RBMT-3 Novel Task	Low average
	Delayed recall - RBMT-3 Novel Task	**Average**
Visual Perception and Construction	Visuospatial/Constructional Complex figure copy – RCFT	Low average
Information Processing Speed	Information Processing Speed The speed with which the brain processes and responds to information. Estimated using DKEFS C/W Interference	**Well below average**
Executive Functioning	Cognitive Flexibility Estimated using DKEFS C/W Switching and TEA Visual Elevator subtest	Well below average to below average
	Organising and sequencing – RCFT	Low average
Emotional Functioning	Depression (DASS21)	**Extremely severe**
	Anxiety (DASS21)	Moderate

Neuropsychological Summary:

Cognitive Functioning

The ACE-III is a brief cognitive screening tool (which is sensitive to dementia). It is scored out of 100 and assesses 5 cognitive domains: attention, memory, fluency, language, and visuospatial abilities. Jess scored 83, marginally above the cut-point for dementia (being 82). Her greatest difficulties were in attention and memory domains, which impacted her overall score. Jess' intellectual functioning was estimated in the low average range.

Attention

Diagnosis of ADHD in adulthood involves retrospective interview for childhood behaviours. The DIVA 2.0 is a structured interview which screens for core ADHD symptoms throughout the lifespan. There are three parts which are applied to childhood and adulthood: the criteria for attention deficit, criteria for hyperactivity-impulsivity, and the age of onset and level of impairment.

Using the DIVA 2.0 to structure the clinical interview, Jess endorsed nine of nine inattentive symptoms in adulthood and six of nine inattentive symptoms in childhood. These symptoms included: not paying close attention or making careless mistakes, difficulty maintaining attention, not listening when spoken to, not following through with instructions or finishing tasks, difficulty with organisation, avoiding non-preferred activities, losing things, being easily distracted, and forgetful. Jess also endorsed three of nine hyperactive/impulsive symptoms in both childhood and adulthood: fidgets and squirms, run around or climbs on things, and being on the go as if "driven by a motor." Overall, this indicated clinically significant concerns with attention with a lifelong persistent course.

The TEA is a standardised assessment for adults aged 18-80 years which assesses selective attention, sustained attention, attention switching and divided attention. Overall, as measured by the TEA Jess performed consistently in the well below to below average range on all tasks (all below the 4th percentile). Jess struggled the most with tasks involving sustained and divided attention. This matches Jess' report about difficulty staying focused when she completes tasks at home and struggling when she has had competing demands at work.

Memory

The RBMT-3 assesses memory as it applies to everyday tasks. The subtests of the RBMT-3 assess aspects of visual, verbal, recall, recognition, immediate and delayed everyday memory. Prospective memory skills and the ability to learn new information are also measured.

As estimated by the general memory index on the RBMT-3, Jess' overall level of memory functioning was well below average (0.2 percentile). Tasks which involved a delayed recall component were the most difficult for Jess. Jess also struggled with tasks where she was required to remember verbal information. She performed marginally better on visual tasks. However, on the delayed recall trial of the RCFT which also involves visual memory, Jess' performance was impaired by her disjointed approach to initially copying a complex figure. Jess appeared unable to see the gestalt of the picture and connect aspects to improve encoding and later recall. This suggests difficulty with planning and problem-solving and was potentially due to attentional difficulties, more than memory.

Jess found the prospective memory task (on the RBMT-3) difficult and was visibly frustrated and confused. This is understandable as Jess has daily difficulty remembering to follow through on self-appointed tasks, and regular activities like taking her medication. Difficulty with prospective memory can result either from memory deficits or from impairment of executive functions, including attentional impairments.

Jess' best performance was on the Novel task of the RBMT-3; her performance was in the average range. This task involves procedural memory and is a measure of new learning. The task required Jess to learn a new skill, which she then repeated immediately and later recalled. Jess enjoyed this task as there was a visual aspect, and she found it interesting and therefore paid attention to what she was doing. This aided Jess' memory for the task when she had to perform it again after a delay.

Summary and Clinical Impressions

Jess is a 59-year-old woman who was referred for neuropsychological evaluation to determine if she met diagnostic criteria for ADHD. As Jess had a diagnosis of schizoaffective disorder and schizoid personality, this assessment was requested as medication typically prescribed for ADHD is not recommended for individuals with a history of psychotic episode.

ADHD was suggested due to ongoing concerns regarding attentional difficulties, distractibility, periods of hyper-focus, an inability to plan and complete tasks, and disorganisation. These concerns had a profound impact on Jess' sleep and her ability to manage herself, her home, and to keep a daily routine.

Based on educational and occupational history, and a brief screen of Jess' intellectual functioning using the ACE-III, Jess' intellectual ability was estimated to be in the low average range. This means Jess' intellectual functioning is within the expected range for her age, albeit at the lower end of that range and therefore unlikely to fully account for the impairment described above.

Jess' memory was also assessed, and her overall level of memory functioning was well below average. Jess especially struggled with memory tasks which had a delayed recall element. The decreased performance between immediate and delayed recall indicates an encoding difficulty. Based on observation during assessment, this was potentially because Jess struggled to concentrate and stay focused on the initial task.

During assessment Jess also had considerable difficulty with a prospective memory task. Prospective memory is a measure of a person's ability to remember to do something in the future. This reflected Jess and her sister's description of Jess' difficulty remembering daily tasks for example, taking her medication. Difficulty with prospective memory can result either from memory deficits or from attentional impairments.

In her daily life, Jess described at times being hyper-focused and preoccupied with new or enjoyable activities. This was reflected during the Novel task of the RBMT-3. This is a measure of new learning and Jess talked about enjoying the task. Therefore, her attention was better and her performance improved. She remembered and described details of the task a week later. This suggests if Jess' focus could improve, aspects of memory may also improve.

ADHD

Diagnosis of ADHD for adults requires at least five symptoms of inattention and/or hyperactivity and impulsivity. Several of these symptoms must have been present prior to age 12 and occur in two or more settings. These symptoms must also interfere with or reduce social, academic, or occupational functioning.

There was clear indication from interview and assessment that Jess had consistent and clinically significant difficulty with attention. Symptoms included: difficulty sustaining attention, seemingly not listening when spoken to, not following through with instructions, difficulty staying on task, not following tasks through to completion, difficulty with persistence and planning, avoiding non-preferred activities, losing things and being forgetful.

On formal assessment of Jess' attentional abilities, she performed in the well below to below average range for selective attention, sustained attention, attention switching and divided attention. Observations during assessment were that Jess struggled with sustained and divided attention and was distracted by extraneous detail. This reflected Jess' experience of school and of previous employment where Jess' inability to concentrate made it difficult for her to understand complex instructions and deal with competing demands.

There was also indication these symptoms were present for Jess in childhood and adulthood. Based on interview with Jess these difficulties had been consistent at school, university, work, and home. Collateral information from Jess' sister confirmed Jess had attention difficulties since childhood. In adulthood, Jess has continued to have difficulty managing herself and her time which impacts sleep, and her ability to organise and maintain her home.

In terms of alternative explanations for Jess' difficulties, Jess' inattention does not occur exclusively during a depressive episode or in the course of psychotic disorder. The described behaviours don't fluctuate with Jess' mood. According to Jess and based on clinical notes when Jess' mood is improved, she just better tolerates these difficulties. In addition, while Jess does experience anxiety, the inattention is not due to excessive worry or rumination.

Taken together, results from testing, behavioural observations, review of available records, interview with Jess and collateral information indicate Jess meets criteria for **Attention-Deficit/Hyperactivity Disorder, predominately inattentive presentation**. Jess has longstanding concerns related to inattention, which reduces the quality of her everyday functioning at home and elsewhere.

Despite several difficulties Jess has learned skills over time to recognise when her low mood becomes problematic. She understands that without support she may go on to experience psychotic episode, and as a result Jess is very good at seeking help when she needs it. Jess fiercely values her independence and has hobbies and activities which interest her and occupy her time, such as painting and photography. If Jess were able to improve her focus and concentration, and better organise her home to accommodate her artwork these activities would be more enjoyable for Jess.

Recommendations

From a mental health perspective Jess is currently on a successful medication regime and has support from CMH and (community support group). Working alongside these supports and attending group activities and appointments provides some structure to Jess' time.

It should be noted when considering medication as treatment for ADHD that while Jess would like to know if another medication would be beneficial, her preference would be to preserve her relatively stable presentation. While Jess has remained curious about ADHD explaining her functional impairment, she has concerns about becoming unwell.

That said Jess' functional impairment because of her inattention and lack of focus is considerable, and Jess would benefit from more structure and routine in her life. In the past behavioural interventions around time management, setting a routine, and improving sleep have been unsuccessful for Jess.

1. As Jess' functional impairment is profound, a well-managed and monitored trial of medication could be worthwhile in managing Jess' symptoms of ADHD. Medication in conjunction with behavioural strategies could support Jess to develop her ability to self-manage, and positively impact her sleep, mood, and cognition.

Other recommendations:

2. Follow-up neuropsychology assessment in approximately two years (or earlier if otherwise indicated) would be useful to monitor any potential decline in Jess' cognitive functioning.

3. Encourage Jess to break tasks down into smaller parts, so they are more manageable. This will help Jess feel less overwhelmed by art projects, improve her focus, and allow her to take frequent breaks.

4. Jess often finds herself hyper-focused with an activity on her tablet or other mobile device, going down a "google wormhole" as Jess described. It could be beneficial for Jess to install an app which reminds her to take frequent breaks. This may be enough to break Jess' hyper-focus and remind her to attend to other activities which need her attention, including eating and sleeping.

I trust this report provides you with information useful for deciding whether Jess' symptoms of ADHD would benefit from medication. If you have any questions or comments about this assessment, please contact me.

Discussion

My honour's dissertation and doctoral thesis, in part considered factors which are relevant to the assessment, diagnosis, and treatment of ADHD. This research focused on ADHD amongst children and looked at the assessment process from both the perspectives of health professionals and the experience of whānau with children who have been assessed for ADHD. This case presented the opportunity to undertake an assessment for ADHD, which I had not previously done. This has contributed to my development as a clinician and will inform my research with first-hand experience of the complexities of the assessment process.

Guidelines for Assessment

As assessment is complex, the MOH (2001) have previously developed guidelines intended to assist in the assessment and treatment of ADHD in young people between 5 and 13 years. While these guidelines have not been updated or expanded to include older populations, the overall premise of the assessment process remains relevant. The guidelines advocate multimodal assessment, where information is based on family and social history, school functioning, behavioural observations, behaviour rating scales, and diagnostic interview (MOH, 2001). Furthermore, MOH guidelines stress the significance of parents/caregivers and teachers as co-assessors and contributors in the diagnostic and management process. The guidelines were helpful in deciding what information was important to gain, and how I might gather this information from an adult client.

In addition to MOH guidelines, in the DHB setting in which this assessment was undertaken, Adult Type ADHD Guidelines set out a common process for working with adults with ADHD (Doron, 2016). These guidelines are based on current literature and ADHD guidelines from other countries, in recognition there is no evidence-based therapy approach for adults with ADHD in NZ. The guidelines informed the process of the current assessment to meet with DHB requirements. This indicated the DIVA 2.0 diagnostic interview and/or the Adult ADHD Self-Report Scale (ASRS-v1.1) should be used as an initial screen for the presence of ADHD symptoms in childhood and adulthood. As symptoms were indicated by the screen, a full assessment was done.

Treatment of ADHD

According to Medsafe (2017) one of the more commonly known medications used to treat ADHD, methylphenidate hydrochloride (or Ritalin), is a central nervous system stimulant. Medsafe classifies Ritalin as a Class B controlled drug, so that it is subject to prescribing restrictions and requires a special authority number to be prescribed. As a stimulant, Ritalin is thought to have a paradoxical effect with individuals with ADHD by increasing the amount of dopamine in the brain and thereby focusing inattentive individuals and helping to calm hyperactivity. However, as was relevant in the present case, stimulant medications should not be prescribed for individuals with a history of psychotic episode. DHB guidelines laid out alternatives for prescribing physicians, as well as other treatment options (Doron, 2016).

Reflections

My intent in undertaking this assessment was to experience how it was in practice to assess an adult suspected of having ADHD. The first thing I noticed was that observing Jess did not give an indication of how functionally impaired she was. In talking with Jess, it wasn't immediately obvious how difficult it was for her to concentrate which is because inattentive symptoms are often less noticeable than hyperactive symptoms. Once Jess and I started assessment it became obvious how problematic the inattention was; despite Jess wanting to perform to her best and trying her hardest to concentrate, she could not maintain her focus and attention.

Working with Jess during the assessment, gave me genuine insight into how it must be for her in her everyday life. Jess' inability to concentrate was even difficult to assess. Walking Jess through tasks, while making sure I was maintaining test integrity and trying to keep her focused during assessment sessions, was exhausting. As Jess was interested in the assessment process, the hyper-focus she had spoken about kicked in. Jess seemed willing to go on endlessly with assessment sessions. However, reflecting on how tired I was during our sessions, I wanted to make sure Jess was able to perform to the best of her ability and so intervened to break the sessions up (even when our progress was slow).

I also learned from speaking with Jess' sister, what Sheryl's experience was of having supported Jess for the past 30 years. The DSM-5 (APA, 2013) describes how "inadequate self-application to tasks" from people with ADHD is often interpreted by others as laziness and irresponsibility. This perception certainly coloured the relationship between Sheryl and Jess; they had many negative interactions because Sheryl would not accept that Jess was unable to organise herself and her thoughts. Jess also said she felt criticised by her sister and would avoid telling her things. I did hope Jess might share the report with her, so Sheryl might understand a little more about the nature and extent of Jess' difficulties.

This was a complex presentation and a challenging assessment. It was challenging because the client was an adult and I was asking Jess and Susan to recall how things were during their childhood, some 50 years ago. Jess' parents were also no longer alive to be able to contribute to the assessment and there were no school or medical records available for Jess from childhood. There were also other primary psychiatric diagnoses to consider, comorbid mood and anxiety symptoms, and potentially OCD. Everyone involved in supporting Jess (psychiatrist, psychologist, key worker) thought she had problematic inattentive symptoms and related functional impairment. With a little questioning and a review of available admission records and clinical notes, there was a 20-year history documenting Jess' difficulty organising herself and her home. However, before the psychiatrist considered treatment options, they wanted a confirmed diagnosis of ADHD. Therefore, I was deliberate in making sure the assessment was thorough and methodical. I wanted to be certain there was evidence of ADHD in childhood, adulthood and none of the other presentations better explained these symptoms. It was very important to gain collateral information, as otherwise I would have only had Jess' self-report and the results of assessment.

One of my recommendations was that Jess' symptoms were impairing enough to consider a medication trial. The DHB guidelines clearly describe that a newly medicated client be monitored closely and initially be seen by the prescribing psychiatrist every two to three weeks (Doron, 2016). The guidelines also specify a key worker should be assigned to the client to gain feedback on the efficacy of the medication/current strength and potential side effects. The advantage of working in a multi-disciplinary team with psychiatrists, nurses, occupational therapists, social workers and psychologists, is that (usually) a key worker is able to be selected from the team who best meets the needs of the client (based on their discipline and training). Knowing this was the process gave me confidence to make this recommendation, as I wanted to support Jess to stay well.

Overall, it is easy for me to pick apart guidelines for assessment and critique them based on best practice and my own personal ideas about how they should be enacted. Entering the internship year, I knew I would undertake an assessment of ADHD, so I could better understand what was involved. I am hoping through my research to make suggestions about how culture (as defined by ethnicity, and specifically regarding Māori culture) is attended to and included in assessment and treatment. As I reflect on whether I affected that for Jess, I didn't explicitly talk about her about being from South Africa, though I did ask her questions about her experience of school for example, and how that compared with other children. I tried to understand Jess' experience as it fit within the era and culture in which she was raised. I can see that through thorough assessment culture is considered as you seek to understand this person’s lived experience and look at their behaviour in context. So, it depends how the assessing clinician takes this into consideration and how the person being assessed feels this was included in the assessment. There are several factors which the clinician considers and doesn’t explicitly state to the person when doing an assessment. The wondering I will include in my research is how to convey to a person you have tried to understand their behaviour in the context of their individual circumstances, which includes their cultural background.

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